

School of Public Health

Faculty of Health Sciences

Out of the Blue

**Giving and receiving care: Aboriginal experiences of care-giving in
the context of mental illness**

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Declaration

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

Signed:

Michael Wright

Date:

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Abstract

This thesis is an exploration of the experiences of care-giving for Indigenous people living with a serious mental illness. The research included the experiences of those being cared for and those providing care. Due to past negative research experienced by Indigenous people, the study was conducted as a critical ethnography using multiple culturally appropriate methodologies and under the direction of a Study Reference Group. Participants were recruited through a person known to them, a culturally safe method of introduction. Thirteen in-depth case studies were conducted over 18 months, and participants' stories were constructed through multiple interviews, feedback and workshop sessions. Findings included the identification of a serious disconnection between mental health providers and Indigenous Australian families living with serious mental health issues. This disconnection was due to mental health providers lacking understanding of Indigenous needs and of the complexity and concepts of Indigenous care-giving. One outcome from this study was the proposal of an Indigenous care-giving model. The key elements of an Indigenous model of care-giving are the importance of relationships and reciprocity in holding and sustaining culture, and the significance of cultural responsibility. When mental health providers lack understanding of these attributes it has serious implications for their interactions with Indigenous people. This thesis offers recommendations for future research and for improved standards for mental health care provision.

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List of Abbreviations

ABS	Australian Bureau of Statistics
ACSS	Aboriginal Community Support Service
AMA	Australian Medical Association
ATSIC	Aborigines and Torres Strait Islander Commission
CDEP	Community Development Employment Programme
DYHS	Derbarl Yerrigan Health Service
GRAMS	Geraldton Regional Aboriginal Medical Service
HREOC	Human Rights and Equal Opportunity Commission
MAE	Masters of Applied Epidemiology
MCMC	Merced Community Medical Centre
NATSIHC	National Aboriginal and Torres Strait Islander Health Council
NATSIHS	National Aboriginal and Torres Strait Islander Health Survey
NCEPH	National Centre for Epidemiology and Public Health
NHMRC	National Health and Medical Research Council
RMIT	Royal Melbourne Institute of Technology
SHBBVP	Sexual Health and Blood-borne Virus Program
SRA	Shared Responsibility Agreements
THEMHS	The Mental Health Services Conference
WHO	World Health Organisation

Chapter One: A Nyungar Man's World View – Introduction

1.0 Introduction

The inspiration for this study occurred a number of years ago when I was working as the manager of an Aboriginal mental health service. Having previously worked in a large teaching hospital as the Aboriginal social worker I was very uncomfortable with the relationships between hospital staff and Indigenous people. The attitude of health professionals in the hospital toward Indigenous people, I believed, was quite patronising. There was never any indication of any form of collaboration between the patient, their family and the doctor with regard to the patient's treatment regime. Patients were, if anything, under pressure to conform to the directions of the medical staff. Medical staff identified themselves as the 'experts' who knew what was best for the person. It was a difficult place to work. I left that position and a couple of years later I was employed as the manager of an Aboriginal mental health service. Not long after commencing this job, I attended my first Mental Health Service conference (THEMHS) in Sydney. Before attending the conference I had little knowledge or experience of the breadth of the mental health sector, and specifically, was unaware of the influential role of consumers.

The first keynote speaker at the conference was a woman living with a serious mental illness. She was amazing! Never before had I heard such an eloquent and powerful presentation. This extraordinary young woman living with a serious mental illness, spoke not as someone living with a chronic illness, but as a person with an authoritative message of care-giving and mental illness. The commanding manner in the way she delivered the keynote address to the mental health professionals was inspiring. It was a transformational moment for me. I was also encouraged because her presentation gave me a vision of what care-giving could be like for Indigenous people living with a serious mental illness. Her speech convinced me that Indigenous people and their families living with a serious mental illness can have greater control over their own future. I still live this dream; I am hopeful that this and similar studies will contribute to the realisation of the dream one day.

The burden of mental illness on a global scale, when recorded in the 1990s, was considerable, accounting 'for almost 11 per cent of the total disease burden' (Hayman-White, Sgro and Happell 2006, p. 3). The situation in Australia in the same period was worse, with a slightly higher disease burden at approximately 13 per cent, as well as approximately 30 per cent of the non-fatal disease burden. A study by Henderson and others on the prevalence of mental illness in Australia during the mid 1990s identified that more than one in five persons had a mental illness (Henderson, Andrews and Hall 2000). The morbidity of the disease was found to be significant, with anxiety being the most prevalent of the disorders, followed by substance-use and then affective disorders.

Henderson's study also showed that the co-morbidity of a mental disorder with a physical disorder was present in approximately half of the participants; particularly prevalent physical disorders being kidney disease and chronic bronchitis (. A disturbing statistic from the Henderson study was the high percentage of people living with a mental health problem who did not seek professional care (Henderson, Andrews and Hall 2000). As Hayman-White, Sgro and Happell (2006) indicated, 64 per cent of all persons who had one or more of the common mental disorders had not accessed a health service in the previous twelve months.

Knowledge about the incidence and prevalence of serious mental illness in the Indigenous Australian community is limited (Swan and Raphael 1995). What is evident is that there are major concerns in the Indigenous community about the lack of support for Indigenous families living with a serious mental illness. This study aims to gain a clearer and more comprehensive understanding of the issues that impact on the quality of care-giving for Indigenous Australians living with a serious mental illness.

The approach that I have adopted in this research is reflected in this chapter: that it is essential that I weave into my research practice an ethical approach that spans all aspects of the research process and that respects and values human-to-human interactions (Denzin and Lincoln 2005b). In this chapter I cover the three pivotal domains of knowledge development that led to my own Indigenous research approach. The chapter has been organised into six parts:

Terminology offers an explanation for my use of the terms Aboriginal and Indigenous for this study.

Background to the study provides an overview of the focus of the study in the following three areas: (1) experiences of care-giving in a mental health

context, (2) Indigenous epistemology and (3) racism. It also includes an overview of the significant historical events from an Indigenous Australian perspective and in particular how racism has contributed to the current health and economic status of Indigenous people.

Widening the fracture of racial discourse explores the ontological and epistemological assumptions underpinning Indigenous research. It explores how the traditional approaches held within the academy for doing qualitative research are in conflict with Indigenous epistemological and standpoint positions.

On framing the work provides a positioning of the study from the researcher's personal life experiences. It highlights significant events that have shaped my life as a Nyungar man in a society where 'Whiteness' is the colour of privilege.

The silence is deafening covers the four pivotal domains of knowledge development that led to the approach adopted for this study. It includes an overview of the intellectual and emotional challenges that were present in the early stages of the study.

Overview of the thesis provides an overview of the main points and arguments that will be presented in the thesis.

1.1 Terminology

In this study I have used the terms 'Aboriginal' and 'Indigenous' and other cultural group descriptors interchangeably. I use the term Indigenous to include both Aboriginal and Torres Strait islander peoples. There are instances in the study when I refer to the 'Nyungar' people when referring to the Aboriginal people of the South West region of Western Australia. The reason I continue to use the term Aboriginal in preference to 'Indigenous' is that a word I am more familiar with, for it is a term I grew up with. When I refer to a more macro descriptor for Aboriginal people in Australia and internationally I have used the term Indigenous. I have interchanged between these two descriptors depending on the context and who I am describing. I have used the term Aboriginal in the research questions and in the title because the participants were more familiar and comfortable with the use of that term.

Throughout this study I have capitalised the terms 'White' and 'Eurocentric' to signify Anglo European peoples who colonised the country. I have chosen to capitalise the terms 'White' and 'Black' as the terms Aboriginal and Indigenous are always

capitalised as a mark of respect to the people. Similarly I chose to capitalise 'West' and 'Eurocentric' when broadly referring to European and 'Western' culture.

1.2 Background to the study

Sphere and focus of the study

The research question for the study is: *How are the experiences of care-giving constructed for and by Aboriginal people living with a serious mental illness?*

Understanding care-giving from an Indigenous perspective within the context of mental illness was the study's primary focus and the primary intellectual task. This approach was based on my understanding that within the mental health system currently there is limited understanding of Indigenous systems of knowledge and there are few culturally appropriate models of care for Indigenous people living with a serious mental illness. For example, the report by Swan and Raphael (1995) found that mental health for Indigenous people is intricately linked to holistic health outcomes. While the report suggested that any loss of mental well-being impacts greatly upon their spiritual and physical well-being it did not provide understanding of the Indigenous framework.

The second area of intellectual enquiry was to investigate how an Indigenous epistemology could be included as part of the theoretical framework for the study. All research methodologies, whether qualitative or quantitative, are based on their own particular ontology and epistemology. It was important for me as an Indigenous researcher to locate this study within its own unique epistemological situation. This included an Indigenous epistemology within the theoretical framework ensuring that the study was firmly grounded in an appropriate Indigenous context.

The third area of intellectual inquiry was to further explore how racism contributes to the separateness and objectification of Indigenous people, and therefore to their experiences within health systems. When investigating the issues of cultural racism it is important to note how cultural racism in Australia has privileged non-Indigenous people, resulting in disenfranchisement and marginalisation of Indigenous people (Watson 2005). In Australia it has been Indigenous people who have been the main targets of racism (Moreton-Robison 2000; Paradies 2006a). It is now widely accepted that there are three forms of racism: individual, institutional or systemic and cultural. The first two forms, individual and systemic, are more easily understood than the concept of cultural racism which Jones (1997, p. 14) defined as the 'individual and institutional expression of the superiority of one race's cultural heritage over that of another race'. In Australia, cultural racism began at the time of

colonisation with its core organising principle being that European culture is far superior to other cultures, including Indigenous cultures, and this cultural racism continues to this day (Jones 1997).

Service context for participants

Western Australia has had a chequered history of response to the mental health needs of Indigenous people and, at this point in time, does not have any Aboriginal controlled community mental health services. To my knowledge there have only ever been two Aboriginal community controlled health services in Western Australia that have had a dedicated mental health unit. The first was Derbarl Yerrigan Health Service (DYHS) and the second was the Geraldton Regional Aboriginal Medical Service located approximately 300 kilometres north of Perth (GRAMS).

The Perth based Aboriginal community controlled health service, Derbarl Yerrigan Health Service, had a specific mental health unit, the Aboriginal Community Support Service (ACSS), which operated from 1996 to 2002 when it was de-funded. I was the manager of the service from 1997 to 2001 so I had an intimate and in-depth knowledge of the services available, the context and the scope and range of client needs. At the end of my tenure the service employed 13 staff – eight Aboriginal mental health support workers, two social workers, one mental health nurse, a sessional psychiatrist (.2) and a manager, and was providing mental health support to approximately 100 clients and their families. The agency brief was to provide a medium to long term service to Aboriginal people and their families living with a serious mental illness. The service was centred on an ‘inreach’ model of practice and it required that workers engaged with clients in the environment of the clients’ choice. ACSS workers provided support and assistance with the full range of issues presented by clients including but not limited to: managing medications, convening psychiatric reviews, assisting with accommodation, dealing with Centrelink, child protection issues. Workers engaged with multiple systems, including health, justice, welfare and education, on behalf of their clients. For example, support was provided to clients who went to prison and this included assistance to ensure a smooth transition from prison to community after release. In 2002, on the claim of ‘budget constraints’, the Western Australian government de-funded ACSS. At this time the Western Australian Aboriginal community was given the assurance that Aboriginal clients supported by ACSS would continue to be supported – by mainstream services. Unfortunately, this does not seem to have occurred. Anecdotal information suggests that many ACSS clients slipped through the gaps and that mainstream

services do not have the networks and skills base to adequately service Indigenous families.

The GRAMS mental health unit no longer operates. Instead the mainstream public mental health system has an Indigenous mental health unit which has state-wide responsibility in providing policy direction for mental health services for Indigenous people.

The research into care-giving and mental health for Aboriginal Western Australians, which forms the basis for this doctoral thesis, is needed to provide evidence about the experience of Aboriginal people within the mainstream mental health system. Hopefully this type of evidence and other Aboriginal research may be considered by those providing policy direction and considering how to construct more effective service models for the future.

Overview of significant historical events

Colonisation in Australia began for Indigenous people with the establishment of the British penal settlement in Botany Bay in 1778; it then progressively moved outwards, as settlers claimed land for economic purposes (Reynolds 1989). The pastoral industry escalated the expansion which resulted in increased numbers of Europeans who arrived as free settlers. Australia, as a newly colonised country, was ripe pickings for these new settlers. There was no government opposition to individuals clearing the lands of Indigenous people for their own financial benefit (Reynolds 1982). Europeans brought with them diseases such as measles, chicken pox and influenza, all of which decimated the Indigenous population because they had no immunity to these introduced diseases (Attwood 1989). Deliberate genocidal acts towards Indigenous people, including massacres and even feeding Indigenous families poisoned flour, further decimated the population. In resisting the aggressive acts of colonisation Indigenous people used fighting and warfare skills which were small in scale compared to European methods as there had never previously been the need to engage in large-scale military tactics. The Europeans had guns, horses and organised military forces, and with this superior advantage they won the war for the land (Reynolds 1982).

What is noticeable is how history has misrepresented Indigenous people. According to Attwood some historians have portrayed Indigenous people as being passive and offering no resistance to the appropriation of their lands. This is patently false and there are numerous and significant texts that provide detailed accounts of Indigenous resistances and warfare (Attwood 1989; Evans 1999; Loos 1982).

Western Australia and other states, like Queensland, introduced legislation designed to control the movements of Indigenous people, and if necessary to remove and place them onto government controlled settlements. These acts, including the *Aborigines Act, 1905* in Western Australia, were highly paternalistic and extremely harsh for their aim was to give the State absolute and total control over the lives of Indigenous people. This legislation included the right to remove children from their families, manage people's financial affairs and even determining who they could marry. These paternalistic and harsh Acts were in place in some states, including Western Australia until well into the 1960s. A more perverse element in this tale which is not always immediately transparent is cultural racism, and 'by the 1890's Australian policy makers were obsessed by race. Emergent nationalism became inextricably involved with ideas of the White Australia' (Reynolds 1996, p. 132).

As a result of these and other acts of colonisation it is now widely acknowledged that the health and wellbeing of Indigenous people is poor. *Overcoming Indigenous Disadvantage*, the report commissioned by the Council of Australian Governments (2003), identified that Indigenous people living in Australia still experience high levels of disadvantage. In Western Australia the life expectancy for Indigenous males and females is 15 to 20 years less than that of the total population with 39 percent of Indigenous people living with a disability or chronic health condition (Department of Indigenous Affairs 2005).

The statistics for the health and wellbeing of Indigenous people continue to be disturbing (Australian Bureau of Statistics 2008). Incarceration is also issue; Indigenous youth were over-represented in juvenile detention centres around Australia. The rates of incarceration in juvenile detention centres of Indigenous young people aged between 10 and 17 years are higher than those for all Australians in all jurisdictions (Australian Bureau of Statistics 2003).

These statistics reflect the ongoing multi-factorial issues related to social disadvantage including poverty, racism, passive welfare and alcohol and substance misuse, all of which result in poor health outcomes. Indigenous people have experienced the worst aspects and indignity of what colonialism offers, and its legacy continues on today in poor health and wellbeing outcomes (Australian Bureau of Statistics 2008).

1.3 Widening the fracture of racial discourse

The term 'fracture' has been applied to describe the analytical process that interrogates power relationships. 'Fracture' is a term used by Weis and Fine (2004,

p. xx) to describe their analysis of race so as to ‘destabilize the representation of institutional coherence, integrity, and stability’. Importantly, having an understanding of the linkages between Indigenous care-giving, Indigenous epistemology and racism in the context of colonisation is critical if we are to conceptualise and conduct appropriate public health intervention. This section explores the ontological and epistemological assumptions underpinning Indigenous research and how the traditional approaches held within the academy for doing qualitative research are in conflict with Indigenous epistemological and standpoint positions.

Issues of representation

The impact of colonisation in Australia has had a powerful influence on the knowledge systems within Indigenous culture. Indigenous ontology and epistemology have been de-legitimised by the dominant positivist theories of the colonisers, including the introduction and influence of ‘science’. In particular the dominant view held by the White colonisers that their culture was racially superior and that other racial groups were ‘primitive’ and accorded the status of ‘Other’ (Attwood 1992; Nakata 1998a; Rigney 2001). In other words, only White epistemologies have been legitimised or acknowledged. Tiffin (2006, p. 99) states that ‘[d]ecolonization is a process, not arrival; it invokes an ongoing dialectic between hegemonic centrist systems and peripheral subversion of them; between European or British discourses and their post-colonial dis/mantling’.

Care-giving should be seen in the broadest sense as a human activity, but it has been socially constructed into gender roles so that it is now viewed as predominately a women’s role. This study explores the topic of *care-giving and how it is constructed by Aboriginal people living with a serious mental illness*. It explores care-giving using Indigenous ontology and epistemology, Indigenous feminist standpoint theory and Indigenous standpoint theory, and examines theory through the lens of race, class and gender.

Understanding Indigenous ontology and epistemology

Research requires an understanding of epistemology and ontology. The reasons these are important notions is that they are the personal lenses of the researcher; they reflect the researcher’s values and lived experiences (Denzin and Lincoln 2005b). Denzin and Lincoln (2005a, p. 21) offer a framework for the qualitative researcher:

Behind these terms stands the personal biography of the researcher, who speaks from a particular class, gender, racial, cultural, and ethnic community

perspective. The gendered, multiculturally situated researcher approaches the world with a set of ideas, a framework (theory, ontology) that specifies a set of questions (epistemology) that he or she examines in specific ways (methodology, analysis).

Debate continues on the merits of Eurocentric methodologies and their relevance and applicability in Indigenous settings, given the difference in ontology and epistemology between Indigenous and non-Indigenous approaches (Battiste 2008; Nakata 2007; Tuhiwai Smith 2003). The distinction between the terms ontology and epistemology as they apply to Indigenous and non-Indigenous people is critical, if we are to appropriately position Indigenous research methodologies. Crotty (1998, p. 10) defines ontology as 'concerned with "what is" with the nature of existence, with the structure of reality as such'. He defines epistemology as being 'concerned with providing a philosophical grounding for deciding what kinds of knowledge are possible and how we can ensure that they are both adequate and legitimate' (Crotty 1998, p. 8).

From the early 1990s through the period of post-positivism there has been a proliferation of new interpretative and qualitative research designs and of multiple methodologies, which some have called 'a crisis of representation' (Denzin and Lincoln 2005a, p. 18). This has allowed the space to emerge for Indigenous researchers and for the beginnings of an Indigenous research methodology (Denzin and Lincoln 2005b; Moreton-Robinson 2006; Rigney 2001). The shift from the traditional decolonising language of research, has vindicated the voices of those Indigenous researchers who have long argued that Eurocentric based research practices have been a major contributing factor to the continuing oppression of Indigenous people. They have argued that post-colonising practice has been legitimised by Eurocentric based research practices (Bishop 2005; Denzin and Lincoln 2005b; Moreton-Robinson 2000; Tuhiwai Smith 2005).

Even with this change in circumstance the position of Indigenous scholarship in the academy is still tenuous and, until very recently, there has been no official acknowledgement of Indigenous ontology and epistemology (Denzin and Lincoln 2005b; Foley 2003; Tuhiwai Smith 2005). Indigenous ontology and epistemology is still being de-legitimised (Battiste 2008; Moreton-Robinson 2000; Nakata 1998a). Even qualitative research methodologies *as understood and recognised within the academy* have narrow conditions and assumptions attached to them that preclude Indigenous methodology as well as other methodologies that do not fit into the dominant paradigms Eurocentric based research methods (Madison 2005; Tuhiwai

Smith 2003). Regrettably it still appears that the academy still actively legitimises some aspects of the colonial position.

The academy's position that 'pure' research is 'unbiased and objective', delegitimises researchers who use a constructivist approach (qualitative research methods), even when engaging the concept of 'bracketing', and therefore excludes their research from serious consideration and inclusion in scientific discourse (Daly et al 2007; Denzin 2001). In relation to the issue of having one's knowledge delegitimised, the Afro-American feminist Patricia Hill Collins (1990) argues her standpoint as a Black Afro-American academic. She maintains that as part of her association of racial belonging within the Afro-American community there is an intrinsic wisdom and knowledge which is neither recognised as unique nor acknowledged as offering a viable alternative view, by her White academic male colleagues. She argues that this is because it does not fit neatly into the dominant western based knowledge process. Collins's Afro-American-centric feminist epistemology, that is, her methodological approach of looking within and of speaking from the position of her own experiences, offers an alternative that presents a challenge to the academic world. This personalised approach has been criticised by the purists within the academy, for they disapprove of researchers locating themselves within the text and consider that it breaks the fundamental rule of the positivist research practice of objectivity (Collins 1990).

The objective rule in positivist research rests upon its so-called immutable laws of duality, meaning that the researcher is required to be an observer only and to position him/herself outside of the research process, and definitely, not to be influenced by what is happening in the study (Guba and Lincoln 1989). In contrast, Collins (1990) positions herself alongside the participants involved in her study and uses an auto-ethnographic approach. She validates her method and through her use of 'concrete experiences' maintains that this is a legitimate method of the collection and analysis of data.

The academy's belief that research 'objectivity' is possible and superior to other methods has also been challenged by critical researchers who have argued that adopting the position of 'objectivity' is at best impractical, or at worst disingenuous, as researchers '[r]esearchers who opt to be objective in their approach do so at some risk for they "hide behind the cloak of neutrality"' (Weseen and Wong 2000, p. 34). Critical ethnographers argue that it is impossible to do social research effectively if one adopts the objectivist position and Madison (2005, pp. 7-8) enunciates this clearly:

What many early researchers did not recognize was that their stalwart 'objectivity' was already subjective in the value-laden classification, meanings and worldviews they employed and superimposed upon peoples who were different from them.

Denzin and Lincoln (2005a, p. 21) highlight the reality of the personalised research lens:

The gendered, multiculturally situated researcher approaches the world with a set of ideas, a framework (theory, ontology) that specifies a set of questions (epistemology) that he or she then examines in specific ways (methodology, analysis).

This is particularly relevant for Indigenous researchers. If for no other reason than the effect of colonisation, research poses a set of unique issues for Indigenous researchers and their communities. The notion of 'objectivity' in an Indigenous context is impractical given the importance of cultural obligations and commitments that are inherent in Indigenous settings (Moreton-Robinson 2000; Rigney 1997; Tuhiwai Smith 2003). The Indigenous world is about shared obligations and commitments that displace and reject Eurocentric research practices that are too rigid and that do not encourage reflexivity. What is more practical is 'reciprocity' in Indigenous research. As Bishop (2005, p. 124) states:

Reciprocity in indigenous research, however, is not just a political understanding, an individual act, or a matter of refining and/or challenging the paradigms within which researchers work. Instead, every worldview within which the researcher becomes immersed holds the key to knowing.

Reinforcing this view is the Indigenous woman academic, Irene Watson, who states 'we are situated in different territory which is alien to the other, and while that difference is huge, we share and occupy the same landscape' (Watson 2004, p. 96).

The importance of an Indigenous epistemology in research is now beginning to be acknowledged by some in the research community (Denzin and Lincoln 2005b; Mihesuah 1998). In addition, there is recognition among Indigenous scholars across their cultures of the presence of a universal Indigenous epistemology based on similarities of cultural valuation and resistance to colonisation. Tuhiwai Smith (2005, p. 86) highlights this in her description of Indigenous people, as 'Aboriginal peoples can be defined as the assembly of those who have witnessed, been excluded from, and have survived modernity and imperialism'. Indigenous Australians are survivors of colonisation and similar to other Indigenous groups they, as scholars, are committed to challenging and changing the influence of colonialism, namely, exploitation, oppression and racism (Foley 2003; Tuhiwai Smith 2005). The presence of an Indigenous theoretical standpoint is important for the advancement

of Indigenous scholarship. In particular, Indigenous scholars will need to be dissenters from the status quo and agents for change who are actively engaged in the struggle that deconstructs the dominant Eurocentric paradigm if they are to conduct research that is of real value to their communities and families (Bishop 2005; Moreton-Robinson 2006).

The academy is still not convinced that an Indigenous epistemology can guarantee research validity, and claims that Indigenous epistemologies lack research rigour and relevance (Foley 2003; Moreton-Robinson 2006). A similar criticism has been directed at feminist epistemology, because it does not fit neatly into the Eurocentric knowledge base. In order to embrace an Indigenous epistemology it is imperative that academics understand the philosophical issues around the perceptions of Indigenous knowledge and truth. The academy and those within it who have power and privilege can also control the knowledge validation process and sometimes academic elites have suppressed thoughts and ideas that do not fit the usual Eurocentric knowledge base. There are layers of control that are often employed in academia to screen out or exclude some knowledge bases (Collins 1990). For example, research conducted by certain groups, such as by feminists or Indigenous people, can be criticised for using methodologies that lack validity and rigour by very narrow definitions, and then those same narrow definitions are used to argue and claim that those who use Indigenous or feminist ideas and theories do not produce credible research (Denzin and Lincoln 2005b). For this reason Indigenous and feminist researchers have challenged the views held within the academy on certain research methodologies and demonstrated that they are often biased towards specific privileged positions and as a result are outdated (Collins 1990; Tuhiwai Smith 2003).

There is still the question about who can articulate an Indigenous epistemological position. Some argue that this is a subject that only indigenous researchers can express (Foley 2003). As an Indigenous researcher I do not agree entirely with Foley's position, for I believe that just as feminists have realised that the values and philosophies that underpin feminist epistemology can also be accepted and embraced by men, so it is my view, that the values and philosophy of an Indigenous epistemology can also be acknowledged by non- Indigenous researchers. What is unique about an Indigenous epistemological position is the focus on values, connection and inclusiveness as the baseline for research rigour (Rigney 1997). This is in direct comparison to Eurocentric epistemological frameworks which are grounded in the concepts of separation (Collins 1990; Tuhiwai Smith 2003).

Gaining recognition for an Indigenous epistemology will not be easy just as feminism struggled for acceptance in the world of the academy (Crotty 1998). Irrespective of the fact that Indigenous epistemology may be a difficult concept for some academics to embrace, it is an idea and concept that is gaining acceptance, some academic legitimacy and increased numbers of supporters (Bishop 2005; Denzin and Lincoln 2005b; Tuhiwai Smith 2005).

Indigenous feminist standpoint theory

The issue of a unique feminist standpoint or epistemology provides the opportunity to reflect on both the feminist and the Indigenous feminist standpoints (hooks 1990, 1995, 2000; Collins 1990; Moreton-Robinson 2000). White feminist theorists began the process of critically analysing the injustices in society by deconstructing the relationships of gender roles which have ascribed privilege and power to men (Crotty 1998). A criticism by Indigenous women and by women of colour is that feminism has not interrogated race or 'Whiteness' as a position of power and privilege (Collins 1990; Fine 1997; hooks 2000; Moreton-Robinson 2000; Watson 2004).

A major issue for Indigenous women has been the lack of interrogation by non-Indigenous women of their privileged positions, for most western societies continue to privilege 'Whiteness'. Whiteness as a social construction or indeed the concept of race is not being interrogated by the majority of 'White' feminists (Moreton-Robinson 2000; Watson 2004). Indeed, it is believed that feminism is only just beginning to explore this lens of oppressions. According to most Indigenous and Afro-American women feminist scholars; race has been excluded from the feminist debates for political purposes (Collins 1990; Moreton-Robinson 2000; Watson 2004). This issue is central in the relationship between Indigenous and non-Indigenous women, as Moreton-Robinson (2000, p. xix) states, '[a]s long as whiteness remains invisible in the analyses "race" is the prison reserved for the Other'. The issue of deconstructing the privilege of race is critical, and 'unpacking privilege should become a mediation of discomfort, not comfort, because privilege is about occupying a very, very comfortable space' (Watson 2004, p. 98). Feminists are not blind to the reality of systemic racism, but some are blind to their own privileged positions. In Moreton-Robinson's view (2000, p. xx), 'feminist's knowledge of systemic racism is easily abstracted from their embodied experience as white middle class women'.

In a society that demeans the role of women, even though there are shared experiences, Indigenous women's experiences are very different. An Indigenous

woman's standpoint 'is informed by social worlds imbued with meaning grounded in knowledges of different realities from those of white women' and is shaped by

an inalienable connection to land; a legacy of dispossession, racism and sexism; resisting and replacing disparaging images of ourselves with self-defined images; continuing our activism as mothers, sisters, aunts, daughters, grandmothers, and community leaders, as well as negotiating sexual politics across and within cultures. (Moreton-Robinson 2000, p. xvi)

Therefore, an Indigenous woman's standpoint is different from that of other women of colour, for land and culture are critical in the understanding of an Indigenous women's standpoint.

The living force is alive in the power of Aboriginal women to remain connected to this country [Australia], often under extreme duress, and where that strength of Aboriginal woman is able to find our space one which is nurturing of women. To endure the suffering and to survive in an altered space, altered by the changes brought throughout Australia's colonial history. It is a hard track to walk but Aboriginal people do it. (Watson 2004, p. xx)

Towards an Indigenous Standpoint Theory

Defining a distinctive Indigenous standpoint theory will require the Indigenous scholar to develop an in-depth understanding of the non-Indigenous epistemological positioning. As Nakata (1998a, p. 4) states, Indigenous scholars 'must first immerse ourselves in and understand the very systems of thought, ideas and knowledges that have been instrumental in producing our position'. This will not be easy because historically Eurocentric scholarly systems have had ownership of the production of Indigenous knowledge. The difficulty will be in legitimising an alternative voice even if the voice is Indigenous. The particular difficulty for Indigenous scholarship is that scholars will be expected to articulate the Indigenous voice within 'the framework of Western understanding, logic and rationality' (Nakata 1998a, p. 4). Not only is this necessary for the legitimacy of an Indigenous standpoint because it will need to be assessed for its scientific rigour, but it will need the academy's approval. Although difficult, this is not impossible. As Indigenous scholarship, at this time (in 2008) is still in its early stages of development and because of the lack of any recognised Indigenous standpoint theory, Indigenous scholars are naturally drawn to other particular social theories, many of which are nevertheless structured around a 'decolonising' framework (Bishop 2005; Moreton-Robinson 2000; Rigney 1997; Tuhiwai Smith 2005).

Certain social theories are associated with past practices that have harmed Indigenous people; they are encumbered with historical baggage (Tuhiwai Smith

2003). There are some Indigenous scholars who argue that certain post-modernist theories have further undermined Indigenous epistemology and ontology (Bishop 2005; Rigney 2001; Tuhiwai Smith 2005), and that post-modernism has ignored Indigenous standpoints (Foley 2003). The development of an Indigenous standpoint theory will be influenced and shaped by Indigenous researchers, and importantly, it should be seen as not some static event, but an evolving process, which fits with the notion of a 'bricoleur'. The theoretical bricoleur is a researcher who has read broadly on a range of topics, including gender, class and race issues as well the different methodological approaches, constructivism, cultural studies and critical inquiry (Denzin and Lincoln 2005b). The researcher as a theoretical bricoleur can apply and utilise a variety of theoretical and methodological approaches, and he or she 'works between and within competing and overlapping perspectives and paradigms' (Denzin and Lincoln 2005a, p. 6).

Indigenous scholars are constantly searching for practices that are culturally safe for working with their communities (Coffin 2007). There are certain social theories that do have a natural fit for Indigenous scholarship (Foley 2003). Some of the theories that do offer culturally safe approaches include critical inquiry, feminism and postmodernism because they present liberating and enlightened knowledge systems. They are unfettered by ideology that seeks to constrain, as Foley (2003, p.: 45) notes, they are 'guided by a vision that there is more than just one worldview and interpretation'.

The focus of critical inquiry is to interrogate, through self-reflection, and then dismantle the presence of hegemonic ideologies in contemporary western societies that repress and oppress the marginalised and disenfranchised (Carspecken 1996; Sykes 2006). Critical inquiry, through its interrogation of societal conditions, rejects the dominant positivist theories held within the discourse of science and importantly; critical theory interrogates the inequitable positioning in society of certain groups based on race and class (Madison 2005). It is therefore understandable and appropriate that Indigenous scholars use critical theory to interrogate the processes of colonisation and its relationship to domination and control, particularly how certain groups have been privileged in society because of race (Foley 2003).

The values that underpin the constructivist paradigm, those of critical inquiry and feminist theory, fit well with Indigenous methodologies because their approach is relativist, and subjective, based on the assumption that stakeholders are partners in this process, and that they are co-creators in what emerges from the study (Fine and Weis 2005; Guba and Lincoln 1989; Lather 1991). The methodologies of critical

and feminist theorists, have been criticised by the academy for their apparent lack of rigour, particularly the use of a specific form of narrative (Weseen and Wong 2000). The view has been touted within the academy that there has been a 'dumbing down' of research with the introduction of written styles within the constructivist paradigm. This new style of writing, which presents the narrative in a more 'journalistic' style is considered less meticulous, and therefore less rigorous (Guba and Lincoln 1989). Critical theorists, however, argue that narratives should be written in a style that does not exclude or marginalise participants, for all research should be about the transfer of knowledge to stakeholders, in a way that is meaningful for them (Lather 1991; Madison 2005). Unfortunately, qualitative researchers are constantly having to argue their position of legitimacy, as Denzin and Lincoln (2005a p. 8) reiterate, '[p]ositivists further allege that the so-called new experimental qualitative researchers write fiction, not science'. There is, however, still a sense of scepticism towards qualitative research even in the public health area (Daly et al 2007).

Constructivist epistemology locates a philosophical position around the assumption of multiple socially constructed realities. The interpretive or hermeneutic paradigm states that there are multiple socially constructed realities, and that these are not restricted by any single natural laws. The reality constructed by individuals is always interactive. Social constructions are shared phenomena; there is not one truth, but rather many possibilities because of the multiple constructions of reality (Guba and Lincoln 1989).

The dominant views of the privileged group of researchers are now being challenged; there is now recognition that positivism can provide all of the answers in research, for '[t]he province of qualitative research, accordingly, is the world of lived experience, for this is where individual belief and action intersect with culture' (Denzin and Lincoln 2005a, p. 8). History has shown that elite groups, namely White men with power and privilege, have controlled the validation process for research, which has been used in the past to suppress feminist and Indigenous approaches (Collins 1990). Indigenous and Afro-American researchers have taken on the challenge for the recognition of Indigenous and Afro-American epistemologies by the academy. The challenge remains real as there is still the opposition within the academy (Collins 1990; hooks 2000; Moreton-Robinson 2000; Nakata 1998a; Rigney 1997; Tuhiwai Smith 2005).

Critical theory, feminist theory and an Indigenous standpoint theory have been applied in the development of a theoretical framework for this study.

Positioning an Indigenous Standpoint Theory

Indigenous cultures share a common experience of oppression (Battiste 2008; Mihesuah 1998; Nakata 1998a; Tuhiwai Smith 2003). Through the effects of colonisation, Indigenous people have been dispossessed of their land, encountered acts of genocide, and experienced serious disruption to family life by the forced removal of children (Moreton-Robinson 2000; Nakata 1998a; Tuhiwai Smith 2003; Zubrick et al 2005). This shared experience which has permeated into the consciousness of all Indigenous people is the source for a framework for a distinctive Indigenous epistemology (Bishop 2005; Collins 1990; Tuhiwai Smith 2003). The development of a distinctive Indigenous standpoint theory can come at a cost. Unfortunately, because of the impact of colonisation many Indigenous communities are particularly vulnerable to destabilising influences from within their own communities. One example is occurring in the United States where Afro-Americans communities are experiencing a crisis of identity, specifically, who is allowed to identify as an Afro-American. The powerful influences of hegemony are present, not only in the dominant White culture and but also in the consciousness of Afro-American people where it resides as the dominant hegemonic force that questions racial identity (hooks 1990). Indigenous Australians themselves are held within these same powerful hegemonic forces as they too are grappling with the same issues. Racial identity is being questioned both within the Indigenous and non-Indigenous communities; the argument presented is that Indigenous Australians living in traditional settings are the real 'Aboriginal' people, urban based Indigenous Australians are not considered as being authentic (Moreton-Robinson 2000; Paradies 2006b).

Racial identity is just one of the plethora of concerns confronting Indigenous people. It can be argued that racial identity is both necessary and critical in the understanding of an Indigenous standpoint theory for recognition and acceptance of a person's Indigenous status is essential for their sense of self. As Paradies states, (2006b, p. 359) '[t]his intense questioning of authenticity which can hit you with the force of a sledgehammer, is due to the profound disruption that white-skinned Indigenenes represent for the Black-White racial dichotomy, so fervently clung to in Australia'. Cultural legitimacy is the critical point; by planting the seeds of doubt on who can identify as being Indigenous has the potential to de-legitimise Indigenous epistemology (Bishop 2005). The non-Indigenous position may not be intentional but by creating doubt it therefore reinforces their argument that there is no need for an Indigenous standpoint theory. Indigenous researchers will need to act decisively, as

Nakata (1998a, p. 4) states 'we need to this in a way that will speak to those knowledges, that will speak within the discourse, but will extend the discourse to include what has been hitherto submerged, our understanding of them and how they give expressions to relations of power'.

There is a clear epistemological division, according to Crotty (1998, p.8), who further states: '[e]pistemology is concerned with providing a philosophical grounding for deciding what kinds of knowledge are possible and how we can ensure that they are both adequate and legitimate'. In New Zealand, the powerful hegemonic forces have continued to undermine Maori culture as the dominant colonial paradigms continue with the 'social pathology' theme of research with Maori communities. By misrepresenting Maori culture as inferior to the culture of the coloniser, it has 'perpetuated an ideology of cultural superiority that precludes the development of power-sharing processes and the legitimisation of diverse cultural epistemologies and cosmologies' (Bishop 2005, p. 110). Indigenous researchers will need to confront the disturbing trends of 'social pathology' research, as it not only misrepresents Indigenous people but it can reinforce a sense fatalism within communities.

Indigenous researchers have a special relationship with their communities; their lives entwine, and they share similar day to day life with all its struggles and experiences (Bishop 2005; Moreton-Robinson 2000). Importantly, there is the shared understanding of racism and discrimination that gives a special quality to the relationship (Moreton-Robinson 2000; Tuhiwai Smith 2005). There is also the experience of sharing ideas and strategies on how to interact in a society that is inherently racist and discriminatory (Tuhiwai Smith 2005; Watson 2004). As the number of Indigenous researchers rises they will increasingly be recognised as being a valuable resource for their knowledge of community and they will be sought after as experts or specialists in the respective disciplines. More importantly as Indigenous intellectuals they will be able to access a broader knowledge base; for many their education has come from multiple sources – not just from the Eurocentric based education system but also from their Indigenous communities (Moreton-Robinson 2000; Watson 2004; Weber-Pillwax 2001). Indigenous scholars generally have a broad based learning approach, which has been imbued into their consciousness (Menzies 2001), as well as an awareness of the connectedness of all the issues impacting on Indigenous people and their lives (Bishop 2005; Moreton-Robinson 2000; Nakata 1998a; Tuhiwai Smith 2005).

This awareness comes at a cost, for Indigenous researchers are constantly reminded of the importance of remaining connected to their communities (Tuhiwai Smith 2003). There is always the responsibility associated with being Indigenous and the implications of those inherent responsibilities (Anderson 1996; Bishop 2005; Dunbar et al 2004) which require the Indigenous researcher to be a community member first and a researcher second (Moreton-Robinson 2000, Tuhiwai Smith 2003). Indigenous researchers know that doing research with Indigenous people always needs to be supported by the community. Tuhiwai Smith (2003, p. 5) states:

Indigenous researchers, who in their own communities, work partially as insiders, and are often employed for this purpose, and partially as outsiders, because of their Western education or because they work across clan, tribe, language, age and gender boundaries.

Indigenous researchers are embracing all methods of research. There are some Indigenous scholars who argue there is a place for science and appropriate positivist research. They argue that positivism can be a powerful instrument in the de-colonising of current research practices, through the raising of consciousness of their functions and locations to the sources of oppression (Rigney 2001). As a qualitative researcher, and a researcher who is applying the theoretical perspectives of critical inquiry, it is my view that qualitative research can be equally effective because its focus is on interrogating and dismantling the structures of power that privilege certain people in society based on race, class, gender and sexuality (Fine and Weis 2005; Foley and Valenzuela 2005). Indigenous scholars engage in the de-construction of western ideas and knowledge; they do not want to reproduce colonising practices, but to offer an alternative, an Indigenous standpoint (Foley 2003; Nakata 1998a). Rigney (2001) has begun the process by offering an alternative position of an Indigenous theoretical standpoint; he proposes three core inter-related principles – resistance, political integrity and privileging of Indigenous voices.

Resistance in Indigenous research

The notion of resistance has been an ongoing one for Indigenous scholarship for it has been constrained because of racial tensions and privilege. Watson (2004 pp. 105-06) describes this tension for her as an Indigenous woman:

We grow up a space where the rules are determined by white people. As you said, the notion of white middle class politeness prevails and there can't be angry voices in that space or sick and tired voices, or voices that don't speak in an academic voice.

Indigenous researchers understand the need for firstly, the recognition of the resistance by Indigenous Australians in exposing the sites of oppression in Indigenous Australia, and secondly, the dismantling of these sites of oppression. Because of its racist past, Australia is finding it difficult to accept an Indigenous epistemology (Lake and Reynolds 2008; Watson 2004). This is also true for Indigenous people in other parts of the world. The legitimacy of an Indigenous theoretical standpoint theory is being continually chipped away by the ongoing negative representations of Indigenous culture (Bishop 2005).

Political activism necessary for doing Indigenous research

Indigenous research has for too long being controlled by non- Indigenous researchers, often conducted from a position of political 'neutrality' (Weseen and Wong 2000). Indigenous research is always political, so researchers need to be aware of this reality and be prepared to state their political positioning (Madison 2005).

Benefiting Indigenous voices in the research process

Indigenous scholarship is focused on the representation of the Indigenous voice, in a positive and liberating form (Bishop 2005). There are limitations for Indigenous scholars in adopting this approach, for Indigenous people are not necessarily distanced or detached from what Foley (2003, p. 48) calls 'colonial hegemony', but, regardless, most Indigenous researchers are aware and respectful of their cultural obligations, and in particular to their communities (Moreton-Robinson 2000; Watson 2004).

The academy is aware of the paradigm shift in social theory, as Denzin and Lincoln state: 'Researching the native, the Indigenous Other, while claiming to engage in value-free inquiry for the human disciplines is over' (Denzin and Lincoln 2005a, p. 22). The challenge this presents to Indigenous scholars is immense for the scholarly texts they and other scholars refer to have mostly been written by non-Indigenous scholars and as a result these (non-Indigenous) scholars have the legitimacy and power (Moreton-Robinson 2000). There are still difficulties confronting Indigenous scholars in positioning their legitimacy for they

have their own consciousness of their historical experience. Unfortunately, it is often only a consciousness that can be translated into attitude and demeanour, because there is no language, no 'acceptable' alternative to contest and to influence debate about these issues, that fits the requirements of academic convention (Nakata 1998a, p. 4).

The current dominant views of non-Indigenous scholarship that has positioned Indigenous knowledge and production needs to be contested; it is time to begin the important process of acknowledging an Indigenous standpoint. In an attempt to progress the debate Foley (2003) provides four points that underpin an Indigenous standpoint theory, and reminds us that they need to be flexible and applicable in other Indigenous settings. They are:

1. For an Indigenous standpoint theory to have legitimacy the researcher and the researcher's supervisors must be Indigenous.
2. The Indigenous researcher needs to have competency in social theories (critical theory, feminism, post-structuralism etc). The aim is not to reproduce past practices but to be conscious of these theories' limitations and strengths.
3. The research should be of benefit to the Indigenous community, initially to the researcher's community and then to the wider Indigenous community. The aim is that the research should be for the benefit of the community and **not** the academy. The knowledge gained for the research is to be owned by the community and **not** by the researcher.
4. If possible and wherever relevant the research should be first recorded in the traditional language of the group and not in English, and if in English it should be the second version of recording.

Foley's four criteria offer a valuable contribution to the development of Indigenous standpoint theory, and he claims that the criteria have been authenticated by Indigenous elders across several continents. Importantly, the Indigenous peoples consulted on this perspective have lived with the effects of colonisation and its impact on their respective cultures (Foley 2003). The positioning of an Indigenous standpoint theory within the academy is both necessary and urgent, as for too long the production of Indigenous knowledge has been controlled by non-Indigenous scholars (Tuhiwai Smith 2003). Now is the time for the acceptance of an Indigenous standpoint theory that will empower Indigenous communities (Collins 1990; Foley 2003; Moreton-Robinson 2000; Nakata 1998a; Rigney 2001).

Finally, as the researcher for this study I am intimately aware of past research practices and the negative impacts these practices have had on Indigenous families and communities (Tuhiwai Smith 2003). As an Indigenous doctoral scholar I am under no illusion about the negative community feelings towards research, and know that most research is still regarded with deep suspicion and hostility by

Indigenous people (Rigney 1997; Tuhiwai Smith 2003). Therefore the development of an Indigenous standpoint theory is necessary and important in order to address the unique issues that are complex in nature and that are confronting Indigenous people. As Denzin and Lincoln (2005a, p. 1) note of the role of qualitative research:

Sadly, qualitative research, in many if not all of its forms (observation, participation, interviewing, ethnography) serves as a metaphor for colonial knowledge, for power, and for truth. The metaphor works this way. Research, quantitative and qualitative, is scientific. Research provides the foundation for reports about and representations of 'the Other'.

Therefore, it is critical that Indigenous scholars be reflexive and critical when investigating the unique aspects of doing research with Indigenous people.

1.4 Positioning the study

This section includes a personal overview of the researcher's life and a discussion of the significant events that have shaped the researcher's life as a Nyungar man. As a Nyungar man I am particularly interested in the structures in society that directly or indirectly support racism, particularly cultural racism, and how culture determines power and privilege. The Afro-American historian and activist, W.E.B. DuBois, stated in 1900 that the problem of the twentieth century was the 'problem of the color line' (cited in Lake and Reynolds 2008, p. 1). As an Indigenous person where did I position myself in the research process, researcher or Indigenous community member? There were times where I had immense doubt and confusion as to my role, not only as a researcher but also in relation to the power and privilege this role offers.

Racism is present in Australia, and as Jones (1997, p. 371) notes it is not necessarily always easily detected, and he calls it the 'new racism':

What is important about the new racism is its claim of logic and rationality of thought and judgement. That is the new racist is not a bigot, is not antiblack, or anti-Asian, or anti-Hispanic, but simply a staunch defender of those valued beliefs and practices and custom and way of life that makes ours [not mine] a great society.

This study explores the day to day experiences of Indigenous Western Australians living with serious mental illness, and I am aware that racism is a part of their every day experience.

Knowing the place for the first time

There have been many truths revealed in my life as a researcher. The most obvious is that life is a continual journey of discovery and as student of life there is a

continual moving between spaces of learning. It has been important to be grounded in this truth. If neglected there is the danger of losing perspective and in the process humility. Humility is a wonderful teacher.

I am a Nyungar Yuat Indigenous man and my mother's and grandmother's *booja* (country) is located less than 100 kilometres north of Perth, in the area known as the Victoria Plains, which includes the townships of Mogumber and New Norcia. As an Indigenous man I am constantly reminded of the realities in the Indigenous world and more importantly of my core responsibilities; of commitments and obligations to my family and to the Indigenous community. As an Indigenous researcher I know that I have a responsibility to the well-being of my community.

As an Indigenous researcher I take seriously the responsibilities and obligations of this position. A recent experience was a reminder of these responsibilities. I had attended an academic seminar of researchers presenting on their research. I was shocked and stunned by a presentation given by a colleague whose presentation was interesting and topical, but unfortunately, I believe, quite prejudiced with no disclaimer of research bias being given by the researcher. What was of concern was that the findings presented were not only biased but the statements were without substance. I was very angry for I believed the views offered in the presentation were not only inflammatory but were difficult to substantiate or refute because the researcher's own bias was presented as fact and provided no defence of the philosophical position upon which entire research project had been based. This was a defining moment in my experience as a researcher, for I was reminded of the Maori academic Russell Bishop's (2005) reference to 'social pathology'.

Unfortunately, I was unable to reconcile this at the time. I asked my supervisor and mentor for advice on how I could avoid doing the same and experiencing a similar fate. They suggested that I should examine my own motivations for conducting research and become as fully aware as possible of the events that had led me to becoming a social researcher and to my beliefs in the legitimacy of knowledge which derives from social research. They suggested that not only was this an effective way of deconstructing personal issues and identifying the personal strengths and limitations that would affect the research but also that such self-understanding is a pre-requisite to being able to approach data analysis without undue researcher bias.

This was a very important moment in my post-graduate learning process. I am intimately aware of the impacts of social inequalities, poverty being one of the main drivers of inequality in the Indigenous community, as well as the impact of racism.

This was the situation for most of the participants recruited for the research project. They are among the most disenfranchised in our society, as many live in poverty, and under constant surveillance and scrutiny by State and Federally controlled institutions that administer justice, welfare and income support. I therefore felt personally responsible in the role of social researcher. The study was guided by the principles of social justice. There were no deliberate instances of reproduction of colonialist practices or misrepresentation of the participants as the 'Other'. This can be difficult for what Michelle Fine calls 'working the hyphen' (cited in Weesen 2000, p. 33). In the activities of daily life, there will always exist ambiguities and the fusing of identities. If researchers are not mindful of the pitfalls in the research practice they could easily become absorbed and seduced by the processes of research, which, if not addressed, can result in the separation. This occurs when the researcher creates distance between themselves and the participants and results in referring to them as the 'Other' (Weesen 2000).

The remainder of this section explores the motivations, experiences and the knowledge development which have guided the researcher on the path to being an Indigenous doctoral scholar.

Not ceasing from exploration

In 1967 I left school at 15 after completing Year 10 and joined the workforce, never imagining a career as either an academic or as a researcher. Both my parents were barely literate, my mother who is Indigenous, had little formal education, and with her sisters and brother spent a short period in New Norcia, a Catholic Mission, where the focus was on teaching her domestic skills. These domestic skills were her entry into the workforce as she worked as a domestic and nanny for farming families in rural areas and in the city for professional families. My mother experienced the humiliation and shame of having two of her children removed from her care as babies. I have five siblings and two of my three older siblings were removed from my mother. I know she was saddened by their removal. My only sister saw our mother for the first time while she was in a coma, a few days before she died. My sister told me of her visit and how when she spoke to our mother, even though she was in a coma, a tear rolled down her cheek. My sister was comforted by seeing our mother and being with her during her final days.

Like most mothers, she had aspirations for her children; her dreams were that at least one of her children would 'work in an office environment'. I managed this for a brief period, after leaving school, which pleased her immensely. My early working

career was spent in the construction industry as a as a rigger/scaffolder. This was a great learning experience; the two main lessons learned were firstly, the value and strengths of teamwork and secondly, the importance of acquiring a skills base. In the construction industry, which is highly competitive and very dangerous, the value of teamwork is highly regarded, for to be able to work in a team environment is essential for safety, even survival. The team approach and the importance of building the skills within the team environment are considered essential for an effective working environment. These attributes have been an asset in my choices of future career options.

When in 1986 I enrolled in the Aboriginal Bridging Course at Curtin University, I was initially sceptical of my decision, for like most Indigenous people of my generation, I was not entirely convinced that I was capable or even deserving of 'going to university'. I believed that I was not clever enough. I surprised myself, for not only did I enjoy the opportunity of learning but found that I excelled and as a mature age student I graduated from the Aboriginal Bridging Course as Dux of the year. The experience of the Bridging Course was both liberating and incredibly satisfying. I value so much the learning that occurred and I am grateful for the commitment and energy of the lecturers and my peers. That year was the catalyst for my own intellectual development.

The completion of the Aboriginal Bridging Course solidified and consolidated my interest in social justice issues. I had always been concerned with Indigenous issues but prior to undertaking studies I felt inadequate, primarily because prior to doing the Aboriginal Bridging Course I did not have the confidence to engage in the debates in the public arena; I chose the silent voice. I must admit I did feel frustrated at my lack of skills in being able to articulate, so I was able to recognise that I had a silent voice but it was not necessarily a powerless voice. This situation changed dramatically when I began tertiary studies, for being a student provided a platform that immediately increased my opportunity to be more engaged and to respond to social issues. Importantly, studying at this level provided me with additional skills that enabled me to be more effective in addressing social issues because I could articulate the concerns more clearly and more strategically.

Uncertain futures

In the year after the Bridging Course, 1987, I enrolled in a Bachelor of Business course at Curtin but soon discovered that I was not suited to the course and changed to an Arts degree. After two years of study, in 1989, I took time out and

commenced work at the Centre for Aboriginal Studies for a year. This was a very challenging year; I was going through a marriage break-up, which was difficult. It was in July of that year that was to be the most shattering and life-changing. My daughter died at the age of 16 years after a long illness. Her death was both crushing and transformational.

After my daughter's death I spent a considerable period in mourning, trying to make sense of life and of my place in the world. Questions of mortality, of the unfairness of someone so young, so vibrant and so full of life should die at such an early age. I spent long hours reflecting on life and of its priorities. Emerging from this experience I came to realise, that life is both joyous and painful; that loss and grief are part of life, as is joy and abundance.

Life works in mysterious ways. I divorced and have since remarried. Unknown to us before our marriage, but soon after, my wife was diagnosed with a serious debilitating condition. Since her diagnosis she has spent long periods in hospital. Her condition has been at times life threatening and there have been major adjustments to our life. She now requires constant medical care. Even though her condition is serious, she has adapted wonderfully to her new life, one that she and I did not envisage. Her situation is a constant reminder of the sanctity and impermanence of life. I may have grand plans for my life, but it is important to be mindful to take nothing for granted, life is tenuous and that there is only this moment, and to live it fully.

Arriving where we started

After leaving the Centre for Aboriginal Studies, and after a break of three years, I returned to study Social Work at the University of Western Australia. After completing Social Work, I worked for a year as the Aboriginal Social Worker at Royal Perth Hospital. Throughout my working career, particularly in these later years, I look for and thrive on challenges; most, if not all, the activities I have been involved with are challenging. For example, I spent four years managing an Aboriginal mental health service, growing the agency from four staff to 13, including a sessional psychiatrist, three social workers, a mental health nurse and eight Aboriginal support workers. In 2002 I commenced the Masters of Applied Epidemiology (MAE) Aboriginal Health at the National Centre for Epidemiology and Public Health (NCEPH), Australian National University. My placement for the two year period of the course was with the Sexual Health and Blood-borne Virus Program (SHBBVP) in the Western Australian Health Department. I was employed

in the SHBBVP for a further two years after completing the MAE. But something was missing and it was, I believe, inevitable that I would at some stage commence a PhD. When the opportunity presented I jumped at the chance.

1.5 The silence is deafening

On being reflexive

Entering into the domain of post-graduate study has been both exciting and daunting. As an Indigenous man, the first in my family to embark on such a journey, it has been a challenge. Being reflexive is not only about co-producing the reality of Indigenous people's lives and mental illness, but also what Weseen and Wong (2000, p. 33) describe as 'a set of self-reflective points of critical consciousness around the questions of how to represent responsibility-that is, transform public consciousness and "common sense" about the poor and working classes'. An entry in my journal early into the process provides an insight into the internal tussles in coming to terms with doing a PhD:

Today was a good day in fact the weekend was very productive in sorting my mind about doing my PhD. I spent the afternoon in the library and reflecting on what approach to take in this journey of a PhD. In my readings I discovered that for this to be a transforming experience it will require that I be open to new ideas and to ways of seeing the world. For whether, it is being with family, sitting on the beach, looking at a sunset, doing gardening or walking my dogs they are all experiences and opportunities that allow spaces for reflection. Engaging in reflective practices provide a critical pathway for immersion into the work of post-graduate studies. Combined with discussions with a range of people, including academics, colleagues, friends and family, I believe, will also create spaces for reflection. Slowly the realisation of the transformational experience of doing post-graduate studies is beginning to permeate. I am aware for the need to practice wisdom and mindfulness if I am to explore all the options, so as to engage in a process of 'leaving no stone unturned' in my exploration of the participant's experiences.

There have been a few critical moments of inspiration enabling the shaping of the project. Initially there was a belief that the PhD process would uncover a single truth, but the process opens into many possibilities, as Denzin and Lincoln (2005b, p. 5) state: '[o]bjective reality can never be captured. We know a thing only through its representations'. The reality is that as a qualitative researcher it is not possible to isolate a single truth, but rather to be reflective and learn of other people's life experiences through their storytelling. This, unfortunately, leads to the perception that qualitative research of being less valid than quantitative research methods, because of the multiple truth outcomes. The positivist methodological position, based on the belief that there exists one point of reality to be discovered if reason is followed, is most popular in health research. This has resulted in qualitative

research often being discounted and of no place in the world of health research (Guba and Lincoln 1989; Morse 2004).

This view that qualitative research is less valid is now being contested by qualitative researchers (Denzin and Lincoln 2005b; Morse and Field 1995; Rice and Ezzy 1999). Many researchers engaged in a particular form of qualitative research, using critical inquiry as their framework are stating an alternative position, as well critiquing other work of qualitative researchers (Carspecken 1996; Fine and Weis 2005; Giroux 1994; Madison 2005). Critical ethnographers critique the work of qualitative researchers, arguing for greater accountability, as Weseen and Wong (2000, p. 34) state: '[t]here has long been a tendency to view the self of the social science observer as a potential contaminant, something to be separated out, neutralised, minimised, standardised, and controlled'. Critical ethnographers argue that qualitative researchers need to be more reflexive in their approach to their work, in particular to their position as a researcher and their representation of Others (Madison 2005). As an Indigenous researcher, I felt that it was very important that the study should both be respectful and sensitive to the Indigenous participants as well as valid and rigorous complying with the requirements of the academy.

Researcher (myself) as a learner

There were many learning experiences during the post-graduate process, some memorable others less so, but regardless, all contributed to the shaping in the development of myself as a post-graduate scholar, the following four learning domains were experienced in the developmental period of the study process.

Lesson 1: Representing voices

There was an extended period of lead time prior to commencing the PhD. This was necessary in refining and narrowing the focus of the topic for the PhD. The refinement process was a long and arduous one. Unfortunately, because it was a long process it was the cause for some angst. As researcher I was at times confused and disillusioned, and I did have an expectation that there would be appropriate guidance given from the more experienced people. Regrettably, the guidance given was not always appropriate, which resulted in strained friendships. Eventually, and not without its problems, the topic for the study was decided: *Giving and receiving care: The experiences of care-giving for Aboriginal people with a serious mental health disorder*. Indigenous mental health was chosen as the topic, and, having worked in the area of Indigenous mental health, I am intimately aware of

the major issues. I was keen to explore the issue of how care-giving is constructed by Aboriginal people living with a serious mental illness.

Lesson 2: Different methods, different narratives

I found the process of trying to identify the appropriate methodology for my project incredibly challenging. The initial research proposal was for a quantitative and qualitative study, this quantitative component was abandoned, because of sampling issues, primarily the difficulty of recruiting a sufficient number of participants. I decided that the project would have to be a qualitative study. There are a plethora of qualitative methodologies and initially I chose grounded theory as the methodology. After reviewing the literature on grounded theory I had serious concerns and doubts about the efficacy of the methodology being applied in an Indigenous setting, particularly aspects which I felt it would compromise the building of trust with participants. I had serious issues with the sampling technique of grounded theory, particularly the recruiting of large number of participants which would compromise the building of trust required for a qualitative study.

Grounded theory is premised on an inductive and deductive approach, and to arrive at a theory requires interviewing multiple participants. I have serious issues with this process. The emphasis on the method of interviewing multiple participants is its strength but also a weakness when applied in an Indigenous setting. Indigenous research methods emphasise a relational approach (NHMRC 2006). Engaging a large sample poses difficulties in working in a reciprocal and respectful process. Working with Indigenous people requires that researchers build trust through the relational process (Pidgeon and Cox 2002). The grounded theory approach does not include following up with participants, for example, returning transcripts or being available. It lacks relational methods. These were all reasons to doubt its efficacy in an Indigenous setting. Indigenous research methodology should be respectful and relational (Battiste 2008; Foley 2003). Personal communication with two highly renowned and respected qualitative health researchers, Janice Morse and Judith Wuest (30 July 2006), with their many years of experience in using grounded theory, confirmed my doubts as I was not convinced after communicating with them of its efficacy. I was still left uncertain that it provided sufficient cultural safety when applied in an Indigenous settings. As this study involves working with Indigenous people I was particularly mindful of the importance of choosing a method that would ensure the right combination of cultural safety and research validity for the study (Foley 2003; Rigney 1997). With regard to cultural safety I was keen to ensure that

the study reflected and respected cultural epistemology implicit within an Australian Indigenous setting.

It was my Indigenous co-supervisor who suggested the choice of the theoretical standpoint for my study. Her view was that because of the history of oppression experienced by Indigenous Australians the most appropriate theory is critical inquiry. She was correct, critical inquiry is the most logical and appropriate, for critical researchers are interested in interrogating the power relationships and how they are the cause for social inequalities in society. The logical next step from critical inquiry as the theoretical approach was to adopt critical ethnography as the methodology. From an Indigenous perspective it is not difficult to recognise the implications of the Eurocentric research practices of being irrevocably connected to European colonialism (Bishop 2005; Nakata 1998a; Tuhiwai Smith 2003). The challenge for me in doing this PhD was that I not reproduce colonialist methods in my research process, and to go even further, and adopt the activist/researcher approach. This involves identifying and labelling the impact of colonialism, the most obvious being racism and how racism continues to disadvantage and disenfranchise Indigenous people (Madison 2005).

Lesson 3: Travellers on the path

Deciding on a supervisor was also a long and difficult experience. Supervision in a cross-cultural context is complex, particularly, between Indigenous scholars and non-Indigenous supervisors (Ma Rhea and Rigney 2002; Tuhiwai Smith 2003). A major lesson I learned in this process is that friends are not necessarily suitable as supervisors. My two initial supervisors lacked the flexibility in allowing me to choose the methodologies, methods and theoretical approaches that I considered were more culturally appropriate and safe (Ma Rhea 2002). Fortunately, it was the support of a colleague who assisted in the recruitment of my current supervisor. My current supervisor adopts a reflexive approach to her supervision. She is aware that supervision in a cross-cultural context is a complex issue, and her reflexive approach allows for the space for an interaction that is respectful, nurturing and productive. As a supervisor she is very insightful and sensitive to the cultural issues involved in doing research with Indigenous people. The process of selecting a supervisor has been a major learning experience. The bureaucratic maze of the academy in regards to cross-cultural supervision needs to be addressed for it is adding to the confusion and difficulties already confronting Indigenous post-graduate scholars (Ma Rhea and Rigney 2002).

Lesson 4: Collaboration as a process

From the outset I was determined that the research project be a collaborative process between the researcher and the community. Indigenous research processes adopt a relational approach to doing research for it is a core aspect of an Indigenous perspective and reality (Pidgeon and Cox 2002; Tuhiwai Smith 2003). As a means to ensure Indigenous authority and legitimacy a Study Reference Group was convened to provide advice and direction for the project. The Indigenous literature on research supports the view that research needs to be relational in its approach, or as Rigney states 'process driven' rather than 'outcome oriented' (Rigney 2001). This is the most significant point of knowledge difference between Indigenous and non-Indigenous research approaches, for Indigenous researchers accept the ethical and moral responsibilities expected by their respective communities (Marker 2004; Rigney 2001; Tuhiwai Smith 2003). There is the cultural responsibility because of kinship and other cultural obligations inherent in being Indigenous. As an Indigenous researcher and activist there is a responsibility to be proactive and focused, as critical research is about challenging societal unfairness and injustice 'within a particular *lived* domain'. This will mean being prepared to work at the edge, for 'the critical ethnographer resists domestication and moves from "what is" to "what could be"' (Madison 2005, p. 5).

The final section in this chapter introduces the reader to an Indigenous standpoint from an Indigenous man's perspective.

1.6 Overview of the thesis

This section provides an overview of the structure for remaining chapters in the thesis. Chapters Two and Three will review the literature, with firstly in Chapter Two, a review on the historical linkages between Indigenous Australians and Australian society, as well as an exploration on racism. In Chapter Three there will be a review of the philosophies of caring, morbidity and mortality rates of mental illness. Chapter Four will provide an overview of the theories that have guided the research process. This chapter will explore the history of sociology, in the context of social theory with a critique of the following theories: postmodernism, post-colonialism and critical theory, and a review of theories of identity politics and the impact of racism. Chapter Five will describe the methods and methodologies used for the study. The chapter will also provide the epistemological positioning of the study, including the concept of Indigenous epistemology and critical inquiry epistemology. Chapter Six and Seven will present the findings from the study. Chapter Eight will present the

findings from the art workshop. Chapter Nine the discussion chapter will apply a critical ethnographic approach with multi-level analysis to explore the experiences of the participants from their positions within family, community and society. Finally, Chapter Ten will conclude with an analysis of the thesis process, by examining the representation of the participant's stories where their lives have been influenced dramatically by the presence of a serious mental illness.

Chapter Two: *Challenging Colonisation* – Literature Review Part 1

2.0 *Introduction*

The introductory chapter developed the rationale for the research with a particular focus on the concept of how care-giving is constructed by Aboriginal people living with a serious mental illness. To give the context for the thesis Chapter Two covers the first part of a review of the relevant literature. It explores the central subjects of mental health care-giving and racism, in particular cultural racism, which has dominated and oppressed Indigenous Australians. There will also be an examination of the link between racism, health and care-giving. An examination of these links is critical to fully understand Aboriginal care-giving experience in the context of any health issue but particularly in the context of mental illness which has additional burdens of social stigma and discrimination. The chapter has been organised into two sections:

Race and modernity: The realities of racism provides an analysis of racism in the context of health and wellbeing of Indigenous Australians. It offers an analysis of racism by reviewing two case studies, a Hmong family and the Northern Territory Emergency Intervention introduced by the Howard Government in 2007.

Uncovering and discovering: history yours or mine? explores the historical linkages between Indigenous Australians and White Australian society, particularly the impacts of colonisation and racism.

Summary: will review the main points discussed in the chapter, and conclude by reviewing the key items to be covered in the following chapter.

2.1 *Race and modernity: The realities of racism*

Defining racism

The question *what is racism?* seems innocuous, but surprisingly it is one usually asked by people who have never directly experienced racism. The literature on racism towards Indigenous people is often confined to Indigenous scholars and

critical theorists (Weis and Fine 2004), with Indigenous scholars writing on racism from their personal experiences (Huggins 2003; Moreton-Robinson 2000; Nakata 2007). Afro-American critical theorist, James Jones, is considered among his peers one of the finest academics who writes on race. Jones (1997) proposes that racism is complex and in contemporary society it should be viewed from individual, institutional and cultural frameworks. These three types are distinguished by their psychological, behavioural, structural and cultural interactions and processes influenced by racialised beliefs and practices.

Racism has its origins in the concept of race which has its own history, often layered with meaning that is then expanded into racism. Jones (1997, p. 364) notes: '[t]he concept of race sharpens differences among people and endows these differences with a certain biological inevitability'. Race, as a social and cultural construction, has been used to separate and categorise groups on the grounds of their physical and cultural difference, resulting in superiority and inferiority of members of those groups. Interestingly, even though there is now sufficient evidence that disputes the notion of a scientific theory of race, it still 'persists as a social and cultural construction' (Jones 1997, p. 364). The issue of race as a biological marker is complex for, as Paradies (2006c, p. 144) states, "'race" is about much more than just skin colour or phenotype and is instead an intrinsically protean concept that is not necessarily either immutable or inheritable'. The concept of race and its differences continues because it contributes to social cohesion, as 'it is the point around which many important psychological and social processes revolve' (Jones 1997, p. 364). Race as a concept is therefore important in the ongoing stability of society.

Racism is a process as it begins with prejudice and discrimination. Discrimination 'consists of negative behaviour toward a person based on negative attitudes one holds towards the group' by that person initiating the negative behaviour' (Jones 1997, p. 11). But racism as a concept is broader than discrimination. Race as a biological concept is linked to the belief that 'biological essences are attached to psychological or behavioural characteristics that are presumed to be heritable' (Jones 1997, p. 12).

In contemporary society there are predominately three types of racism – individual, institutional and cultural. While these three types have their own unique qualities they can and often do occur simultaneously. It is difficult to provide an explanation of the concept of racism that can be condensed into a simple definition. Rather,

because of its complexity, Jones (1997, pp. 12-13) offers the following as central elements of racism:

1. Belief in racial superiority and inferiority.
2. Strong in-group preference and solidarity, as well as the rejection of people, ideas, customs, that diverge from those customs and beliefs.
3. A doctrine of a cultural or national system that conveys privilege or advantage to those in power.
4. Elements of human thought and behaviour that follow from the abstract structures, social structures and cultural mechanisms of racialism.
5. Systematic attempts to prove the rationality of beliefs about racial differences and the validity of policies that are based from them.

Individual racism

Individual racism is often the most overt form of racism and as a result often the easiest to measure. Accounts of personal racism are often complicated by questions of reliability of the respondent, and may distort their accuracy (Paradies, Harris and Anderson 2008). Regardless, perception is valid in giving an account of racism, and this is now well understood with regard to its effects on health. The difficulties in measuring racism are challenging because racism is not always overt and can be layered with other forms of oppression, and these cumulative effects can have long term health consequences (Larson et al 2007).

Race prejudice and racism share the belief in the notion of racial superiority. A racist individual is a person who believes that because of a different physical typology of a racial group, s/he is superior and that the other is inferior. According to Jones the definition of the racist individual is:

One who considers that black people as a group (or other human groups defined by essential racial characteristics) are inferior to whites because of physical (i.e., genotypical and phenotypical) traits. He or she further believes that these physical traits are determinations of social behaviour and of moral or intellectual qualities, and ultimately presumes that this inferiority is a legitimate basis for that group's inferior social treatment. An important consideration is that all judgments of superiority are based on the corresponding traits of white people as norms of comparison. (Jones 1997, p. 417)

Institutionalised racism

Institutionalised racism has been recognised as a concept only since around the 1970s. It is predicated on considerations that institutionalised practices play a major role in the systematic denial of rights and opportunities to members of minority groups and that people upholding these practices may or may not intend to deny opportunities. Institutionalised racism is intricately linked to power. The capacity to

wield power is the difference between prejudice and racism. To have the opportunity to influence and exert control over the type and construction of structures within society allows for the creation and continuation of a racial social order. Jones (1997, p. 438) defines institutional racism as ‘those established laws, customs, and practices which systematically reflect and produce racial inequalities in American [or any] society’.

Society’s institutions can disadvantage certain groups of people when there is disregard for the different cultural affiliations and values held by members of different racial groups. Institutionalised racism is embedded in these systems. Two issues underpin the harmful effects of institutional racism: the first is that the impact of racism is dramatically intensified when it is institutionalised, and the second, that institutionalised racism, when enacted through policy, diminishes the responsibility of individual/s (Jones 1997). Jones further states, ‘institutionalised racism is significant because its effects are widespread can result from overt racism by an individual, or from a negative race-based policy’ (1997, p. 437).

Cultural racism

Cultural racism is insidious, and therefore more difficult to define. Society is imbued with culture which, as Jones put it, ‘is to society as personality is to the individual’ (1997, p. 471). An understanding of culture is critical to the comprehension of cultural racism, for culture ‘is the medium in which racial thinking, racialism, and racialisation processes were planted and have grown’ (Jones 1997, p. 472). The definition for cultural racism proposed by Jones (1997, p. 472) is:

Cultural racism comprises the cumulative effects of a racialized world-view, based on belief in essential racial differences that favour the dominant racial group over others. These effects are suffused throughout the culture via institutional structures, ideological beliefs, and personal everyday actions of people in the culture, and these effects are passed on from generation to generation.

The twin notions of ethnocentrism and hegemony can be deduced from the above definition. Ethnocentrism within racial groups is defined as holding the view and belief that one’s culture is more superior to another culture (Todorov 2006). It can be the catalyst for cultural racism. Cultural racism is the cumulative effect of an ethnocentric worldview. It becomes problematic when this ethnocentric view is also positioned as part of a ‘privileged in-group’ (Jones 1997, p. 473). The combination of privilege, power and ethnocentrism in a society can result in the production of practices and values that serve the interests of group or groups which are privileged, powerful and ethnocentric. The practices and apparatuses implemented and

supported by the dominant group are those that define hegemony. Hegemony, in part, refers to the dominant group in society which, because of its position of power and control, exerts its influence over the values of society. This group then has the power to define cultural values that may disadvantage, marginalise and exclude others (Jones 1997).

Ethnocentrism and hegemony underpin cultural racism the impacts of which, in society, are evident within institutions, ideological beliefs and the day-to-day lived experiences of oppressed groups. This form of racism is much more insidious and divisive, with consequences being transferred from generation to generation. Oppression occurs when one racial group imposes its views and beliefs onto another racial group (Jones 1997).

An understanding of cultural racism is critical too, as it gives meaning to the values and principles that underpin the human experience. The following presents two examples which explore further the issue of racism. The Hmong family and the Northern Territory Emergency Intervention share common experiences of racism, but they also have their own unique issues.

2.2 Racism in the real world: The many faces of racism

Impact of racism on health and wellbeing

There is now clear evidence that links racism with poor health outcomes (Krieger 1993, 2003; Williams 1999; Williams, Neighbours and Jackson 2003; Paradies 2006c; Paradies, Harris and Anderson 2008; Paradies and Williams 2008; Bhopal 1998; Jones 2000; Harris et al 2006; Snowden 2003). A number of studies have shown the link between self-reported experiences of racism and adverse health outcomes (Karlsen and Nazroo 2002; Kreiger 2003; Williams 1999; Williams, Neighbours and Jackson 2003; Paradies 2006a; Paradies, Harris and Anderson 2008). Williams Neighbours and Jackson (2003) and Paradies (2006a) conducted meta analyses on racism and health. The Paradies study was a systemic review of 138 empirical quantitative population-based studies based on self reported instances of racism and health. The study by Williams, Neighbours and Jackson reviewed 53 population-based studies, 24 published on or after the year 2000, linking the relationship between racism, discrimination and health. Indigenous Australians experience racism and discrimination which has been clearly demonstrated to have a deleterious impact on their health and well-being (Larson et al 2007; Paradies, Harris and Anderson 2008; Paradies and Williams 2008; Cunningham 2002; Hall et al 2004; Coory and Walsh 2005). From this growing and

emerging evidence it can now be established that there is a clear link between racism and adverse health outcomes.

Understanding how racism can have negative health outcomes for care-givers is important in the context of this study. In particular, if we are to work in a culturally safe manner with Aboriginal people, it is important that we understand how the combination of racism, ethnocentrism and hegemony can de-legitimise and devalue Aboriginal culture.

In framing the context for a discussion on racism two examples have been used. The first deals with the experiences of the Lee family, a Hmong family living in the United States of America (USA), and their experiences with the health system. The second example is the Emergency Intervention that was implemented in Northern Territory, Australia in 2007. Both examples are used to analyse racism and investigate how racism shapes and influences decision making. The two case study examples are used to illustrate how the voices of marginalised people are often not heard or acknowledged within the hegemonic culture. The section begins with an examination of the tensions around racism, science and health, and then gives some consideration to the methodological challenges of conducting studies focussed on racism and health. The literature on the effects of racism on health is reviewed and, finally, the experiences highlighted in the case studies are linked to the literature on racism.

The explicit nature of racism, when directed toward an individual or group, is often premised on the notion of superiority – cultural, social or even intellectual. An illustration of this type of interaction is the story of a Hmong refugee family and their interactions with the health system in the USA. The Lee family are part of the Hmong community who migrated from Laos in the early 1980s after they had been displaced by war. Their story is personal and tragic as it involves a series of events which resulted in their daughter Lia suffering extensive brain damage leaving her in almost a vegetative state. The case examines their interactions with the White, ethnocentric American health system and the contribution of this system to the damage to Lia's health.

Lia was Mr and Mrs Lee's fourteenth child and, unlike her older brothers and sisters, she was the first child to be born in the United States. Being born in the United States was significant for a number of reasons, not least of which was the fact that she was the first of Lee children to have been born in a Western hospital. Given that Lia's mother had given birth to her other thirteen children in the traditional Hmong

method, to her, the western approach would have been immensely different, perhaps bizarre at best, and incredibly frightening at worst (Fadiman 1997). The family's difficulties with the health system were evident from the beginning; the birth at the hospital and the strangeness and unfamiliarity with the system were the precursor of what was to follow. When Lia was three months old she had a seizure and was taken by her parents to the local hospital, Merced Community Medical Centre (MCMC). For the next four years the lives of Lia and her family were to become intricately entwined with the United States health system and this case provides a unique study of the fatal and near-fatal implications of cultural marginalization within a mainstream health system.

The discussion and analysis of the Northern Territory Emergency Intervention begins with 21 June 2007, a date that will live in the memory for most Indigenous Australians as a day when their rights as a people were compromised. On this day the Prime Minister of Australia, John Howard, and the Minister for Indigenous Affairs, Mal Brough, declared a 'National Emergency' in Indigenous communities in the Northern Territory. It was called a National Emergency because a week before the declaration, the Northern Territory Board of Inquiry into the Protection of Aboriginal Children from Sexual Abuse the *Ampe Akelyernemane meke Mekarle*, '*Little Children are Sacred*' report had been released (Hinkson 2007).

The findings from the '*Little Children are Sacred*' report were very disturbing, unreported incidences of child sexual abuse and widespread alcohol abuse being the main issues. At the top of the list of the report's recommendations was for governments to consult with Indigenous people. The Federal Government chose to ignore this particular recommendation and instead marginalised Indigenous people, in particular indigenous men, from the process, and proposed its 'Intervention'. In the community, the three primary concerns relating to the Intervention were: firstly, the wider impact of measures being proposed, secondly, the lack of consultation with the process, and thirdly, the timing of the Intervention which raised questions of the sincerity of the government in choosing this course of action given that an election was due sometime in 2007. There was some concern that Indigenous people might be being used as pawns in a political game (Behrendt 2007; Dodson 2007; Turner and Watson 2007; Wright et al 2007). This case provides an example of how cultural racism can have unintended effects.

Northern Territory Intervention and Paternalism

Paternalism according to the Oxford Dictionary is defined as 'the policy of governing in a paternal way' (1990, p.872). The Oxford dictionary defines paternal as 'limiting freedom and responsibility by well-meant regulations' (1990, p.872). Paternalism is a form of racism when decisions are made by a race with greater social, institutional, resource and decisional power (non-Aboriginal Australians) towards a race with less power (Aboriginal Australians) without consideration of the racial power differentials existing in the social and national context. In the example of the Northern Territory Intervention the power imbalance between the Office of Prime Minister with the support of the military, police, public service and all other machinery of government directed at Aboriginal people living in remote locations is of the greatest conceivable proportion.

This was a unique situation where the decision maker possessed unilateral fate control including absolute decisional power over the limited resource bases as well as future resource access for the target population (Aboriginal people living in remote communities in the Northern Territory). In a situation of unilateral decisional power the risk for harm is great irrespective of whether the motivation is political, benevolent, paternalistic, and ignorant or racially based aggression and hostility (van Dijk 1992, 1993). In the Northern Territory Intervention those with resources (of one race) made decisions which limited and constrained access to resources for people of another race (Aboriginal people) who, in this situation were already resource-oppressed. The action was racially motivated, made on the basis of race, not on the basis of socio-economic strata or another demographic and therefore constituted a racial act.

Racism in the real world: A Hmong Experience

The story of the Hmong family is relevant to this study because the central issue is a minority family's interaction with a health system, and the cross-cultural issues this raised. The relevance of the case example of the Hmong to Aboriginal experience is in its power as a non-Indigenous example of the serious health consequences faced by people when health professionals do not understand or appropriately respect cultural and ethnic contexts. The fact that people can literally die due to a lack of cultural understanding provides validation for the links between racism (individual, institutional and cultural) and the mortality and morbidity rates faced by Aboriginal people. The Hmong family example illustrates dramatically the challenges of working in health in a cross-cultural setting. The Hmong case highlights the reality

that tragedy can occur, not because medical staff are uncaring, but because they lack insight into a patient's cultural context and worldview. It is a sobering example of what can happen when health care professionals fail to recognise the complexity of other cultural worldviews. It also highlights the consequences of institutional racism and rigidity in policies and procedures which are not able to respond to the wider ecological context in which the individual lives (Bronfenbrenner 1979, 1986, 1994). The case study of the Hmong family illustrates the cultural complexity that care-giving can represent and that needs to be understood from within a complex ecological framework.

The tone of the Lee family's experience with the health system was established fairly early in their contact. Lia's birth in a Western hospital was extremely culturally different for the family, but the system did not recognise these cultural differences and offered no allowance for them in their interactions with the family.

Cultural difference was rarely acknowledged by the health system. This blinkered approach to health provision contributed to, and at times was the cause of, immense and unnecessary angst, hurt and confusion for the family. Indeed, the approach by the health system is quite remarkable. After Lia's first seizure she had multiple other seizures, all resulting in her presenting to the hospital, but it was only after her third hospital visit that the doctors actually gave the family a diagnosis of epilepsy. The communication of the diagnosis happened on this occasions for three reasons, firstly, she was still in the act of having a seizure when she presented, secondly, a cousin who could speak limited English was with the family, and thirdly, the treating doctor had some experience with working with the Hmong community. Previously, when the family presented at the hospital, Lia had usually stopped her seizure/s, and because the family could not speak English there were severe communication problems, and as there were no interpreters at the hospital, Lia was sent home with no treatment (Fadiman 1997).

Was the inaction by the previous treating doctors at the hospital a form of racism, or just incompetence or neglect?

The situation between medical staff and the family began to deteriorate dramatically over the ensuing months and years. The medical staff at the hospital where Lia presented were frustrated by the parents who they believed to be hostile, difficult and non-compliant in following medical procedures. The situation reached the point where the treating paediatrician referred the family to Child Protective Services requesting that Lia be removed from her family and placed into a foster home

placement, citing medical non-compliance for Lia's condition as child abuse. The action taken by the doctor, even with the best of intentions, had dramatic consequences. Any trust, fragile at best, the family had with the health system was shattered, perhaps permanently. The situation between the medical staff and the family deteriorated even more. As the family had lost both faith and trust in the treating paediatricians they had resorted to traditional Hmong practices, while the paediatricians, on the other hand, believed that the family's non-compliance with medication meant that they were neglecting Lia's health. Exactly twelve months after Lia was removed from her family, she returned home to her parents.

During her absence from the family her condition had not improved, if anything her condition was gradually deteriorating. Nine months after Lia had returned home, she had a grand mal seizure, which left her with severe brain damage. The intervention by the hospital was also inadequate. Lia survived the grand mal seizure, but she was clinically 'brain dead'. Fadiman describes the situation thus: 'Here was American medicine at its worst and its best: the patient was reduced from a girl to an analysable collection of symptoms' (1997, p. 147).

Lia did not die but instead, years after this event, she remained alive, lovingly cared for by her parents. The transformation of the attitudes of the medical staff was dramatic – over this time the family went from being seen as 'child abusers' to 'model caregivers'. As one of the paediatricians stated, '[t]hey did a better job than most white families [who] would [have] institutionalize her in a second' (Fadiman 1997, p. 214). This change in attitude was welcomed, but for the Lees something had shifted dramatically, they never fully trusted authority, regardless of the foster care order being lifted, for, as Lia's father stated:

If we allow, they probably would take her away again, but we just love Lia too much and we don't want anybody to take her. My wife watches every day, so they cannot take her. My wife would not let them (Fadiman 1997, p. 215).

The medical system's responses to the Lee family offer an example of cultural racism, the least understood of the types of racism. Jones defines cultural racism 'as the individual and institutional expression of the superiority of one's race's cultural heritage over that of another race' (Jones 1997, p. 14). In the United States, according to Jones (1997, p. 15), 'White Western European religion, music, philosophy, law, politics, economics, morality, science, and medicine are generally considered to be the best in the world'. Racism is about superiority and power of the individual and individual's group, therefore racism is intricately linked with cultural as well as racial differences.

There was an overriding perception held by the medical staff that the Lee family were recalcitrant, unreasonable, sometimes hostile and ungrateful. The dilemma in this situation is doctors' blinkered approach to their work. They do not see themselves as anthropologists or sociologists, so it is almost inevitable that there will be tension when western based medicine is practiced and delivered in a cross-cultural situation (Fadiman 1997). Instances of racism will occur when tensions arise between cultures because positions become polarised when the dominant culture refuses to acknowledge or welcome another culture vastly different from their own.

The challenges of practicing medicine in a cross-cultural situation are real. The Lee family's experience highlights that an interesting exchange between two health professionals underscores the conflictual dynamics between the personal and the professional. Within the medical profession there are four principles that underpin medical ethics: non-maleficence, beneficence, justice and autonomy (Hunter 2007). However, according to Hunter, there is a conflict between two of these principles – beneficence and autonomy. When applied, beneficence translates as paternalism. In working with the process of respecting a patient's independence and ability to choose treatment, some conflict can be expected, as doctors would have some difficulties in working with the principle of autonomy in the course of their work. The following exchange between two practitioners, one a doctor and the other a psychologist, both of whom at worked with the Lee family, illustrates this dilemma.

The conversation between the two professionals began with psychologist indicating "that she had once told a doctor at MCMC [Merced Community Medical Center] that a *txiv neeb* (Hmong shaman) of her acquaintance had a direct line to God", the doctor replied "Well I have a direct line to biochemistry". The conversation between the two continued and shifted onto Lia, and in particular the rights of the patient (child) and of the patient's family cultural beliefs. The doctor began by saying "You have to act on behalf of the most vulnerable person in the situation, and that's the child. The child's welfare is more important than the parent's beliefs". The psychologist disagreed and challenged him by saying that he was a product of his profession, he disagreed by saying "I'd feel the same way if I weren't a doctor, I would feel that I am my brother's keeper". The psychologist was astounded and perplexed and responded by saying "That's tyranny! What if you have a family who rejects surgery because they believe an illness has a spiritual cause? What if they see a definite possibility of eternal damnation for their child if she dies from the surgery? Next to that, death might not seem so important. Which is more important, the life or the soul". The doctor's response was equally emphatic "I make no apology. The life comes first". To which the psychologist responded in an equally determined manner "The soul" (Fadiman 1997, p. 277).

The above example illustrates how the doctor, who is White, believes that his cultural beliefs are superior to those of the Lee family, who were Hmong. Racism is

complex, and it is much more than just the colour of someone's skin, as they 'often centre on essentialised concepts of 'culture' and/or 'religion' as markers of innate difference between social groups' (Paradies 2006c, p. 144). This narrow approach to medicine is a form of cultural and systemic racism. The exchange between the doctor and the psychologist recorded above highlights the realities of cultural racism. Even though the psychologist and the doctor were both White, their views were very different. What was evident in the exchange were the immutable comments by the doctor that western medicine should take priority over cultural issues. Indeed, the doctor's derisive comments of having 'a direct line to biochemistry', in response to the psychologist's comments that the Hmong shaman she knew having a 'direct line to God', is, I believe, an example of cultural racism. A belief, as Jones (1997, p. 472) noted, is 'a racialized world-view, based on belief in essential racial differences that favour the dominant racial group over others'. Racism also shares this complexity, with hostility between cultures, and conflict within cultures.

Racism in the real world: The Northern Territory Emergency Intervention

The Northern Territory Emergency Intervention is included as a case example to illustrate the current political realities and social and political relationships that exist between Indigenous and non-Indigenous Australians. The aim of the case study is to highlight that the corrosive effects of paternalism in regards to the relationships between Indigenous and non-Indigenous Australians are not simply a historical artefact but part of the present day oppression of Aboriginal people. Even though there were perhaps good intentions behind the Intervention, the major concerns include the fact that a modern day democracy overrode democratic, legal and international bureaucratic standards and procedures to impose rules on one racial group. The flawed methodology of the Intervention is also of concern as illustrated in the refusal by the Federal Government to consult with Indigenous people in the Northern Territory and the coercive nature of the bureaucratic response. Studies have shown that in situations where Indigenous people have greater control over their lives, that is, have self-determination, they have better health outcomes (Harvard Project 2000; Cornell 1993; Cornell and Kalt 1993a, 1993b; Chandler 2000). The Northern Territory Intervention did not encourage self-determination but rather, it undermined the principles of self-determination. Self-determination can occur at the macro and the micro level. The Northern Territory Intervention is a strong case example of racial paternalism enacted at the macro level.

The Intervention

In the days following the introduction of the Northern Territory Emergency Intervention on 21st June 2007, the Federal Government proposed a list of measures as part of the Intervention designed, as they claimed, to protect Indigenous children from sexual abuse. It became clear that several of these measures had far reaching consequences, which raised further suspicions of the motives of the government in introducing them. The measures proposed by the Government were so draconian that they required repealing the *Racial Discrimination Act 1975* (Cth) (Behrendt 2007). As the Howard Government had control of both Houses of Parliament, the House of Representatives and the Senate, they were able to ram through amended legislation that repealed the Act, giving the government legal authority to override international Human Rights measures (ABC News 2007; Behrendt 2007). Although the minor parties rejected the changes, Labor Opposition supported the amended legislation.

This was a sad day for Human Rights in Australia. The Federal government's suspension or exemption from the *Racial Discrimination Act 1975* (Cth) of the proposed Northern Territory Intervention in order to implement these draconian measures, was itself a clear statement of racism.

The rationale given for these measures were the findings in the *Little Children are Sacred* report. One of the major recommendations in the report was for consultation with Indigenous people. As architects of the Intervention John Howard and Mal Brough consulted with no Indigenous people in the Northern Territory. The only Indigenous person Brough consulted with was Noel Pearson, head of the Cape York Institute, on the day before the announcement of the Intervention, but not with any Indigenous community leaders in the Northern Territory (Behrendt 2007), or even with the Chief Minister of the Northern Territory who heard of the Intervention like the rest of Australia, when it was released at Prime Minister's Press conference on 21 June. These secret and clandestine methods are enough to raise questions of the true motives of the government.

Another of the contentious measures outlined in the Intervention was to repeal the permit system that gave Indigenous people control over who could enter Indigenous lands. Indigenous people living in the Northern Territory believe that this new measure was driven purely for ideological purposes (Turner and Watson 2007). Questions were asked about how this was linked to child protection (Behrendt 2007). Indeed, as David Ross (2007, p. 244) argued 'permits provide an important mechanism for protecting vulnerable children as they help police with issues such as

grog running and attempts to import drugs into the community'. It appears that many of the stated proposals were instigated to undermine Indigenous self-determination and in particular Indigenous land rights (Turner and Watson 2007).

The Northern Territory Emergency Intervention provided for the compulsory takeover of Indigenous townships, or what Turner and Watson (2007) call, an example of the Trojan Horse approach, and to be able to alter or even terminate funding agreements. The Intervention proposed a reform of the rental system in Indigenous communities in the Northern Territory, which involved increasing rents on public housing in remote communities to market rates, another 'Trojan Horse' initiative designed to move Indigenous people off their traditional lands (Turner and Watson 2007).

The most draconian of the proposals announced in the Intervention was to quarantine welfare payments, the objective being to 'control the way all Indigenous people living in prescribed townships in the Northern Territory can spend their welfare payment (with no provision for exemption)'. This approach is demeaning and disrespectful for it 'treats all parents and carers as if they are irresponsible' (Hinkson 2007, pp. 3-5). The action of quarantining monies legally allocated to individuals is an example of gross violation of human rights (Aboriginal & Torres Strait Island Social Justice Commissioner 2007). Indeed, this action could only be implemented after the government had successfully gained an exemption to the *Racial Discrimination Act 1975* (Cth) for their actions in the Northern Territory.

The Intervention was undertaken on a grand scale. To achieve their objectives the architects of the Intervention needed to control the media. This is an example of hegemony used by governments in defining the cultural values of that society and if need be to discredit and if necessary de-legitimise the cultural values of another racial group (Jones 1997). The media, with the Howard government, played a significant role in portraying Indigenous people living in the Northern Territory as dysfunctional and in need of protection from themselves (Behrendt 2007).

Indigenous Elder, Pat Dodson stated: 'Instead of being treated as First Nations, we have been reduced by the media and government ideologues to sexual deviants and sociopathic automatons' (Dodson, 2007: 22).

Therefore, from the outset of the Intervention, there was a concerted effort on the part of Mal Brough and his supporters to discredit anyone who would dare question their actions or motives (Behrendt 2007). As Pat Dodson (2007, p. 23) stated a number of Indigenous people who 'motivated by the urgency of ending the suffering

in Indigenous communities, have been recklessly naïve in aiding and abetting the Howard Government's agenda'. The government's approach, according to Mansell (2007), was not to seek advice from specialists in the field, but rather to run with the populist view, and with the views of some Indigenous people. The defence from the government and their supporters was highly emotive, trying to attract public approval by describing the Intervention as 'about the children', the rhetoric and slogan, 'Its all about the children' was to garner community support for the government's actions (Behrendt 2007, p. 17). The message from certain sections of the media and from the Federal Government was designed to reinforce public opinion that the situation was both urgent and necessary. There was the continual undermining of those who dared question the motives behind the Intervention which included labelling them as being 'part of the problem' (Behrendt 2007, p. 17). 'This insulting and disempowering tactic is designed to silence those who are going to be most affected by the interventions' (Behrendt 2007, pp. 17-18).

Northern Territory Intervention and Cultural Racism

There is a natural synergy between institutions and culture. Jones expands this thought further when he states: 'Institutions have over centuries maintained a racialised view of blacks that imposes disadvantage on them and denies them opportunity' (1997, p. 513). The Northern Territory Intervention is infused with racist policy and practices. The *Social Justice Report 2007* provides a list of recommendations criticising the Intervention and recommending the repeal or dismantling of legislation, policies and practices implemented during the Intervention. The key recommendation in the report is the reinstatement of the *Racial Discrimination Act 1975* (Cth) (Aboriginal & Torres Strait Islander Social Justice Commissioner 2007).

The institutions employed to implement the Government measures were the Police, Health and Child Protection services, and in this instance, the additional intimidating presence of the Military. Rundle states 'the use of the military to occupy towns and communities in the Northern Territory, Australia has become the first member of the Coalition of the Willing to invade itself' (Rundle 2007, p. 37), meaning a ludicrous situation. The presence of the Military did have the effect of creating unnecessary fear in the communities, as was soon evident by reports of Aboriginal women fleeing into the bush to escape from the police and army for fear that their children would be taken from them. These stories are similar to those of the victims of the Stolen Generations of their mothers fleeing from the police and authorities, demonstrating

that history has a way of repeating itself (Human Rights and Equal Opportunities Commission 1997).

The motive of the Prime Minister John Howard and his government for the Intervention has a historical context. As Pat Dodson states: 'In its eleven years in power, the Howard Government has laid the political framework for a dramatic change of policy which promotes the absorption of Indigenous communities into Anglo-dominant Australian society' (Dodson 2007, p. 25). Furthermore, the undermining of Australian Indigenous traditional life as experienced on communities, is the Government's other motive because, as Dodson commented, '[t]he ravages of alcohol and drugs, violence and child sexual abuse, and the endemic community malaise are the result, they argue, of separating Indigenous settlements from the mainstream Australian economic and social system'. (Dodson 2007, p. 24) This view is supported by the neo-liberals who have argued for the dismantling of Indigenous Australian communities based on the ideology of cultural superiority and cultural racism.

The Northern Territory Emergency Intervention is a clear example of cultural racism, with members of the predominant White culture believing that Indigenous culture is inferior. Mansell quotes an address by John Howard to the National Press Club on the 25 January 2006:

Most nations experience some level of cultural diversity while also having a dominant cultural pattern running through them. In Australia's case, that dominant pattern comprises Judeo-Christian ethics, the progressive spirit of the Enlightenment and the institutions and values of British political culture (cited in Mansell 2007, p. 76).

With views like these held by the elected leader of the country, the recognition of the uniqueness of Indigenous Australians would always be questioned and de-legitimised.

Racism on the micro level is influenced by macro level discourse. Amanda LeCouteur and her colleagues and other researchers found that attitudes at the micro level, that is, at the level of the individual, were influenced by the macro discourse presented in the media of the recurring themes of negative representations of Indigenous people (LeCouteur and Augoustinos 2001; LeCouteur, Rapley and Augoustinos 2001; Huguens 2006; Nairn et al 2006; Hodgetts, Masters and Robertson 2004). A study conducted by Martha Augoustinos and her co-researchers identified a similar pattern of the micro discourse being affected by the views presented as part of the macro discourse. Their study on 'race

relations in Australia' with undergraduate psychology students, showed that public perception has returned to the historic racist themes that frame Aboriginal people as belonging to a primitive culture, having a race based criminal pathology (recalcitrant and undisciplined), posing a threat to White society and generally being unable to cope with modernity (Augoustinos, Tuffin and Rapley 1999) rather than being a group that face a unique and complex range of structural and system challenges. These types of inaccurate, racist stereotypes have been shown to be propagated and supported by popular media and by politicians with personal racist beliefs (Rapley 1998; Nairn et al 2006).

The negative racist representation of Indigenous people that has been popularised by the media (Huygens 2006; Nairn et al 2006; Hodgetts, Masters and Robertson 2004), was very clearly present among politicians and in the language and media used to justify the Northern Territory Intervention (Altman and Hinkson 2007). The media and some politicians clearly misrepresented Aboriginal people, by portraying them as primitive, lacking in discipline, incapable of self-governance and generally dysfunctional (Altman and Hinkson 2007). The language was muted in its tone to reflect the discourse of modern racism of neo-liberalist morality – individualism and self-discipline (Stringer 2007; Brown and Brown 2007). What needs to be noted is that the Northern Territory intervention cannot be considered as an isolated event separate from the context of the previous decade of harassment and racial targeting of Aboriginal sovereignty, resources and groups. From 1996 until 2007, Prime Minister Howard and his government had a relationship with Aboriginal people represented by ongoing negative media portrayal, the removal of core infrastructure and survival resources, the dismantling of Aboriginal institutions, increased restrictions; increased bureaucratic requirements to assimilate to White culture (mainstreaming of services) and increased surveillance (Rapley 1998; LeCouteur, Rapley and Augoustinos 2001). The Northern Territory intervention could therefore be considered as the tipping point of the increased institutional and cultural oppressions enacted over the previous decade by this Federal government.

The effects of cultural racism are damaging to the psyche of the racial group. In Australia the continual undermining of Indigenous culture has had that effect. The continual representation of Indigenous culture as being dysfunctional has the overall effect of creating a sense of demoralisation (Behrendt 2007). Living with this form of racism becomes the central point of reference for Indigenous people, and then it is internalised as the psychological reality of their being (Jones, 1997). Indigenous Australians have experienced the worst elements of colonisation, and with it the

belief by the White colonisers that Indigenous culture is inferior. Racism is all-encompassing, and it is doubly insidious when White Australians do not believe racism exists, and when the Prime Minister can publicly de-legitimise Indigenous culture, reinforcing that view.

There is now an increasing awareness of the cumulative effects of racism. It is bad for one's mental and physical health (Jones 1997, p. 464). Measuring the effects racism has on individual and community is difficult, but if health statistics are a guide then it is clear that racism is bad for one's health. The *Australian Institute of Health and Welfare Report 2008* reports that Indigenous Australians have lower life expectancy, greater levels of disability and compromised quality of life because of poor health (Australian Institute of Health and Welfare, 2008). The report findings were even more disturbing in to the area of mental health:

A higher proportion of Indigenous adults report high/very high levels of psychological stress in every age group. After taking into account differences in the age structure of the two populations, Indigenous Australians were twice as likely as non-Indigenous Australians to report high or very high levels of psychological distress (Australian Institute of Health and Welfare 2008, p. 71).

Linking instances of racism and health issues is difficult, but the sheer scale of Indigenous people reporting instances of racism where they were treated badly because they were Indigenous, is of concern. A study by National Aboriginal and Torres Strait Islander Health Survey (NATSIHS) reported:

About 16 per cent of the 5757 Indigenous adults in the National Aboriginal and Torres Strait Islander Health Survey (NATSIHS) who were asked about their experiences of racism reported that, in that the past twelve months, they felt they had been treated badly because they were Aboriginal/Torres Strait Islander (Paradies, Harris and Anderson 2008, p. 6).

The *Western Australian Aboriginal Child Health Survey*, a study with over a 1000 Indigenous youth, asked them the following question: *In the past six months have people treated you badly or refused to serve you because you are Aboriginal?* There was a 21.5 per cent response to the question (Zubrick et al 2005). In Western Australia, Larson and colleagues found 52 per cent of urban residents and 69 per cent of residents of a regional centre revealed prejudice against Indigenous Australians (Larson et al 2007, p. 323).

Racism, it seems, is enough to make you sick. There is a relationship between poor mental health and racism, as Larson et al state: '[i]nternalising negative racial stereotypes is a consequence of institutional and interpersonal racism and can result in low self-esteem, depression and hostility' (Larson et al 2007, p. 322). Links

between racism and poor health are becoming accepted, the ongoing impact of racism does have health consequences.

The first year of the Intervention

A year after the Intervention what are the results? A headline in *The Age* newspaper on 21 June 2008 which states, 'One year on, child rescue mission's results are patchy and incomplete', is revealing. The main reason given for the Intervention was to eliminate child sexual abuse. The article indicated that the Intervention had not uncovered any evidence of major child sexual abuse occurring in the Northern Territory. Of the health checks done on 773 children, 14 cases had been identified that qualified as abuse, with five of cases being excluded due to insufficient information. Indeed, according to some the monies spent on the Intervention, primarily on wages for Intervention personnel, could have been spent more effectively. Dr Alex Brown, an Indigenous doctor, working in the Northern Territory, said that the money provided for the Intervention would have been better spent on preventative programs. He stated 'The only effective rehabilitation system we have for Aboriginal men is prison because that is where they get fed, are given some education and forced to give up alcohol. That is not the answer' (Skelton 2008, p. 3).

It is now clear that the Intervention was a knee-jerk reaction to get some electoral bounce for a government tired and out of touch with reality. It has now been revealed by Mal Brough that the plan for Intervention was made over a 48 hour period (Siewert 2008). The consequences of this ill-conceived and punitive approach to Indigenous affairs by the Howard Government are still being felt around the country. The Intervention was, the public was told, to address not only the random cases of child sexual abuse occurring in the Northern Territory, but to break more organised child sexual abuse activities. The Australian Crime Commission has reported that they have uncovered no evidence of any organised child abuse activities in the Northern Territory (Siewert 2008).

There are serious questions to be asked about the motives, implementation, and now the reporting of the Intervention. The ongoing deferment of the *Racial Discrimination Act 1975* (Cth) is a concern. The Greens Senator Rachel Siewert has stated that the Labor party, with the Greens' support, should reinstate the *Racial Discrimination Act*, for the longer suspension of the Act it continues to be in place it remains 'an international embarrassment for Labor' (Siewert 2008, p. 2). Labor would do well to clearly redress this issue. The Greens continue to challenge the Intervention, they were the only party to denounce the Intervention at the time of its

implementation, and they continue to be outspoken and critical of its continuation under the Rudd Labor Government. As Siewert (2008, p. 2) states, 'we continue to maintain our opposition to the suspension of the *Racial Discrimination Act*, the compulsory seizures of lands, the indiscriminate quarantining of welfare, and the trampling of human rights of Indigenous people in the Northern Territory'.

The inclusion of a discussion on racism in this thesis should now be clear. Racism for Indigenous Australians is a daily reality. Being a target of racism is painful, brutal and disgusting (Jones 1997), but sadly, for Indigenous Australians it is too common an occurrence. To offer resistance is to be targeted and labelled a troublemaker or worse (Behrendt 2007). The central question of this study is how care-giving is constructed by Aboriginal people living with a serious mental illness. These people experience both racism as well as discrimination because of their illness and, as these areas co-mingle in effect, it is important that both racism and discrimination need to be considered.

Overview of the Northern Territory Intervention and the Hmong

Both case examples share more similarities than differences. The differences between the two case examples are the social geopolitical contexts. What was similar in both examples was the shared experience of the different levels of racism, particularly the impact of cultural racism. For Indigenous Australians cultural racism is a major contributing factor to their continued disenfranchisement and marginalisation. Cultural racism is an ever present phenomenon that exists between the coloniser and the colonised (Memmi 1965; Watson 2005; Tuhiwai Smith 2003) and in Australia colonisation continues to have a disempowering effect on the lives of Indigenous Australians (Watson 2005; Huggins 2003). As Jones stated, 'culture is to society as personality is to the individual' (1997, p. 471) and therefore culture is integral to discussions of racism.

Two important concepts underpin cultural racism: ethnocentrism and hegemony. Ethnocentrism is the belief in the superiority of one's own culture over another. Hegemony refers to the power and control of a select group in a society which defines the cultural values that may disenfranchise and exclude others in society. Cultural racism is the end product of the cumulative effects of a racialised worldview, one based on a belief in essential racial differences that favour the dominant racial group over another (Jones 1997). The legitimacy of cultural racism is transmitted through institutionalised structures, ideological beliefs, as well as the personal everyday actions of people in the culture. Unless challenged cultural racism in it

many forms can be passed on through the generations to become a historical legacy of oppression. Jones (1997) suggests that most black people (and Indigenous people), particularly those working and living in White settings, have to cope with racism every day. Racism in Australia is insidious in the extent to which it is both endemic and unacknowledged.

There are three propositions relevant to the effects of racism on Indigenous Australians. First, for Indigenous Australians racism is a part of their daily experience (Standfield 2004). Second, the cumulative effects of continual and repeated experiences of racism are stress, trauma and poor health outcomes (Larson et al 2007; Paradies, Harris and Anderson 2008; Paradies and Williams 2008; Stuber, Meyer and Link 2008). Third, the constant presence of racism in a community forms the narrative of 'us and them', so that racism becomes a normalised experience which is experienced across generations on a community level as prejudice. Fourth, White Australia has yet to engage fully with Indigenous people on an equal level. The paternalistic view that Indigenous Australians are incapable of managing their own affairs persists. Regardless of the intentions of the Intervention, the way in which it was carried out, within a wider Australian context of generalised, cultural and institutional racism towards Aboriginal people was and is of grave concern.

2.3 Uncovering and discovering: history yours or mine?

First contact

Early reports about the frontier written by the colonists suggested that Indigenous people were quite passive and offered little or no resistance to the expansion of the colonists into their country (Attwood 1989; Reynolds 2000). This early reporting of Indigenous and non-Indigenous relationships has been challenged by academics who have demonstrated that Indigenous people did display courage and strong resistance to the often cruel and violent dispossession of their lands and their society (Reynolds 1982; 2001). There were protests made by Indigenous people about their treatment; some were successful in having their pleas heard, but many were not. For example, in the Pilbara region of Western Australia the pastoral strike from 1946 to 1949 by Indigenous pastoral workers did achieve some results but it came at quite a cost to those who removed themselves from pastoral work (Attwood 1989). Despite courageous resistance on the part of Indigenous people to the cruel and violent dispossession of their lands, it was in the deaths where it was most felt, with large numbers of Indigenous people perishing because of introduced diseases,

loss and grief from being removed from their lands and forced to the margins of newly established European towns and settlements (Reynolds 2001). Indigenous people were used as cheap labour, and in general neglected and abused by the invaders (Reynolds 1996). There was some opposition to these acts of aggression, namely through missionaries and other well intentioned individuals, but by and large, their efforts made little difference (Attwood 1989; Choo 2001).

Historian Henry Reynolds (1996, p.128) states:

British policy towards the Aborigines was contradictory from the beginning. The early governors in New South Wales and Van Dieman's Land (Tasmania) were instructed to treat them with amity and kindness but no provision was made for the purchase of Aboriginal land.

The work of historians like Reynolds, Rowley (1971 & 1972) and others have illustrated that early writings about Indigenous people were 'essentially Eurocentric; historians tried to understand contact between Aborigines and Europeans from the perspective of the newcomers or at least the European men' (Attwood 1989, p. 136). This shift in historiography has heralded a new way of looking at Indigenous and non-Indigenous relationships (Reynolds 2000; Stephenson 2007). Historian Peta Stephenson draws attention to alternative ways of approaching Australian history when she writes of 'the story of the triangular relationship between Asians, Aborigines and White Australia...A unique and fascinating tradition of cross-cultural alliances, but largely unknown' (Stephenson 2007, p. 2). As Attwood states '[t]he most striking characteristic of the next wave of scholarship was its attempt to understand contact from the point of view of Aborigines rather than Europeans, and to cast Aborigines as active agents rather than passive objects shaped and controlled by European colonizers' (1989, pp. 136-37). Historians have begun to record history of the frontier conflict from Indigenous perspectives, by using oral history as the main source information it has been possible to add extensively to the many nuances of the history wars as they occurred in Australia at the time of the invasion (Evans 1999; Loos 1982; Reynolds 2000). There is now an increasing body of knowledge around the history wars of Indigenous and non-Indigenous contact since the time of invasion (Choo 2001; Cowlishaw 2006; Stephenson 2007).

Clash of culture and religion

Most of the early written accounts of Australian history were by men about men; primarily androcentric in style and ignoring the stories and experiences of Indigenous women, with some exceptions. The issues of class, race, gender and sexuality were absent from the early historical accounts of initial and later contact. It

is fairly obvious that in relation to class Indigenous people were relegated to the very bottom of society (Choo 2001). 'Europeans sought to create a place for Aborigines at the bottom of the European social hierarchy as unskilled landless wage-labourers and servants' (Attwood, 1989, pp. 138-39).

There were sustained efforts by the early colonialists soon after first contact in what Reynolds calls 'the systemic attempt to "civilize" and Christianize' Aboriginal people. (Reynolds 1996, p. 129). These first efforts were by and large useless; it was the second wave of missionaries who were more successful in their efforts to Christianise Indigenous people. For example, the Catholic Mission in New Norcia, in Western Australia established in 1849 by Bishop Salvaldo, was successful in the establishment of a church and Christian community. The Mission at New Norcia was involved in the provision of residential care to Indigenous children who were removed from their families. As well as the Catholic Church there were many other mission groups who were present in Western Australia at this time (Haebich 1988). The Catholic Missions provided limited secular learning, but their main aim was to evangelise and convert Indigenous children to Catholicism (Choo 2001). It is still a matter of conjecture about how successful missionaries have been in the actual conversion of Indigenous people to Christianity. The Christian missions were there to spread an ideology which was the ethics and values of those times, 'the religion was bound up with nineteenth century middle class morality with its emphasis on work, punctuality, cleanliness and chastity' (Reynolds 1996, p. 130).

It has been a consistent theme of those who colonise to de-legitimise and undermine the credibility of the Indigenous culture and their rights as owners/custodians of the appropriated country (Said 2006, p. 96). Cowlshaw (1998, p.155) states 'there is a common perception of colonial regimes as intent on compiling systematic knowledge of the colonised'. This preoccupation with ownership of knowledge provides an insight into the understandings of the mind of the coloniser who is transfixed with the view that culture is an unchanging, permanent and visible reality without any spiritual relevance when compared with a society whose ideological source is based upon Judeo-Christian religion (Said 2006). This naïve view of Indigenous cultures highlights the lack of understanding by non-Indigenous people of the Indigenous world-view based on a spiritual connection to country and of the importance of maintaining this connection for the continuation of Indigenous culture (Grande 2008). This is highlighted by Cowlshaw (1998, p. 156) who states:

Colonial authority indeed has had the ability to command the 'truth' about Aborigines, but does so in a series of typifications and stereotypes which bear scant relationship to what anthropologists call 'Aboriginal culture' or to what Aborigines commonly call 'the law.

This ongoing tension between Indigenous people and new settlers was due in part to different perspectives and a lack understanding of the complex set of issues related 'to looking after country', which is different from the Australian concept of property and land ownership (Foley 2003). It was, as Cowlshaw states, 'Aboriginal conception that the relationship between people and land is itself productive of well being' (Cowlshaw 1998, p. 157). In contrast non-Indigenous Australians viewed the land or country in economic terms; of how it could be exploited for money-making purposes.

Policies and laws

The primary purpose of the policies and acts specific to Indigenous people was to control, exclude and segregate them from the mainstream population. In Western Australia this was enshrined in legislation with the *Aborigines Act, 1905* and subsequent legislation. According to Reynolds there was a constant fear of cross-cultural relationships, for example there was an 'exaggerated fear of disease merged with the moralists' concern with the constant sexual interplay between the young and not so young men of the town and women in the fringe camps' (Reynolds 1996, p. 132). Policies affecting Indigenous Australians were racist and by the 1890s Australian policy makers were obsessed by race and emergent nationalism became inextricably involved with ideas of the White Australia (Lake and Reynolds 2008; Reynolds 1996).

There was a critical decision by Australian legislators, both at the Commonwealth and the State levels, to draw a clear line of demarcation on what they considered the 'half-castes' and 'semi-civilised' Aborigines on the one hand, and the 'tribal full bloods' on the other. It was the intention to segregate Indigenous Australians from each other and to assimilate 'half-castes' into the 'White' population. Colour was to be 'bred out' and, they were to be given education and assistance to achieve that objective. 'Full-bloods' were to be isolated on large reserves where their way of life would eventually 'die out'. The increasing numbers of Indigenous children of mixed descent was a source of continued discontent, for according to Reynolds, '[t]he continuing growth of the "half caste" population was a constant subject of anxious speeches, letters and memos because it appeared to undermine the now almost sacred cause of White Australia' (Reynolds 1996, p.132). The 1937 Canberra

Conference of Aboriginal Authorities was, according to Reynolds, 'the first official meeting to advocate assimilation' (Reynolds 1996, pp. 133-34).

Race and racism have all played a role in the new regime of Australia. The social positioning of Europeans and non-Europeans, including Indigenous people, provides an interesting insight into the race relations of Australia, and the formation of the 'White Australia' policy which placed considerable restrictions on those who were non-European (Haebich 2008; Lake and Reynolds 2008; Stephenson 2007; Choo 2001). The country was founded on the premise of maintaining so-called White racial purity and excluding other races, including Indigenous people from participating in mainstream Australian activities (Attwood 1989; Lake and Reynolds 2008).

Indigenous policies since first contact have been highly paternalistic and draconian as they were designed to completely assume total control of the lives of Indigenous people. These policies decreed the right and responsibility of Governments to remove children, manage financial affairs and even decide who people could marry. In Western Australia, versions of the *Aborigines Act, 1905*, which gave authorities absolute control of Indigenous people lives were still in place well into the 1960s (Haebich 1988, 2008).

Self-determination: Success or Failure?

Self-determination as a philosophy for Indigenous Australians came into effect soon after the 1967 Referendum. The philosophy of self-determination was that 'Aboriginal organisations would both deliver services in more appropriate ways and develop enterprises through which communities could become economically independent' (Cowlshaw 1998, p.148). The philosophy underpinning self-determination was an explicit distancing from the assimilation policy (Cowlshaw 1999). The crisis of assimilation in the late 1960s, according to Morrissey, arose 'from a series of internal and international pressures which cumulatively rendered the assimilationist/White Australia policy package untenable, along with overtly racist social policy' (Morrissey 2006, p. 350). What followed the assimilation experiment was the policy of self-determination but upon serious analysis the intent behind the symbolism of self-determination is not self-evident. The Aboriginal and Torres Strait Islander Commission (ATSIC) model was established during this period of self-determination, but with limited powers (Morrissey 2006). The objective of ATSIC was to be an example of self-determination. There are, however, some commentators who argue that the ATSIC did not achieve the goal of self-

determination that 'was supposed to be the choice of subjects, yet at the same time it was designed and conferred by the colonisers in terms of their narrative...it is invariably a process controlled by the colonisers in which they seek affirmation of their proposals' (Wootten 2004, p. 18). There is an argument and a belief that the abolition of ATSIC was, as Morrissey calls it, 'a symbolically crystallizing moment: the point at which one colonizing narrative supersedes another' (Morrissey 2006, p. 350). For many Indigenous people the demise of ATSIC was a further example of an ideology enacted by a Government intent on controlling the lives of Indigenous Australians within a paradigm where 'the economy is no longer a separate domain of social life, it is social life' (Morris 2004, p. 325).

Indigenous Australia since 1996

The issue of Indigenous and non-Indigenous relationships in Australia continues to be both contentious and challenging. According to Beckett the term the 'Aboriginal problem'¹ has a political dimension; 'this is a "*problem*" that governments rather than citizens are expected "to do something about it"' (Beckett 2004, p. 303). The notion that the Aboriginal 'problem' is somehow the responsibility of government is in itself questionable as it leaves Indigenous people in a very tenuous and vulnerable position. Governments past and present have not been overly proactive in responding to solutions offered by Indigenous people, and, as seen in the Northern Territory Emergency Intervention enacted in 2007, policies can be overly paternalistic and punitive. The Northern Territory Intervention is another example of how Indigenous people have been used as political pawns – it was administered in an election year when short-term action of this nature is popular, and it played to the racist element of the electorate by portraying Indigenous people as dysfunctional in their lifestyle and therefore incapable of managing their own affairs (Bauman 2007; Behrendt 2007; Brown and Brown 2007).

Any measure and interpretation, including the most current statistics on Indigenous Australians, have shown that the Coalition government between 1996 and 2007 and their commitment to the ideology of 'practical reconciliation' were flawed (Rowse 2007). But as policy practical reconciliation was pursued relentlessly regardless of its obvious failing, as described by Morrissey:

¹ The 'Aboriginal problem' in this context as defined by government would be low life expectancy, high burden of disease, family violence, sexual abuse, unemployment, housing issues, and poverty.

The last 10 years of Coalition government have seen an abandonment of any effective social justice agenda by the government and its replacement by a politics of reductionism in which the marginalization of Indigenous people is explained largely in terms of the individual, familial or community pathologies of Indigenous people themselves (2006, p. 348).

The attitudes and actions enacted over the past eleven years by the Howard government in its relationship with Indigenous people have had the effect of adding a new page to the Australian history of racism and of damaging relationships between Indigenous and non-Indigenous people. This was very evident from the beginnings of the Howard government with their refusal to apologise for past abuse of Indigenous people. Indeed, this government actively undermined the substantiated historical accounts of severe oppression of Indigenous people. This undermining began with the rejection of Indigenous historiography, which it referred to as the 'black armband history', and continued with the Prime Minister John Howard's refusal to apologise for nation's shame of the 'Stolen Generation', the abolishment of ATSIC and later with the imposition of so-called 'shared responsibility agreements (SRAs), all of which further oppressed Indigenous people and withdrew precious resources from families and communities. The Howard government systematically unravelled and discarded many years' of trust-building that was fostered under the Keating Labor government and which was beginning to reap solid rewards by the 1990s. Although it could be argued that a fundamental reason for this was that during the period of Australian Labor Party (ALP) government, as Morrissey states, 'a sweeping rhetoric of reconciliation and social justice was never, at any point, underpinned by anything near the appropriate commitment of resources' (Morrissey 2006, p. 348).

What does appear to be consistent in the past, from both sides of politics, is that the rhetoric maybe different but the outcomes are the same. Both governments 'manage' 'their Aboriginal problem' as something out there and because they have to be seen as doing something about it. Indigenous people are a small voting bloc and as a consequence they are used periodically and strategically as political fodder to exact votes, either to embarrass the opposition or capitalise on a situation of suffering. In the past eleven years there has been no noticeable improvement in the living standards of Indigenous people, and if anything it has gone backwards (Morrissey 2003a, 2003b, 2006). Report after report show the appalling state of Indigenous people with no significant shifts in life expectancy across all age groups and no change to the social conditions. In the last eleven years 'deterioration was not from good to bad but from bad to worse' (Morrissey 2006, p. 349). It is argued

that the gulf between Indigenous and non-Indigenous people is now so great that it will require a significant injection of real resource transfers to effect any difference.

The Future: The Apology

On 24 November 2007 Australians went to the polls to elect a new government and, after eleven years in office the Howard government was not re-elected. Instead a Labour government was elected with Kevin Rudd as Prime Minister, and almost immediately there was a dramatic shift in the relationship between Indigenous people and the new government. Particularly for Indigenous Australians, the relationship with the Howard government had reached an all time low, but with the change of government, relationships between Indigenous Australians and the government have improved dramatically.

In the lead up to the election Kevin Rudd had indicated that he would give an apology to the 'Stolen Generations' on behalf of the Government of Australia. In a symbolic action on the first day of the first sitting of the new Government, Kevin Rudd made his public apology on behalf of the Australian people. Something happened in Australia that had been missing for the previous eleven years. Across Australia people came together as one, it was a special moment. It was as if a huge weight had been lifted, the stain of the past eleven years was no more (Barker 2008).

Prime Minister Kevin Rudd has shown his commitment to Indigenous Australians with his government's Statement of Intent in closing the gap in life expectancy for Indigenous Australians within a generation (Joint Media Release with the Minister for Health and Ageing and the Minister for Indigenous Affairs 2008; Rudd 2008b). The future is still uncertain, but with the election of the Rudd Government, the rhetoric has shifted slightly, and hopefully the outcomes will be significantly different.

2.4. Summary

In this chapter there has been an analysis of racism in the context of health and wellbeing of Indigenous Australians. The main point that emerged in the chapter was how complex and persistent the issue of racism is in Australia, particularly for Indigenous Australians. The Northern Territory Intervention demonstrated once more the deeply held paternalistic views of non-Indigenous Australians. Australia is still firmly held in the grip of an ideology of colonisation that supports cultural racism; the belief that Australian Indigenous culture is inferior to non-Indigenous culture. In the following chapter there will a further exploration of the issues of poverty and

racism and how this impacts on the activity of care-giving for Aboriginal people living with a serious mental illness.

Chapter Three: *Writing Across Borders* – Literature Review Part 2

3.0 Introduction

The morbidity and mortality rates of mental illness among Indigenous Australians, and their impacts on the Indigenous people are the primary focus of Chapter Three. This chapter provides an overview of this situation and reviews a range of theories related to care-giving philosophies and the accepted societal standpoint underpinning these philosophies.

Working between the cracks - whose mental health? provides an overview of the prevalence of mental illness and the subsequent burden of the disease on the community and summarises the literature related to mental health and Indigenous people.

The paradox of modernity - the life or the soul? reviews critical issues around the politics of care, such as care and justice, individualisation and the ethics of care. The section also discusses challenges for different care-giving practices, both Indigenous and mainstream, and the cultural and social challenges required to maintain care-giving practice.

Summary: will provide an overview of the main points discussed in the chapter, and conclude by reviewing the main issues to be covered in the following chapter.

3.1 *Working between the cracks – whose mental health?*

Burden of disease

With the burden of the disease on global communities increasing rapidly over time, the issues of mental health have become a major concern at the community level and in terms of policy and service provision. It is estimated that there are currently 450 million people across the world living with a psychiatric or behavioural illness, with a future prediction of the possibility of at least one in four people developing a psychiatric or behavioural illness in their lifetime. The morbidity and mortality impact

on communities is also considerable, with five out of the ten significant listed disabilities resulting from a mental illness and causes of premature deaths primarily due to a psychiatric condition (World Health Organisation 2004).

There is increasing evidence linking poor mental health outcomes to negative social and economic situations. Most at risk are those vulnerable groups living on the margins of society. These include people with disabilities (both mental and physical), Indigenous populations and refugees because they are most at risk of social and economic exclusion (Wilkinson and Marmot 2003). This is a vicious cycle because exclusion increases invisibility, and with invisibility adding to increasing isolation there is a cyclic reinforcement of social and economic exclusion (Mental Health Council of Australia 2005). Poverty among those living with a serious mental illness is endemic, further adding to their enforced isolation and thereby exacerbating a tenuous situation with this very vulnerable group. Global studies have shown disturbing findings that poverty is a leading cause of poor health outcomes and that people who live in poverty usually have poor health (Ruger 2004; Wilkinson and Marmot 2003).

In Australia in the mid 1990s in an adult survey of a household sample, over 10,000 persons were interviewed to estimate the one month and one year prevalence of mental health disorders in adult Australians (Henderson, Andrews and Hall 2000). The results from this study estimated that more than one in five persons had a mental disorder. *Mental Health of Australians*, the report of a study by Andrews and others found that 'anxiety disorders were the most prevalent, followed by substance-use and then affective disorders' (Henderson, Andrews and Hall 2000, p. 204). The co-morbidity of a mental disorder with a physical disorder was also estimated in approximately half of the participants, particularly with conditions like kidney disease or chronic bronchitis. What was disturbing was that 64.6 per cent of persons with a mental health problem did not seek professional care (Henderson, Andrews and Hall 2000).

The Western Australian population at the 2001 Census was 1.9 million. The Western Australian Indigenous population was 66 000, representing 3.5 per cent of the Western Australian population, and 14 per cent of the total Indigenous population in Australia. Western Australia has the third highest Indigenous population, proportionally, behind New South Wales (29 per cent) and Queensland (27 per cent). Poor health is very common among Indigenous people, with high rates of diseases such as diabetes, renal and cardiovascular problems (Australian Institute of Health & Welfare 2008).

It is widely known that Indigenous people in Australia experience disproportional negative life consequences in contemporary society (Germov 2005a). For Indigenous people it is double jeopardy, the marginalisation due to race as well as their susceptibility to illnesses borne by wider society further reinforce negative outcomes; indeed marginalisation has been determined as one of the major contributory factor for poor health outcomes (Lloyd, Tse and Deane 2006).

The statistics for Indigenous people reflect their appalling situation. In Western Australia the life expectancy for Indigenous males and females was 15 to 20 years lower than that of the total population with 39 per cent of the population living with a disability or chronic health condition. In 2001 Indigenous Western Australians had rates of unemployment around two to three times higher than the general population with 19 per cent unemployed compared to 7 per cent of non-Indigenous people. The weekly household income of Western Australian Indigenous people was \$268, the second lowest when compared to other Australian states and territories (the Northern Territory had the lowest \$240) (Department of Indigenous Affairs 2005).

The social impacts of mental health in a market economy

The demise of the welfare state in the mid 1970s and the emerging prominence of a more neo-liberal philosophy has had a powerful influence on the standards of the delivery of mental health care. The introduction of a market based approach on the delivery of health services and the introduction of a tendering process by community sector for the delivery of health programs has had significant impact on people's lived experience (Henderson 2005). It is the view of neo-liberal governments that the provision of health services should be market driven rather than government delivered services for the public need, based on the diversity of need determined by issues of ethnicity and class (Turner 2005). The result of this practice has been the outsourcing of previously government delivered services to the community and private sector whose motivation is either profit making or operating to strict budget constraints. As Henderson (2005, p. 244) states 'services that were once viewed as social rights have been redefined as personal needs to be met by private rather than public means'.

The expectation of neo-liberal governments is for the market to provide health care and for citizens to buy the health care they need: '[t]he target of government becomes the responsible individual rather than the social citizen'. In this new world responsible citizens become paying consumers, and as such are more discerning of what they are purchasing, where '[p]eople are increasingly asked to become

“expert” of themselves” (Henderson 2005, p. 243). The impact of this shift from being a recipient of government-provided services to a consumer competing for health services based on a market economy of supply and demand is evident, and the disadvantaged person is reconstructed as ‘an active agent who is required to take responsibility for seeking expert support’ rather than a passive recipient of welfare support (Henderson 2005, p. 244).

With most western democracies experiencing increasing financial pressures on their health costs there has been the emergence of an expanding privatised health care sector. Private Health care is being embraced by governments as a means to reduce the state’s budget for the provision of health care; by a user pay system with the aim shifting health care to the private sector. The question of power in health is complex and the hierarchical nature of the medical profession further adds to the complexity; this is most evident at the micro level with interpersonal relationships. At the macro level it is the powerful position of the medical professions through their representative bodies, in Australia, the Australian Medical Association (AMA), as well as the global pharmaceutical industry. Those with less power are patients, caregivers and others including unqualified staff working in the system. The dominance of the medical profession is being challenged; the consequences of feminism, consumer and carer activism the landscape is changing with the dominance of the medical profession waning somewhat (Michael Fine 2005).

The impact of a market approach to health care for Indigenous Australians is unknown, but given that many Indigenous Australians still live in poverty, it offers a bleak future. One of the key indicators of inequality is the distribution of wealth, and within Australia there are huge disparities in the distribution of wealth (Germov 2005a). There is a strong link between social disadvantage and health, both globally and locally.

Mental Health and Indigenous People

A major contentious issue for Indigenous people has been the adequacy of mainstream mental health services to respond appropriately to the mental health needs of Indigenous people. There have been a number of high level reports, strategies and policies on mental health highlighting these deficiencies (Australian Health Ministers 2003; Mental Health Council of Australia 2005; National Aboriginal and Torres Strait Islander Health Council 2004; Zubrick et al 2005). A report by Swan and Raphael identified that any mental health service targeting Indigenous

people needs to be holistic for mainstream mental health services are not providing adequately for their needs (Swan and Raphael 1995).

It is clear that mental health and what it means for Indigenous people continues to be an issue that promotes considerable debate (Swan and Raphael 1995; Zubrick et al 2005). This is evident by the lack of understanding by mental health practitioners of the historical issues, past practices and policies that have impacted on Indigenous people as possible causal factors contributing to poor mental health for Indigenous people (Hunter 1995; Swan and Raphael 1995).

'*Not for Service*', the report by the Mental Health Council of Australia released in 2005, showed that there are still significant issues that need to be addressed, the most pressing being the appropriateness and adequacy of the provision of mental health services to the general community. This is even more so for Indigenous people and their care-givers where the report describes the provision of mental health services as being inappropriate and that change is required immediately to rectify this current situation.

The *Social and Emotional Wellbeing Framework 2004-2009* (National Aboriginal and Torres Strait Islander Health Council 2004), is a Federal Government initiative to support and guide organisations in their work to improve the mental health and social and emotional well being of Indigenous Australians. It offers a model for a new direction and has proposed strategies that are aimed at improving the quality of life for Indigenous people, both those living with a mental health illness and for those involved in care-giving roles.

Human Rights and mental health

The Third National Conference on Human Rights and Mental Health held on 8 and 9 September 2005 in Canberra found that cultural prejudice still exists in Australia in the 21st century. The Conference report included as one of its four findings:

The conference found that many Australians experience discrimination through the governmental, penal, legal and health systems because of their mental health, race, skin colour, sexuality, sexual formation and refugee status (The Third National Conference on Human Rights and Mental Health, 2005).

Indigenous people have experienced intergenerational racism and structural discrimination which continues to have a negative impact upon individuals, families and communities (Hunter 2002; Tuhiwai Smith 2003; Westerman 2004). As I have discussed in the previous chapter, in Australia past policies and practices directed at Indigenous people resulted in a form of cultural genocide which included

dispossession and removal from traditional lands and the forced removal of children. These have left a legacy of contemporary trauma and unresolved loss and grief (Petchkovsky et al 2004; Zubrick et al 2005). These acts have all constituted abuses of human rights.

A critical point in recent Indigenous history was the Referendum in 1967 that altered the Australian Constitution to allow Indigenous people the right to vote. In a formal sense for first time under Australian law Indigenous people were recognised as citizens of the country. The event was enormously momentous at the time, and there were high expectations that this event would mean improved living conditions for Indigenous people.

There has been progress since 1967, particularly in the area of self-determination, with the emergence of Aboriginal community controlled and managed organisations. Unfortunately, even with these gains Indigenous people are still disadvantaged; they are over-represented in prisons and have poorer health outcomes. For example, in Western Australia there are still exceptionally high rates of Indigenous imprisonment. In 2004, the rate of imprisonment for Indigenous people was 15 times higher than that of the general population, with males more likely to be imprisoned (Department of Indigenous Affairs 2005). The issue of high rates of mental illness among the prison population is of concern (Human Rights and Equal Opportunity Commission 1993; White and Whiteford 2006), which in itself should be of concern to policy makers.

The Human Rights and Equal Opportunities Commission's *Human Rights and Mental Health Inquiry* (1993) highlighted the fact that Indigenous Australians living with a serious mental health disorder are particularly vulnerable. They are in a double bind situation experiencing both the stigma of living with a mental illness and racism because of their Aboriginality.

Human rights in the Australian context remain a contentious issue (Ife 2004b). During the period of the Howard government (1996-2007), policies directed toward Indigenous Australians were framed around a concept the Government marketed as 'personal responsibility'. In encouraging Indigenous Australians to be more 'responsible' the government introduced measures that limited individual and community choice and forced Indigenous Australians to access mainstream (White oriented) services. These initiatives have usually failed, for there was no real effort to ensure mainstream services were culturally safe or appropriate for Indigenous people. Mainstream mental services have continually struggled with this issue

without much success. What is unfortunate is that the responsibility agenda has allowed governments to act irresponsibly in their duty of care towards Indigenous Australians (Aboriginal & Torres Strait Islander Social Justice Commissioner 2007).

An example of a local Aboriginal service being de-funded or removed and clients shifted to mainstream services was the de-funding of a specific Aboriginal mental health service, the Aboriginal Community Support Services (ACSS) within Derbarl Yerrigan Health Service. The service was de-funded and assurances were given to the Aboriginal community that the clients would be appropriately supported in the mainstream public mental health system. We have anecdotal information that counters this claim: Workers who were employed in ACSS and are now employed in the public mental health system have reported that previous clients of ACSS have disappeared from the system. Some of the clients would have remained at Derbarl Yerrigan Health Service for their clinical care, but their social and environmental and community mental health needs are no longer provided. ACSS provided this service; ACSS workers provided support and assistance with medications, convening psychiatric reviews, assisting with accommodation as well as Centrelink and child protection issues. The health of former ACSS clients is now at risk.

3.2 *The paradoxes of modernity*

The sociology of care-giving

Humanity is by its very nature relational and interdependent, therefore provision of care must play an intrinsic role in the formation of society. As Held (1995b, p. 132) states, 'persons are relational and interdependent, not the individualistic autonomous agents of the perspective of justice and rights'.

Care-giving is a universal experience: as a result of our physical and biological vulnerability and our incapacity to support ourselves at crucial points in our life, we will all need some form of care-giving (Fine 2004). It therefore makes sense to recognise that the receiving and giving of care should be seen as part of our natural life course.

Caregiving due to chronic illness and disability represents something that, in principle, is not very different from traditional tasks and activities rendered to family members. The difference, however, is that caregiving in chronic illness often represents an increment in care that goes beyond the bounds of normal or usual care (Biegel and Schulz 1999, p. 345).

As a social phenomenon care-giving has only recently gained attention by being acknowledged by social researchers and policy makers. Prior to this recent public

recognition care-giving was viewed predominately as either a private issue, that is, care-giving provided within the family home, or public within the closed institution (Michael Fine 2005).

The term, 'carer' is a recent concept; and it was only in 1978 that this term came into use in its modern form, meaning 'someone who provides intensive personal support to a person with ongoing needs as a result of disability or age'. Before this time, the term 'carer', as it applied to individual support, was essentially a private issue, rather than a commodity. It was, as Fine (2004, p. 218) states, 'what C. Wright Mills would have termed a private concern to a public issue'. The influence of market forces on care-giving has seen, for example, the burgeoning in the demand for aged care and child care facilities. Care-giving has become a lucrative business.

The politics of care-giving

Historically care-giving has been confined to the private sphere, or the role of women within the household. It was considered a gender issue, with women's ascription as care-giver given legitimacy under the institutions of kinship and marriage. As Fine (2005b, p. 247) states, care was 'understood primarily as a family responsibility, the tasks routinely falling to women for whom it was seen as natural, taken-for-granted behaviour'.

The political shifts with the demands of caring are related to the shifts in responsibilities, for example, managing the tensions between work, family and other interests. The increases in child care facilities, the deinstitutionalisation for people living with disabilities and with a mental illness, and the move for the elderly to remain in their homes, are all examples of the pressures of contemporary life (Biegel, Sales and Schulz 1991). The impact of these societal shifts has had sweeping consequences for the emergence of an industry built around the care-giving role. Care-giving has been given status, but has retained its gender bias – care-giving is still considered the role of women. The entry of care-giving into the marketplace has therefore allowed more women to enter the workplace as caregivers. This change in both demand and opportunity has had twin effects, firstly, providing opportunity for women to enter the workplace because of the demand of more caring roles outside of family, but secondly, simultaneously placing greater demand on women who are still required to perform the care-giving role in families. As Fine (2004) states that there have been two major developments that have initiated these shifts. The first is the growth of the welfare state and the community sector; the emergence of professionalising the concept of care-giving in the public

sphere. The second is the role of feminism and its influence on the social and political fabric of society.

The shift in the debate about the inequities of care-giving owes its increased profile to the feminist movement and ‘the large-scale entry of married women into the paid workforce and the changing domestic forms of late modernity are perhaps the most significant’ (Fine 2005b, p. 248). The influence of feminism on the debate of care-giving cannot be underestimated (Held 1995a, 1995b).

The issue of how work can impact on person’s private life was and continues to be an emerging concern,

[n]ot just for understanding women’s lives but for social life in its entirety (the changing patterns of social policy that are continually redefining the boundary between personal and social responsibility. Care is no longer simply a question of private household preferences (Fine 2005b, p. 248).

Until very recently, just in the last 50 years, the provision of care has become clearly delineated for the ‘care provided at home, was quite distinct from the formal care provided in institutions’ (Fine 2005b, p. 248).

Defining and Counting Carers

The Australian Bureau of Statistics has conducted national surveys every five years in an effort to estimate the numbers of carers in Australia. The Australian Bureau of Statistics has provided two definitions for the term ‘carer’, that of carer and primary carer. The Australian Bureau of Statistics (1998) defines the term ‘carer’ as:

a person of any age who provides help or supervision with everyday activities to any person with a disability or long-term health condition, or to any person aged 60 years and over. The help or supervision has to be ongoing, or likely to be ongoing, for at least six months.

The Australian Bureau of Statistics (1998) definition for the term ‘primary carer’ is:

a person of any age who provides the most help or supervision to a person with one or more disabilities. The assistance has to be ongoing, or likely to be ongoing, for at least six months and to be provided for self care, mobility or communication. A small proportion of primary carers (less than 1 per cent in 1998) are younger than 15 years of age.

The ABS (1999) survey noted that women are more likely than men to become a carer at some stage in their life. Women accounted for more than half (56 per cent) of all carers, and a greater proportion of them were primary carers (73 per cent of those under 65, and 62 per cent of those aged 65 and over). Spread across all age groups young carers (those aged under 35) represented a relatively small proportion of the total (6 per cent of men and 8 per cent of women). One reason offered for this

situation is that with this group most are caring for people who are relatively young with a disability rather than for older persons. The survey identified clear gender-based differences in rates of caring in the older age groups. For example, approximately one in five women in the 35 to 64 year age group (22 per cent) were in a care-giving role, compared with 15 per cent of men. In the group aged 65 years or older, there were more men than women who were in a caregiver role (23 per cent men compared with 16 per cent women) (Fine 2004, p. 221).

The organisation Carers Australia (2006) estimates that besides the emotional and physical costs in caring there are significant economic costs incurred as well. They estimate that carers are foregoing potential earnings of up to \$4.4 billion a year. Families continue to pressure governments to recognise these sacrifices. As well as the economic costs, caring for someone living with a serious mental illness can be psychologically and emotionally exhausting (Orona 1997). For example, when having to work with mental health providers carers often describe these experiences as extremely difficult and frustrating. A constant theme for those in caring roles is that life can be at times extremely arduous, and made the more difficult by insensitive and inflexible mental health systems (Happell and Roper 2006; Mental Health Council of Australia 2005).

Those involved in care-giving to the mentally ill feel abandoned by the system and are struggling with the increasing demands that are being placed upon them. Carers are under enormous pressure with many suffering from stress related and depressive disorders, particularly older carers or women caring for an elderly parent with dementia (Human Rights and Equal Opportunity Commission 1993).

The struggle over care-giving

It is obvious that the majority of care-giving is being provided by women, with an estimate of 75 per cent of care-giving to the elderly being done by female relatives. This has given rise to what social researchers call the 'Sandwich Generation' that is the multiple role responsibilities being undertaken by women, as wife, mother and caregiver to elderly parent or parent-in-law (Biegel and Blum 1990). This had led to the many unresolved issues of how women manage work and care-giving. What is known is that being a carer can be the cause for extreme emotional stresses with increased levels of depression, feelings of anxiety and helplessness, hopelessness, emotional exhaustion, low morale, distress, feeling of isolation, guilt and anger (Nolan, Grant and Ready 1996; Raveis, Siegel and Sudit 1990).

There is an ongoing debate around the issue of care which is unfortunately still presented in a narrow form from a gender perspective. Fine (2004 p. 220) argues that currently there is a strong emphasis on 'the plight of primary or sole carers in national policy, a concern that reflects the origins of debates about care as a gendered issue in which care came to be defined as an exceptional set of activities undertaken by women as a familial or household duty'. Fine (2004 p. 220) believes that linking women to care-giving is essentially unfair, for:

Care is still seen as private individual concern, as a one way activity in which the active agent, the carer, does something to the other, passive, recipient. We might think of this as the carer-dependent model or paradigm of care.

The challenge then is how to move beyond this very self limiting model of care, for rather than seeking and reporting heroics it is much more respectful to legitimise the activities of caregivers and to reward appropriately.

Problems emerge in the public sphere of care-giving when 'care may be reduced through work practices in current aged care facilities to no more than the tending of bodies, especially in advanced stages of dementia where the recipient lacks the cognitive and personal capacity to respond' (Fine 2005b p. 251). Feminists contend that more often 'when care involves attendance to the physical needs of others...it is treated as "dirty work", hidden from others, penalizing those who do it in the process' (Fine 2005b p. 252). But as always there are, as some feminists have suggested, a hierarchy in the caring professions, with those at the bottom involved directly in the physical activities of caring and those at the top involved in activities that do not require physical contact.

Individualisation and care-giving

'Individualisation' as a concept needs to be considered in the care-giving context. History will show that in modern times Western society has privileged certain individuals over groups. Individualisation, in the context of care-giving, is now the preference in society and its advocates have argued that it has allowed for the emancipation of individuals

from the traditional constraints and provides the basis for the development of new forms of sociality, in which autonomy, linked to the rights to be an individual, is achieved and recognized through social relations. (Fine 2005b, p. 254)

Feminist literature has challenged the position of individualisation and has offered a different view. For example, feminists have deconstructed the term 'family responsibility'. Family responsibility, they claim, is code for women in households

burdened totally with the responsibility of care in the contemporary family (Held 1995a; Jaggar 1995; Tronto 1995). The concept of individualisation has a cultural dimension, and it has proven to be a pathway to emancipation, from living 'a life for others' to realising 'a life of one's own' (Fine 2005b, p. 254). For Indigenous women the situation can be more complex; individualisation can have its place, but community and family are also very important, for family and culture are intertwined (Crosato, Ward-Griffin and Leipert 2007). Watson (2004, p. 105) comments on the tensions of being an Indigenous woman in contemporary Australia:

There is no shifting from the individual accumulating power. So the opportunity to integrate caring and sharing has not been talked in a bigger circle of women. Indigenous women do but then struggle within the containment of the Indigenous boundaries imposed by the separation between Indigenous and non-Indigenous. So the caring and sharing world view from an Indigenous perspective tries to continue to breathe life into this declining, eroding and disappearing Indigenous space.

The social impacts of care-giving

The debate around private and public care-giving remains a topical one. As Fine (2005a, p. 147) states, 'although most care is provided through and within the family, there is little research on care and informal care-giving that explicitly addresses care as a relationship of power'. It has been primarily feminist scholarship that has highlighted the issue of the politics of care-giving in the private and public spheres. The activity of informal care-giving, in the private spheres and hidden in the concealed domain of the family, has only recently been exposed because of the emergence of married women into public life through their engagement in work and politics.

The impact of change of care-giving within families has had dramatic consequences. This change has resulted in the emergence of a burgeoning and profitable 'care Industry' which, through the marketplace, provides care for a price. Thus the availability of professional care-giving has allowed more women to enter the workplace (Fine 2004).

The introduction of professional community care approaches has experienced difficulties, for, as Fine states, 'in the face of the new demands made upon them, health and social care services are portrayed as being in almost constant crisis in virtually every advanced society' (Fine 2005b, p. 249). The change in the public sphere in relation to caring has had a profound impact on the way care-giving is provided.

The individualization of human service delivery implies both an attempt to tailor the service to fit the preferences and circumstances of the individual recipient, and the provision of opportunities for the recipient to take part in the decision-making concerned with the planning, organization and delivery of the particular service concerned. (Fine 2005b, p. 256)

The main beneficiaries of this social change have been predominantly White middle class women (Tronto 1993). Women of colour and Indigenous women are yet to experience fully the benefits and opportunities of feminism (Collins 1990; Watson 2004). Because of poverty and racism, Indigenous women are often denied even the basics of human rights.

Ethics of Care-giving

Some feminist scholars have argued for the inclusion of an 'ethics of care' involves 'a disposition towards others, and a set of values and practices traditionally associated with women that should not be abandoned' (Fine 2005a, p. 148). The feminist social researcher Joan Tronto, according to Fine, has developed a framework that encapsulates the principles of the 'ethics of care' and has identified four phases to the care-giving process. They are firstly, 'caring about' (others); secondly, 'taking care of'; thirdly, 'care-giving'; and fourthly, 'care receiving'. Tronto 'advocates an ethic of care as a positive public value, transforming the existing moral boundaries by moving care from a peripheral value to a place "near the centre of human life"' (Fine 2005a, p. 148). Tronto offers a robust position, and as Fine suggests, 'part of Tronto's intention in defining care so broadly, appears to be to counter the way that the values of care-giving have been marginalized, subjugated and contained' (Fine 2005a, p. 148).

Virginia Held, another feminist scholar, broadens the debate by arguing that justice has been neglected in the care debate. Held argues that modernity has distorted the debate for 'justice is a value appropriate to the public sphere of the political, while care belongs to the private domains of family and friends and charitable organizations' (Held 1995b, p. 128). The feminist position is unambiguous, justice and care are not simply an issue relevant in the public sphere, but they are also a concern that needs to be acknowledged in the private sphere. Justice is badly needed, both in the family and the State, as there is definitely a need to ensure that vulnerable families are afforded the protection of the mechanisms of justice (Held 1995a, 1995b). Regrettably, it is those involved in providing care who are often the most vulnerable, '[p]roviding care has always fallen disproportionately to women and minorities, who do the bulk of unpaid or badly paid actual work of caring for those needing it' (Held 1995b, p. 129). The challenge for society is to ensure that

administrators implement policy that reflects the principles of both justice and care-giving, as Held (1995b p. 130) states:

[m]oral theory should provide guidance for choice about actions and policies, and the problem of choosing between the interpretative frameworks of justice and care often persists after we have clarified both frameworks.

The challenge is to move the policy position from an abstract concept to another level of understanding which combines care and justice. Care-giving, however, remains a site of conflict, often between caregivers and care recipients (Tronto 1993). This situation is often exacerbated by the actions of the health system; as Tronto states, 'those giving direct care are frequently beholden to decision making hierarchies, and forced to give care in ways that they would not personally choose' (cited in Fine 2005a, p. 148).

The impact of the policy of deinstitutionalisation on families

In the 1950s throughout the Western world there was a shift in the treatment of mental illness with the introduction of deinstitutionalisation which involved releasing people with a mental illness from secure institutions and mental hospitals back into the community. Deinstitutionalisation has to be the single most influential policy in the area of mental health; its implementation has had an enormous impact on every aspect of community life (Biegel, Sales and Schulz 1991). The original intention of the policy, which I and many others believe was an admirable one, is that it allowed for the release back into the community of individuals diagnosed with a mental illness who had been locked away and living in intolerable situations. This, in part, was made possible because of the development and availability of more effective anti-psychotic medication (Hayman-White, Sgro. and Happell 2006).

There has been a shift in the global policy of deinstitutionalisation. In the USA there are now some researchers who question aspects of the policy in the context of mental health (Biegel, Sales and Schulz 1991). There are some researchers who believe that the policy has led to a greater burden on families today because mental health patients who would have been hospitalised in the past are now treated in the community based programs. Biegel and Schulz (1999) use the term 'transinstitutionalisation' to describe this emerging phenomenon of patients moving from across institutional settings, the number of people institutionalised because of their mental illness not changing, the only change being their changing institutions. Detractors of the institutionalisation policy do so not for its intentions, but because of its lack of planning (Biegel, Sales and Schulz 1991). Some social researchers now argue that deinstitutionalisation has led to a greater burden on families today

because mental health patients who would have been hospitalised in the past are now being managed in community based settings. These agencies usually have fewer resources and as a consequence limited effectiveness (Beigel 1991;; Henderson 2005). It is true that the number of people in mental institutions has decreased over time, but instead of being sent to hospital people with a serious mental illness are simply referred elsewhere. There has been an increase in presentations to other non-specialist mental health care institutions, and these are not always appropriate. For example, the rise in the number of inmates in prisons with a serious mental illness is an emerging and serious issue (Biegel, Sales and Schulz 1991; Human Rights Equal Opportunity Commission 1993; White and Whiteford 2006).

In Australia mental health services are being stretched; health professionals now have higher caseloads and as a result are not able to devote the time required to effectively work with individual clients and families (Henderson 2005). As Biegel and Schulz (1999, p. 348) note, 'a number of researchers believe that the combination of these factors has caused greater strains on families today than in the past, with families having to make up for gaps and inadequacies in the service delivery system'. The intention behind deinstitutionalisation as a policy was to benefit those living with a serious mental illness, but the unintended consequence has been a shift in accountability, for now families are required to shoulder greater responsibility for care, often beyond their level of skills and resources.

The arrangements in Australia have been that when a family was unable to care for a family member the state assumed that carer role (Fine 2004).

Deinstitutionalisation changed this arrangement. Since the 1950s, with deinstitutionalisation there has been greater involvement by consumers and their caregivers in the processes of treatment and care for people living with a serious mental illness. In recent time the formalising of consumer and carer networks has improved the situation to some degree (Henderson 2005). However, the emergence of the professional care approach has diffused the issue, with the result of hybrids or new forms of mixed care arrangements (Michael Fine 2005b, p. 249). These continued shifts within mental health in the care paradigm has had varied results.

The relationships between mental health services and families of those living with a serious mental illness have at times been quite tumultuous (Williams and Mfoafo-M'Carthy 2006). Henderson notes 'the families of the mentally ill were largely viewed as a source of pathology, necessitating professional intervention to allow them to care effectively for mental ill family members'. Families of relatives living with a

serious mental illness have had to continually challenge these dominant views held by the medical professions. Carers and those living with a serious mental illness have had to challenge and fight for their rights to be equal partners in their care. Critics of the carer and consumer movement have argued that acquiescing was 'a response to "welfarist politics" which encouraged passivity and professional "policing" of social and family life' (Henderson 2005, p. 249). Proponents of the neo-liberal view argue is that 'consumers are compelled to make choices, seek knowledge and adopt health-promoting behaviours' (Henderson 2005, p. 244).

Indigenous families of people living with a serious mental illness

The lack of credible research on the impact of race and ethnicity in the care-giving role for persons with a mental illness is of concern. Care-givers of persons of African-American descent living with a serious mental illness are requesting more involvement in the entire care process. With African American caregivers and care recipients, according to Beigel (1997), race or culture was not identified as either a major barrier or even as a solution in the delivery mental health services. What was an issue in the delivery of mental health services was the focus on the individual living with the mental illness rather than having a family focus. The issues are complex for these families, with racism a major concern, which, according to Beigel (1997, p. 176), 'cannot be addressed simply by offering a smorgasbord of services and resources for families'. Rather, as their studies show, there is a need for more meaningful partnerships between mental health service providers and the families of African-American people living with a serious mental illness. The families are requesting that service providers respect and value their contribution in the care process.

African-American people living with a serious mental illness according to Biegel, Johnsen and Shafran (1997, p. 163) 'have even greater needs for family support than do Caucasian consumers, given the fact that they have higher rates of use of in-patient mental health services'. For those living with a mental illness their concerns were not with mandating for the family to be involved in treatment care programs, but rather that there should be more attention to capacity building for caregivers. A major barrier to effective care-giving was the 'inadequacies of family caregivers that prevent them from becoming meaningfully involved' (Biegel, Johnsen and Shafran 1997, p. 176). For African American people living with a mental illness the issue remains the quality and accessibility of services, as well as changes to the mental health system so that they provide more support to caregivers (Dilworth-Anderson, Williams and Cooper 1999).

In Indigenous families there is limited knowledge about mainstream mental health practices (Lette, Wright and Collard 2000). This lack of knowledge has meant that there is considerable mistrust, suspicion and fear around the authenticity of a diagnosis and treatment of mental illness for Indigenous family members. There have been many stories from Indigenous families recounted to mental health workers, both Indigenous and non- Indigenous, of traumatic experiences of forced hospitalisations, resulting in clashes with police and of distressing encounters with mental health practitioners in hospitals and in the community (Lette, Wright and Collard 2000). The recurring theme for Indigenous caregivers has been the need for mainstream mental health services to recognise and provide for more holistic mental health care that encompasses the emotional, psychological and spiritual needs of caregivers and of the person living with the mental illness (Vicary and Westerman 2004).

Little is understood about what constitutes care-giving to Indigenous people living with a serious mental illness. The unique character strengths involved in caring are not always evident, but occasionally stories are told that offer unique insights into the lives of caregivers that reveal remarkable resilience, strength and resistance. The stories of caregivers are often a mixture of both joy and tragedy. Such stories are important because they provide a view into the lives of caregivers and of their discoveries in their journey of understanding of a mental health from a deeply personal perspective (Mental Health Council of Australia 2005; Zubrick et al 2005).

In the event of a mental illness emerging in a family member, Indigenous families are often in a dilemma. Hospitalisations would, under normal circumstances, be the preferred option, but because of negative experiences with mental health there is considerable scepticism (Lette, Wright and Collard 2000). There is unfortunately little understanding of the psychological trauma experienced by Indigenous people in interactions with mental health providers which adds to the difficulty in the relationship (Westerman 2004; Wright 2000; Zubrick et al 2005). When mental illness occurs there is a need to be able to recognise the wide range of symptoms that indicate stability or being unwell. When families are not equipped or lack the necessary resources to respond to a mental health crisis it adds further to the stress of their experienced (Orona 1997). It is an unfortunate reality for most Indigenous families that they lack resources and are often unskilled when caring for someone living with a serious mental illness (Swan and Raphael 1995).

Mental illness is a chronic condition. Indigenous families have shown that even though they lack physical resources they do not lack emotional resources when

responding to chronic illness. It has been shown that Indigenous families show remarkable resilience, compassion and insight when confronted with difficult life situations. The Indigenous kinship system can provide considerable support through the immediate and extended family networks. The extended family network and their involvement and support can be very important for those involved in caring for Indigenous people living with a serious mental illness (Zubrick et al 2005). This support may go unnoticed and as a result be under-utilised by mainstream mental health providers. On the other hand there is a risk, as mental health practitioners may exploit these resources, so measures need to be in place to ensure that this does not occur (Ife 2004b). Meaningful partnerships between families and mental health providers are essential in the recovery process of someone living with a serious mental health disorder (Eley et al 2006).

The issues for Indigenous people living with mental illness and their families are multifactorial. For Indigenous families living with a serious mental illness, racism is ever present. Mental health service providers often have no understanding of the impact of racism and how it can compromise quality of life for all concerned – patients and their families. Unless there is both an understanding and a recognition by mental health service providers that institutional racism exists, and that this means there will be ‘both intentional and unintentional racial biases...may be prone to adverse, and relatively unconscious, reactions to members of racial groups’ (Jones 1997, p. 465) Sadly, there are still sections of the Australian community who have largely a negative perception of Indigenous Australians. It is therefore highly likely that among mental health professionals these same negative perceptions exist.

3.3. Summary

This chapter has explored the epidemiology of mental illness in the context of the bio-social-medical-spiritual burden of disease and its impact on Indigenous Australians. What was uncovered was how, since the last major review of Indigenous mental health in the mid 1990s, the situation in regards to service provision is still woefully inadequate. Indigenous people still remain disenfranchised in regards to appropriate services for their families and community. The chapter explored the critical issues of care-giving in the context of mental health as impacts on Indigenous Australians. Care-giving in an Indigenous context has its own characteristics; however, mainstream services are still not recognising this fact. Indigenous Australians are still being required to accept services that are not culturally safe or appropriate. Racism is still an ongoing issue for Indigenous

Australians, and service providers are part of the problem. Policy makers continue to ignore this reality and as a consequence Indigenous Australians are suffering unnecessarily. The next chapter will begin to build a theoretical framework for the interrogation of inequality for Indigenous people living with a serious mental illness due to racism, power and privilege.

Chapter Four: *Toward a New Beginning* – Theoretical Perspectives

4.0 Introduction

Racism continues to impact on the lives of Indigenous Australians in the context of health and wellbeing as was identified in Chapter Two. As racism is a core feature in the lives of Indigenous Australians it is imperative that an appropriate theoretical framework be located for this study. This chapter provides the theoretical framework that underpins the study. It begins with a discussion of postmodernism and its relationship with decolonisation and goes on to explore of the concept of theory as praxis. Praxis in this context is the process of linking the skills of theory to research methods. Finally, in this chapter I reinterpret critical social theory, in particular, the challenging issues of developing adequate theory and research in a post-colonial era. The chapter has been organised into four sections:

Postmodernism and race: The challenge to critical inquiry begins by reviewing the relationship between postmodernism and decolonisation. It will explore the relationship between identity politics and racism. It concludes with a discussion on critical theory.

Theory as praxis explores the concept of theory as praxis in the context of social research. The application of theory in social research provides the framework for the methods of conducting social research,

Decolonising theory: Toward a new beginning provides a reinterpretation of social theory, in particular, the challenging issues of theory and research in a post-colonial era.

Summary: will provide an analysis of the main points and arguments discussed in the chapter. It will conclude by reviewing the main points to be covered in the following chapter.

4.1 Postmodernism and race: The challenge to critical inquiry

Decolonising the map: The challenges for postmodernism

Postmodernism and post-colonialism are important in providing the lens for the analysis of history and the processes of colonisation that have impacted on the lives of Indigenous Australians. Since the 1950s and the decline of modernism as the pre-eminent and dominant theoretical ideology, postmodernism has had a profound effect at all levels of society. Shapiro (1995, p. 187) states postmodernism 'has cut a wide swathe through everything from architecture and art to dance, television, philosophy and politics'. Postmodernism was seen as the panacea that would unshackle the oppressive qualities of modernism (West 1999).

To fully understand postmodernism it is important to have an understanding of modernism, for according to critical theorist Henry Giroux (1995, p. 42), the philosophy of modernism was central to the positioning of Eurocentric values:

Modernism's claim for the superiority of high culture over and against popular culture, its affirmation of a centered if not unified human subject, its faith in the power of the highly rational conscious mind, and its belief in the unequivocal ability of human beings to shape the future in the interests of a better world.

Modernism has had a profound impact on societies influenced by Eurocentric thoughts and ideas. The period of modernism, from the late 1700s to the mid 1900s, heralded the beginnings of dramatic social, political and cultural change (West 1999). As an historical moment the modernist period was considered reformative as there was no domain in society that was unaffected by the shift to the modernist paradigm. It affected all spheres of influence from art to architecture to music and literature. The architects of the modernist ideology were reformists and visionaries, for they believed that science and technology could be used to improve and reshape the environment. Capitalism and the forces of capitalism were the main beneficiaries from the modernist ideology of this period. West (1999, p. 52) states: 'the great paradox of Western modernity is that democracy flourished for Europeans, especially men of property, alongside the flowering of the transatlantic slave trade and the New World slavery'. Modernist ideology legitimised and privileged the patriarchal elite. Eurocentric culture prospered under modernist ideology because it supported the oppression and marginalising of racial and ethnic difference (McLaren 1994; Collins 1990). Because of these repressive activities modernist ideology is now considered antiquated and unacceptable by many prominent social change theorists (Giroux 1995).

Postmodernism has challenged a number of assumptions central to the philosophy of modernism. For example, postmodernism challenges modernism's philosophy of science and technology being the main drivers of positive change for society. More importantly, postmodernism has challenged modernism for its support of a version of history that commends, legitimises and celebrates the expansion of European civilisation and the growth of industrialised Western countries. Postmodernism has sought to redress the inequities in society by trying to shift the power from the most privileged and powerful to the less powerful in society (Giroux 1995).

Ironically, there is a certain ambiguity that co-exists with the idea of postmodernism. As West (1999, p. 67) notes, '[t]he very term *postmodernism* reflects fear of the future; it is a backward-looking term'. The idea that postmodernism has been offered as panacea and propels society into the new era of liberation is false, for history will show that it has failed dismally. For example, if the end of global conflict was a measure of progress in this new age of postmodernism there is no evidence of this occurring. In recent times, since 1989, there have been numerous civil wars, located mainly in the world's poorest regions, with the world's rich, the beneficiaries of postmodernism when translated into economic terms, insulated from the violence affecting the world's poorest inhabitants (Armitage 2008).

Postmodernism as a theory is significant because it offers critical theorists the opportunity to understand the multifaceted relationships between culture and the institutions of dominance (Giroux 1995). The challenge for postmodernism in the 21st century is in maintaining its relevance. Postmodernism does offer insights for critical theorists into how the structures of authority are understood, and importantly, it challenges critical researchers to be suspicious and sceptical about western institutions based on Eurocentric values and ideology (Kohli 1995).

In its defence postmodern ideology has tried to address the inequities in society by arguing for a shift in the dynamics of power from the most privileged and powerful to the less powerful in society (Giroux 1995). Giroux argues that modernism and postmodernism as ideologies can co-exist. He believes that both modernism and postmodernism offer much to the discipline of critical inquiry. Even though the two disciplines appear contradictory, ideologically opposite and even theoretically inadequate, there is a mutual relationship that can provide critical theorists with an opportunity to rethink the association between research and radical democracy (Giroux 1995). Rather than choosing between the philosophies of modernism and postmodernism, Giroux (1995, p. 37) cites Ernesto Laclau (1988) who states,

'postmodernism cannot be a simple rejection of modernity, rather, it involves a different modulation of its themes and categories'.

Postmodernism in the 21st century will need to be reflexive if it is to remain relevant, particularly in relation to Indigenous people. The impact of colonisation has had serious implications for Indigenous people; they need the opportunity to construct and legitimise their own epistemological and ontological meaning because of the dominant influences of the Eurocentric ideology and values of the coloniser (Tiffin 2006). Eurocentric ideology has permeated throughout the colonised world, the challenge for postmodernism will be to argue a clear position that can deconstruct colonialism as well as providing a platform that acknowledges and legitimises Indigenous cultural knowledge (Battiste 2008). For example, it needs to reject strongly the position of Eurocentric superiority, particularly the practice of measuring Indigenous societies against Eurocentric values (Grande 2008). Postmodernism has had an immense impact on the development and understanding of the discourse of critical theory, and, if used wisely, postmodernism can be powerful agent for change in this dark and turbulent period in history because as a philosophy it can offer new insights into how the structures of authority are understood (McLaren ed. 1995).

The philosophy of postmodernism has an explicit link to this study as this study is exploring the question of how the experiences of care-giving are constructed by Indigenous people, in an historical, political, social and cultural context. The philosophy of postmodernism as an ideology can assist in the design of an appropriate theoretical framework for answering the research question. As Giroux states (1995), postmodernism offers much for the critical theorists by demonstrating the association between research and radical democracy.

Reinterpreting the colonialist influence: The importance of post-colonial theory

The influence of post-colonial practices on the world as we know it cannot be underestimated (Tiffin 2006). The rise of the colonial powers and their domination of many of the world's cultures have left a sad legacy that still continues and in some situations even flourishes today (Memmi 1965). Grande (2008, p. 234) states 'the demon to be purged is the spectre of colonialism'. Colonisation has had a dramatic impact on Indigenous cultures worldwide, and its effects are still evident in the 21st century.

Colonialism has had a corrosive and ongoing effect upon Indigenous people (McCaslin and Breton 2008). Ashcroft (2002, p. 1) reminds us that '[m]ore than

three-quarters of the people living today have had their lives shaped by the experience of colonialism'. Post-colonial theory emerged from the earlier theories of Commonwealth Literature and of Third World Studies, with the aim of interrogating the universal effects of European imperialism (Macy 2001). The term 'postcolonial' is complex; it can be ambiguous and misleading (Crowley and Mathews 2006; Rizvi, Lingard and Lavia 2006; Sykes 2006). Denzin, Lincoln and Smith (2008, p. xiv) offer an explanation for this ambiguity 'we trouble with the concept postcolonial with asking, where was the colonial ever post? The term postcolonial functions as a temporal marker implying linearity and chronology'. According to Ashcroft (2002) the term 'post-colonial' is a more accurate term, for it describes how different cultures have, and are responding to, the process of imperialism from the beginning of their colonisation experience to the present time. Denzin and Lincoln citing Swadener and Mutua, agree with Ashcroft when they state: 'we prefer the term post-colonial to imply a constant, complex, intertwined, back-and-forth relationship between past and present' (2008, p. xiv).

The impacts of colonisation and imperialism have had serious detrimental effects for Indigenous people. In the arena of knowledge development and political advocacy in particular, they have restricted dramatically the ability of Indigenous people to firstly, construct their own epistemological and ontological meanings, and secondly, to gain legitimacy of their epistemological and ontological positions, because of the dominant influences of ideology and values of the coloniser and oppressor (Battiste 2008; Tiffin 2006). McCaslin and Breton (2008, p. 513) outline two reasons for the continued presence of the influences of colonialist ideology. The first is that the ideology and *modus operandi* of colonisation is through 'the rule of force [and] is inherently oppressive and cannot somehow turn benign or benevolent'. The second is that the insidious effect of the intergenerational influence of colonisation of 'programming that turns little babies into colonisers is very deep, very entrenched, and certainly strongly reinforced by rewarding colonisers with every privilege and advantage.

The challenge for post-colonial theory is in positioning its relevance. One area that has become the battleground for post-colonial theory is education (Rizvi, Lingard and Lavia 2006). The importance of education cannot be understated for the production and dissemination of Indigenous knowledge is critical in the emancipatory process (Denzin, Lincoln and Smith 2008). This is the reason why post-colonial theory has critiqued the role of language in supplanting and legitimising colonialist rule. The language of the coloniser is still considered the 'master

narrative' (Cook-Lynn 2008). For example, English and other European languages are still the *lingua franca* spoken among colonised peoples (Ashcroft 2006). Within academia the languages of the colonisers hold the superior positions and as a consequence are the most privileged, and continue to be the dominant language/s, spoken, read and written. The continued influence and dominance of post-colonial ideology is perpetuated through the power of language. This has resulted in cultural hegemony which is still present in modern literary activities; including education curriculum, particularly the writings of history in post-colonial societies which legitimise and perpetuate Eurocentric processes and principles by stating them as superior and absolute and not owning perspective or bias (Ashcroft 2006).

Decolonisation is the goal for Indigenous people, and as Tiffin (2006, p. 99) states: '[d]ecolonization is a process, not arrival; it invokes an ongoing dialectic between hegemonic centrist systems and peripheral subversion of them; between European or British discourses and their post-colonial dis/mantling'. One of the objectives of decolonisation should be the re-interpretation and rewriting of the dominant discourses of the coloniser (Battiste 2008). It should begin with the deconstruction and reconstruction of the colonial 'master' narratives that have misrepresented Indigenous history and then to reinterpret these narratives into a more meaningful and accurate post-colonial discourse that gives a more accurate portrayal of history (Cook-Lynn 2008). This presents an enormous challenge for countries like Australia because there has been no post-colonialism period as the colonisers remain with their structures of oppression, including the 'master' language of the coloniser (Moreton-Robinson 2000). As Ashcroft claims, all post-colonial societies are 'still subject in one way or another to overt or subtle forms of neo-colonial domination, and independence has not solved this problem' (Ashcroft, Griffiths and Tiffin 2006, pp. 1-2).

Identity politics and cultural racism

The values underpinning identity politics are the values of a just society, which provides for freedom and equity for all members (Crotty 1998). Identity politics emerged from the 1960s and became the counterforce to dominant modernist ideology. Its emergence was in response to the lack of interest shown by society to the issues of the marginalised and disenfranchised. Identity politics allowed silenced and disenfranchised groups to emerge from the margins and confront the dominant culture which was legitimised and supported by modernist ideology (Giroux 1994).

Unfortunately, the notion of identity being solely the domain of the progressive left no longer applies for 'identity' has now been appropriated by neo-liberalism and used by its proponents to diminish the gains of equality in society. There are concerns with this developing situation, as Giroux (1994, p. 34) states:

There is also the politically shortsighted willingness to abandon identity politics at a time when right-wing conservatives are reappropriating progressive critiques of race, ethnicity, and identity and using them to promote rather than dispel a politics of cultural racism.

The emergence and popularity of identity politics has altered dramatically the theoretical landscape. Giroux claims that the rise of the New Right or neo-liberalism was partly a counter-response to the emergence of identity politics in the 1960s. Furthermore, neo-liberalism has become 'one of the most pervasive and dangerous ideologies of the 21st century' and its pervasiveness is evident 'not only by its unparalleled influence on the global economy but also by its power to redefine the very nature of politics and sociality'. (Giroux 2008, p. 182)

Neo-liberalism has as its core belief that the market should be the final arbiter in deciding the structure of modern society. Neo-liberalism or rather market forces have continually undermined the principles of democracy, the welfare state and the values of community cooperation through non-market activities. The impact of neo-liberal values on societies has been all encompassing. The philosophy of neo-liberalism that promised emancipation because of individualism through the market place has been the mantra of neo-liberal governments. Neo-liberalism is now an accepted phenomenon with alliances between governments and global corporations (Giroux 2008). Who knows what the future holds for the philosophy of neo-liberalism for as Madeleine Bunting wrote in the *Guardian Weekly* on the 10 October 2008 during the global share market crash, 'We are now witnessing the collapse of this absurd economic orthodoxy [neo-liberalism] that has dominated politics for nearly 30 years' (Bunting 2008, p. 19). We await the outcome with some trepidation for the future.

In the United States and in other parts of the world there have been 'culture wars' where dominants go to war against peoples whose ideologies they perceive as threatening (Giroux 1994). Australia has also witnessed an embrace of the ideology of a neo-liberalism approach to 'culture wars' (Abbot 2004). The insidiousness of the 'culture wars' by the supporters of neo-liberalism is to muddy the water of popular thought for they do not want a critique of colonisation and an interrogation of racism. It is about populist symbolism 'deploying cultural pluralism as a slogan which

displays difference without mentioning dominant relations of power and class oppression' (Giroux (1994, p. 39). The purpose of the 'culture wars' in the United States and Australia is to re-frame the language of race to a more sanitised and acceptable form that is non-confrontational and non-judgemental (Grande 2008).

Neo-liberalism, according to Giroux (2008, p. 183) 'reproduces the conditions for unleashing the most brutalizing forces of capitalism'. The narrative of neo-liberalism has now become the 'master' narrative. The 'culture wars' have facilitated this process shifting the focus from race to the repression of culture in favour of homogeneity. 'Let us all be one people' is the marketing ploy of those selling the politics of loyalty and patriotism (Abbot 2004). This has proved to be a very successful and clever manipulation of language, or language reframing (Cook-Lynn 2008). Language is merely a tool and its potency is not the language itself but rather how it is used.

The debate has now shifted to how White people experience discrimination. As Giroux (1994, p. 38) states:

One instance of this hegemonic project is the politics of representation that suggests that whites are the victim of racial inequality. In this discourse the social gravity of poverty, economic exploitation, and class divisions is removed from the analysis of race.

The focus that should be occurring in Australia, but which has been absent for the past two decades, is on the social inequality which is demonstrated in the reality that if you are Indigenous or from a marginalised group you have a greater chance of experiencing poverty, service discrimination and poor health outcomes (Dodson 2007). The reframing of language has successfully shifted the debate from addressing the inequities experienced by non-White racial groups to a focus on the needs of the majority, White population. But to voice these concerns about the shift is to be accused of being obstructionist. The question of identity has taken on a new meaning, but not as it was originally intended as a focus on difference; it has now become part of the 'culture wars' and the politics of representation in controlling populist dialogue (Giroux 1994). The politics of representation is evident in Australia. For example, Indigenous Australians are portrayed as receiving special treatment and politicians in particular have constantly used this ploy in portraying Indigenous Australians as receiving preferential treatment (Hanson 1998).

Across the western world there has been a dramatic shift in the representation of race. The spread of neo-liberalism has changed the discourse of race from difference to something more generic and less challenging, to a form of cultural

representation (Giroux 2008). Unfortunately, this reframing of the language of race has had overwhelming acceptance in western society. Neo-liberalism has had an impact in successfully reframing the debate of the politics of race, and there are now two important issues at risk. The neo-conservative ideology has firstly, moved the debate from social justice and equality, to cultural difference, and secondly, it has successfully engaged and convinced the media in engaging in the 'culture wars' by reframing the debate so that race is no longer issue of social justice but of cultural representation. The challenge for social progressives to re-engage in the discussion by reinforcing the importance of the role pedagogy can play in reframing the debate, through the development of a new politics of difference (Giroux 2008, Grande 2008, Ladson-Billings and Donnor 2008).

There is a concern that the philosophy of identity politics is becoming unpopular and irrelevant because of the cleverly marketed neo-liberal rhetoric that it is separatist, exclusive and reactionary. Without the mitigating influence of identity politics the future would look bleak, for the ideology of neo-liberalism is not only re-shaping the cultural landscape, it is becoming an oppressive force for its reinvigoration (Giroux 2008). The ideology of neo-liberalism is reframing the critiques of race, ethnicity and identity for the purpose of promoting cultural racism as a political issue (Ladson-Billings and Donnor 2008). Identity politics is still the most effective tool to blunt the ideology of neo-liberalism. Race has become a 'hot button issue' and conveniently used by neo-liberalists as a marker of social disorder and civic unrest and identity politics clearly demonstrates how it can be more than just a one-dimensional theoretical approach, to now a more functional entity that has moved to a more centralist position. Identity politics as a discipline can critique the impact of colonisation and interrogate the politics of racism.

On critical inquiry

The influence of critical theory on the practice of research has been transformational. Critical theory has its roots in Marxism through a group of Jewish Marxist academics who formed the Institute for Social Research in Frankfurt, Germany, in 1924. Their academic work focused primarily on Marxism and the tensions between capitalism and society. After World War II some of these academics, under the leadership of influential Marxist scholars Adorno and Horkheimer, regrouped and established the Frankfurt School in Germany in the early 1950s. Jurgen Habermas, a student of Adorno, eventually critiqued the work of his teacher Adorno on Marx's theory of history. It is through this critique that the early beginnings of critical theory emerged (Crotty 1998).

Critical theory is about the interrogation of the dynamics of power. It is concerned with such questions as who in society has power and how they maintain power. Within this theoretical framework, privilege offers certain rewards, most notably power. Further, critical theory suggests that what underpins privilege and power is their relationship with race, class, gender and sexuality. Emancipation occurs through a process of self-awareness and collaboration with others who believe in similar values that respect liberation, equality and social justice. Critical theory is about interrogating and exposing the barriers that inhibit or prevent peoples' experiencing their own and their community's liberation (Kincheloe and McLaren 2005). The influences of the misuse of power in society are often unclear, they are not always transparent and therefore difficult to expose. Combined with structures in society that are complicit, including the media, the powerful and privileged elites use many varied forms to either coerce, threaten or bully in order to achieve outcomes for their own benefit. The processes of democracy therefore demand ongoing interrogation and analysis (Kincheloe and McLaren 2005).

The term 'hegemony' is used to describe the relationship between the powerful and the oppressed. The powerful in society can, through the mechanisms of government, influence the disenfranchised into believing that as a group their interests are not being compromised, and that they are not being exploited or oppressed (Gramsci 1988). Hegemony affects how we shape and give meaning to everyday occurrences. It determines and manages the construction of ideas and how they are legitimated. It is this process that subtly changes the perceptions and meaning of common sense in society (Gramsci 1988). This subtle shift is like 'water dripping on stone' and the political implications are significant, particularly around issues on identity and race (Mansell 2007). When interrogating the debate on race and identity the focus is not on racial difference, for that would be too obvious, but it is upon the repression of culture in favour of homogeneity. Contemporary politics is not about celebrating diversity but about imploring the populace to be 'one people' that is, the politics of nationalism and patriotism which ignore racial and ethnic oppression within the national whole.

There is a natural relationship between hegemony and ideology; for hegemony to be present it needs to be supported by the presence of an ideology (Giroux 1994). Critical theorists understand this relationship and they challenge and interrogate structures within societies that support and collude with an ideology that supports oppression and social injustice (McLaren ed.1995). This requires the interrogation of the ideologies that are used to propagate fear, submission and resentment. Critical

theorists have an understanding of the tensions between the powerful and the not-so-powerful, but because of the existence of an ideological hegemony, those who are less powerful are less likely to challenge the position of those in more powerful positions. Therefore there is a need to critically interrogate the dominant discourses and to expose the benefits of such discourses to the privileged and powerful (Kincheloe and McLaren 2005).

Indigenous Australians have historically experienced oppression which, in this country, has taken many forms. It has included the attempts at extinguishing Indigenous language and cultural activities, the fragmentation of family units, the exploitation of Indigenous labour and the failure of granting rights as a people. Any research with Indigenous Australians has to be conducted within this historical context (Foley 2003; Nakata 2007). Within the context of this study the participants have an experiential understanding of racism, discrimination and disadvantage, but often experience a difficulty in connecting the dots between their 'personal lives' and the historic, economic, and racial relations within which they exist (Fine and Wies 2005, p. 67). It is relevant that in exploring how care-giving is constructed by Indigenous people living with a serious mental illness, this study is framed within the context of the historic, economic, and racial relations within which they and their carers exist.

4.2 Social theory as praxis

Social theory as a theoretical perspective is critical in the development and implementation of a qualitative study. This is particularly relevant when a qualitative study uses critical theory as its theoretical framework. As the critical theorist Madison (2008, p. 391) states: 'How can there be such a thing as critical methods without critical theory or politics and political theory?'

Social theory as praxis

The feminist critical theorist Patti Lather (1991, p. 11) defines 'praxis' as being 'the self creative activity through which we make the world'. Macy (2001, p. 311) also provides a definition for 'praxis' as 'the Greek word meaning "doing"...widely used as a synonym for purposeful human activity'. Critical theorists are interested in social theory being transformative, but unfortunately, most social theories are overly passive and distant (Carspecken 1996). Criticisms of certain social theories, particularly most postmodernist theories, has been their irrelevance to the poor and marginalised (Lather 1991). Not all social theorists can, or do, work with the most disenfranchised and poor, the exceptions are critical theorists who work with the

most marginalised groups in society. The critical theorist and medical anthropologist, Paul Farmer (1997, p. 263) who has worked in Haiti with the poorest and most disadvantaged, claims that for many Haitians 'life choices are structured by racism, sexism, political violence, and *grinding* poverty'. As a critical researcher, Farmer works with this theoretical approach that is both relevant and transformative and through his work he has been able to capture the lived experiences of the Haitian population. The critical theorist Madison states she is 'determined to teach and write in ways that recognize the importance of theories that inform a critical approach to methodology-a critical approach that is guided by political theory that matters on the ground' (2008, p. 392).

Regardless of its limitations social theory does provide an important lens in viewing the world. For example, the concept of ecological analysis proposed by Uri Bronfenbrenner (1979, 1986, 1994) can be particularly useful in that it considers that all individuals are nested within layers of historical and social influence. Bronfenbrenner's is a particularly useful concept when applied to the experiences of Indigenous people. Social theory does not claim to be an exact science, however, for this study it offers an alternative that provides a framework for analysis of how care-giving is constructed by Indigenous people living with a serious mental illness.

Social theory as praxis for transformation

The emergence of social theory in the post-positivist period offers both opportunities and challenges. The importance of critical social theory is its ability to interrogate the elements that contribute to suffering and oppression, and praxis for transformation occurs when it provides strategies for the dismantling of structures that contribute to the suffering and oppression of the poor and disenfranchised (Farmer 1997; Fine and Weis 2005). Importantly, critical social theory provides qualitative researchers the opportunity to engage in a partnership between researcher and participants in the meaningful construction of knowledge and co-creation of an understanding of their reality (Guba and Lincoln 1989). When conducted effectively, research based on critical social theory can provide the opportunity for emancipation for participants (Fine and Weis 2005).

Poverty is still the main driver for disadvantage, illness and premature death, and as a consequence it increases the likelihood for structural violence to occur. The poor are also more likely to suffer in silence (Farmer 1997, p. 280). Therefore, the focus of social theory should have a 'transformative agenda' (Lather 1991, p. 51). The Brazilian critical theorist Paulo Freire (1974) who worked with the poor in Brazil, had

a transformative agenda. He used the methods of education creatively as a means of transforming the situation for the poor. Freire, as an educationalist, was a visionary, he emphasised and reinforced that it was the people who had power over their words; this was a unique pedagogical method.

The term 'pedagogy', according to Denzin and Lincoln (2008, p. 7), '[t]o teach in a way that leads... is always ideological and political'. The concept of pedagogy as a teaching method is important in the application of critical social theory as it provides an understanding of the tensions that exist for critical social theorists. Feminist critical theorist Patti Lather, citing Lusted, defines pedagogy as 'the transformation of consciousness that takes place in the intersection of three agencies – the teacher, the learner and the knowledge they produce' (1991, p. 15). The challenge for critical social theorists is not merely to deconstruct pedagogy but to aim for a more liberatory pedagogy. In the process of working with social theory there is always the possibility for 'false consciousness' (Fine and Weis 2005). 'False consciousness', a term which has Marxist origins, according to Lather (1991, p. 59) is 'the denial of how our common sense ways of looking at the world are permeated with meanings that sustain our disempowerment'.

Using critical social theory as a means for transformation can be both difficult and contradictory. There is always the risk of enhancing 'false consciousness'. 'It is precisely this question that postmodernism frames: How do our very efforts to liberate perpetuate the relations of dominance?' (Lather 1991, p. 16) This is particularly so when participants can be 'self-consciously immune and independent, disconnected and insulated from history, the state, the economic context and "others' (Fine and Weis 2005, p. 67). The concept of 'emancipatory knowledge through social theory building' is a skilful method that enhances consciousness, increases awareness of the contradictions blurred or distorted by everyday understandings, and thus 'directs attention to the possibilities for social transformation inherent in the present configuration of social processes' (Lather 1991, p. 52).

Emancipatory theory building has two aims. Its first aim is to raise consciousness. As a social theory it can be transformative for it works at the interface between participants and society, demystifying 'false consciousness' and the dismantling of structures that oppress individuals and groups because of their race, class, gender and sexuality (Lather 1991). The second aim of emancipatory theory building is to challenge the notion that social theory should be apolitical. There is an ethical imperative for critical social theory to challenge the notion of 'false consciousness'

(Lather 1991). Critical social theorists understand this challenge when they conduct research with the aim of providing pathways out of the oppression to liberation through the process of empowerment (Carspecken 1996; Madison 2005; Sykes 2006). As a transformative tool, critical social theory can contribute to the dismantling of structures of oppression to enable emancipation (Carspecken 1996; Farmer 1997; Fine and Weis 2005).

4.3 Decolonising theory: Toward a new beginning

On interpretation: Using critical theory and post-colonial theory as a critical pedagogy for change

Critical theory and post-colonial theory share a common beginning. Both theories emerged from social upheaval, and they both share a common philosophy of working with and for marginalised and disenfranchised groups. As Denzin and Lincoln (2008, p. 2) note both theories seek forms of praxis and inquiry that are emancipatory and empowering. Cultural studies, including post-colonial theory, provide critical theorists with a lens to interrogate the range of cultural phenomenon in the context of their social, political and historical positioning (Kincheloe and McLaren 2005). The experience of colonisation and imperialism has had a significant impact on Indigenous people worldwide. It is important for Indigenous people to be able to construct their own epistemological and ontological meaning because of the negative impact of the ideology and values of the coloniser (Battiste 2008; Nakata 2007; Tuhiwai Smith 2003). The objective of post-colonial theory is to re-interpret and rewrite the dominant discourses of the coloniser; the deconstruction and reconstruction of the colonial narratives to a post colonial discourse (Tiffin 2006).

The challenge for countries like Australia is that the coloniser remains. The literature of the coloniser is still the dominant discourse used in most educational institutions (Foley 2003; Rigney 2001). The discourse and narrative of the coloniser are still taught and presented as core reading and text for Indigenous students. Cook-Lynn (2008, p. 331) states, '[p]art of what has been going on in this intrusion is what I call the "master narrative" (i.e., the White man's version of who we are as native peoples). This master narrative is everywhere, and it is blatant, and it is my view, at least, an arrogance that is unremitting'. This has been problematic for Indigenous Australians and the post-colonial counter-discursive initiatives challenge the underlying assumptions embedded in colonial discourse and endeavour to deconstruct and reveal the fictitious nature of the dominant narrative (Tiffin 2006).

It is, therefore, of immense importance that the praxis of critical pedagogy is part of the skills base for critical theorists and post-colonial theorists. According to Denzin and Lincoln (2008, p. 8) the definition of 'critical pedagogy' is 'to performatively disrupt and deconstruct these cultural practices in the name of a more just, democratic and egalitarian society'. Critical pedagogy at this current historical moment faces, 'a crisis of enormous proportions' (Giroux 2008, p. 181). The reasons for the crisis is twofold, firstly, the view that education, politics and democracy should be regarded as separate issues, and secondly, the practice of 'using education to train workers for service sector jobs and produce lifelong consumers' (Giroux 2008, p. 181). Critical educators are concerned that the current political situation of neo-liberalism is undermining the teaching of critical thinking. Giroux (2008, p. 187) states:

Pedagogy as a critical practice should provide the classroom conditions that provide the knowledge, skills, and culture of questioning necessary for students to engage in critical dialogue with the past, question authority and its effects, struggle with ongoing relations of power, and prepare themselves for what it means to be critical, active citizens in the interrelated local, national, and global public spheres.

Indigenous educators are acutely aware of these tensions. In Grande's view, 'Indigenous educators need to theorize the ways in which power and domination inform the processes and procedures of schooling and develop pedagogies that disrupt their effects' (2008, p. 236). Critical social theorists need to have an understanding of the relationships between critical hermeneutics and the production of knowledge. According to Kincheloe and McLaren (2005, p. 311), '[t]he hermeneutic act of interpretation involves, in its most elemental articulation, making sense of what has been observed in a way that communicates understanding'. Hermeneutics, in the research context, is about making sense and providing some validity to the act of interpretation. The task of critical social theorists is to interrogate the narrative for its validity. As some social theorists argue, there can be multiple interpretations of any text, but these interpretations are influenced by the privileged position of the author/s who have the final word (Kincheloe and McLaren 2005; Tiffin 2006). Critical hermeneutics when used by critical social researchers can be transformative. Qualitative researchers familiar with critical hermeneutics, in Kincheloe and McLaren's view, 'build bridges between reader and text, text and its producer, historical context and present, and one particular social circumstance and another' (2005, p. 311).

Critical social researchers have the opportunity for constructive bridge building in the hermeneutic process between the reader and the text and the text and its author; a process referred to as the hermeneutics circle. A critical understanding of the layering of text is an important skill in the process of critical hermeneutical analysis (Kincheloe and McLaren 2005). The benefits and importance of the skills of critical hermeneutics in the interpretations of text in research cannot be underestimated for critical researchers. Social researchers engaged in critical hermeneutics in their interpretations of texts will provide a broader and more comprehensive approach to the application of research methods and findings.

Critical social theorists are naturally sceptical of any claim that there is only one truth from an interpretation of an experience (Lather 1991). Critical social researchers risk invalidating their methods if they do not apply a hermeneutical approach to their research practices particularly 'learning from the hermeneutic tradition and the postmodern critique, critical researchers have begun to re-examine textual claims to authority' (Kincheloe and McLaren 2005, p. 311).

Critical hermeneutics positions critical researchers around values that challenge power, social injustice and oppression. Critical theorists like Freire explored through the application and interrogation of critical hermeneutics the epistemological conditions of existence and the conditions that shape the experience. Therefore, critical researchers should engage in critical hermeneutics in their research processes. The critical interrogation of texts, exposing the way power is propagated by the privileged and is then used to oppress people, perpetuate social injustice and commit human rights abuses, is one aim of critical researchers. Importantly, it is also the aim of critical researchers to defend the rights of the vulnerable, the powerless and disadvantaged groups in our society (Kincheloe and McLaren 2005).

On bricolage and critical theory

The term 'bricolage' was first used by the anthropologist Claude Levi-Strauss (1966) in *The Savage Mind* (Kincheloe and McLaren 2005, p.316). The more recent use of the term bricolage was introduced by Denzin and Lincoln (2005a) to describe the process of using multiple methodological practices. According to Denzin and Lincoln, the theoretical bricoleur is a researcher who has read broadly on a range of topics, including gender, class and race issues as well the different methodological approaches, constructivism, cultural studies and critical inquiry. The researcher as a theoretical bricoleur can apply and utilise a variety of theoretical and methodological approaches. Denzin and Lincoln describe the researcher-as-bricoleur theorist as

one who 'works between and within competing and overlapping perspectives and paradigms' (Denzin and Lincoln 2005a, p. 6). There are other critical theorists who have also broadened the concept of bricolage to include an analysis of social theory. Bricolage is, however, not without its risks, for as Kincheloe and McLaren state (2005, p. 316) 'bricolage can also imply the fictive and imaginative elements of the presentation of all formal research'. The concept of bricolage within the theoretical process requires researchers to be more reflexive and aware of the importance of social theory being a critical part of the social research process. Kincheloe and McLaren (2005, p. 316) note:

As one labours to expose the various structures that covertly shape our own and other scholars' research narratives, the bricolage highlights the relationship between the researcher's ways of seeing and the social location of his or her personal history.

The challenge for the critical theorist is to apply both the concepts of bricolage and critical hermeneutics to understand the world as multiple layered and complex. It is the tension and complexity held within research and social theory which allows for the concept of bricolage. Kincheloe and McLaren's view (2005, p. 317) is that all observations of the world are consciously or unconsciously shaped by social theory and that 'such theory provides the framework that highlights or erases what might be observed'. The focus for critical social researchers should be on the interpretation of events in the presence of multiple realities. It is therefore the task of the researcher-as-bricoleur to interrogate and identify the structures of power and to disclose their influence on society. In using the concept of bricolage in their analysis of social theory, critical theorists can interrogate at depth their appropriateness. Critical theorists, as bricoleurs 'act upon the concept that theory is not an explanation of nature-it is more an explanation of our relation to nature' (Kincheloe and McLaren 2005, p. 317).

Critical bricolage can strengthen the processes of critical research, as it enables elasticity and reflexivity. It allows for the research process to be more eclectic, and by being reflexive it encourages flexibility in the research. The method assists in critical social research as it allows for the critical research process to reinterpret and articulate theories and research methods. Critical theorists do understand the multiplicity of realities in critical studies; therefore the concept of bricolage needs to be included in the analysis of social theory (Kincheloe and McLaren 2005).

Choosing an appropriate theoretical framework for this study proved to be a challenge. As an Indigenous researcher, I decided that one of theories for this study

would be critical social theory which would allow for an appropriate investigation of how care-giving is constructed by Indigenous people living with a serious mental illness. There is a relationship between, critical social theory and critical bricolage, both allow for flexibility and of the presence of the multiplicity of realities.

Developing an understanding of the nature of reality requires a set of lenses that enable a sound analysis of the situation. Exploring the issues of mental health requires skills that acknowledge the interconnectedness of life; for racism, poverty and disenfranchisement are intrinsically linked to power and privilege. History plays an important part in the analysis of oppression, particularly in interrogating the structures in society, which groups benefit and who is disenfranchised. A critique of society applying critical social theory enables an understanding of the structures of power in society and, importantly, strategies on how to dismantle these structures.

On Indigenous theory

Being an Indigenous researcher in the world of academia can be very challenging and confronting (Battiste 2008, Tuhiwai Smith 2003). It requires the recognition of cultural responsibilities inherent in being Indigenous. Regardless of cultural difficulties, it is still important for Indigenous people to participate in tertiary studies (Nakata 1998b; Weber-Pillwax 2001). Indigenous people do struggle with the tensions that exist between the Indigenous and non-Indigenous worlds. There are the contemporary challenges of managing the conflicts between the constantly changing industrial and technocratic world and the Indigenous world view (Marker 2004). These tensions are always present as Indigenous knowledge is often viewed as lacking in rigour and relevance. Indigenous knowledge and its representations through literature and science still lack authority and legitimacy within the academy (Battiste 2008; Dunbar 2008; Marker 2004,). As Battiste (2008, p. 495) states:

Indigenous peoples around the world have lived in their natural contexts, acquiring and developing sustaining relationships with their environments and passing this knowledge and experience to succeeding generations through their language, culture and heritage.

The ongoing effect of the colonisation cannot be understated, as 'Eurocentric education and political systems and their assimilation processes have severely eroded and Indigenous knowledge' (Battiste 2008, p. 497). The Eurocentric approach to education, does not value diversity, but is still modelled on the 'difference and superiority of Eurocentric knowledge and processes' (Battiste 2008, p. 498).

The academy has played a significant role in the continued oppression of Indigenous knowledge and indirectly, culture (Battiste 2008). In particular, the discipline of science with its positivist approach has been used by some scholars as the blunt tool to push forward an agenda that criticises Indigenous knowledge as being irrelevant to modernity (Foley 2003). There are still criticisms from within the academy that Indigenous knowledge systems lack 'rigour'. The presence of oral communication and language as the source of Indigenous 'knowledge's', with its narrative on the importance of relationships with land and country is considered by the academy as, primitive and irrelevant (Marker 2004). Indigenous knowledge systems are contained within values that include cultural responsibilities to family, community and land that extend beyond the parameters of academia (Foley 2003; Weber-Pillwax 2001).

Indigenous researchers understand that Indigenous knowledge systems include the people, the land, and the customs and ritual that are the vessels of culture. Indigenous people entering universities are confronted by mainstream assumptions held by the academy that do not recognise or acknowledge Indigenous knowledge systems (Foley 2003; Nakata 1998b; Weber-Pillwax 2001). Recognition by the academy of Indigenous knowledge in the 21st century should not be an issue, if population were a measure, for more than 5,000 Indigenous peoples live in 70 countries with a world population of over 300 million peoples (Battiste 2008, p. 499). There is still, however, a racist view held by some in the academy, that Indigenous knowledge is inferior to Eurocentric knowledge, and that Indigenous scholars are inferior to non-indigenous scholars. Ladson-Billings and Donnor (2008, p. 74) go on to state:

All scholars of color must know the intellectual antecedents of their cultural, ethnic, or racial group. This is important for combating the persistent ideology of White supremacy that denigrates the intellectual contributions of others.

Mainstream knowledge systems often clash with Indigenous knowledge systems, the discipline of science is one of those knowledge systems (Menzies 2001). Mainstream science views Indigenous knowledge systems as primitive, and like religion, of little or no relevance in the contemporary age of post modernity (Nakata 2007; Tuhiwai Smith 2003). There is often only token acceptance of an Indigenous worldview that speaks of time, space and consciousness in holistic language (Kirkness and Barnhardt 1991). Battiste (2008, p. 499) states:

Indigenous people's epistemology is derived from the immediate ecology; from people's experiences, perceptions, thoughts, and memory, including

experiences shared with others; and from the spiritual world discovered in dreams, visions, inspirations, and signs interpreted with the guidance of healers or elders.

When Indigenous students encounter the world of the university and its dominant ontology and epistemology there is a clash of ideology. Indigenous knowledge systems are about the protection and continuation of the spiritual cosmos (Hanohano 1999; Menzies 2001). The Indigenous worldview, is firstly at the immediate community level and then, where appropriate, to other Indigenous groups. Indigenous knowledge systems are primarily focused on a place and the interrelationships with that specific place. From an Indigenous context, there is a relationship between the local and the global, and this understanding is located within Indigenous knowledge and worldview (Menzies 2001). The importance and relevance of relationships is held within the oral traditions of Indigenous understanding. Marker (2004, p. 108) states, 'An Indigenous theory will inevitably collide with the academy's insistence on separating the sacred from the secular because the story has the power to affect not only the consciousness of the individual, but also the spirit of the person'. The First Nations writer Elizabeth Cook-Lynn (2008, p. 331) introduces the term 'master narrative' to describe the method used by non-Indigenous people to describe the lives of Indigenous people.

The presence of the master narrative is a serious impediment to the recognition of Indigenous knowledge. A key criticism by Indigenous researchers of the academy is the lack of understanding and recognition of Indigenous worldview and its relevance in modern society (Rigney 2001). The production of Indigenous knowledge is unique for, as Cook-Lynn (2008, p. 332) notes, 'myth becomes ritual and ritual eventually becomes literature (i.e., storytelling)'. The lack of acceptance and hubris on the part of academy is the cause of the tension and ambivalence within Indigenous communities towards Eurocentric research practices (Tuhiwai Smith 2003). The lack of humility is an ever pressing issue and continued arrogance by the academy in its failure to recognise Indigenous knowledge is a cause for concern (Battiste 2008; Weber-Pillwax 2001). The pursuit of knowledge for knowledge sake remains an alienating presence but also impedes the progress and development of Indigenous researchers. Marker (2004, p. 109) makes a very important point when he says, '[l]earning about Indigenous ways of relating to land will require decolonization and a depatterning about ways of thinking about time, space, and the true uses of knowledge toward purposes that are not yet at the core of university life'.

4.4 On Indigenous theory and critical theory

Indigenous researchers understand the critical relationships held within society and their communities. Post-modern theories that fit with an Indigenous epistemology are rare, but one theory that does have a relationship is critical theory. Critical theory fits neatly into an Indigenous paradigm as it is about the interrogation of the dynamics of power in society (Kincheloe and McLaren 2005). This is particularly relevant for Indigenous scholars whose lives have been continually transformed and impacted by colonisation; therefore, the issue of interrogating the dynamics of power in a Eurocentric society is important. As Grande (2008, p. 234) notes, '[b]y virtue of living in the Whitestream world, indigenous scholars have no choice but to negotiate the forces of colonialism, to learn, understand, and converse in the grammar of empire as well as develop the skills to contest it'.

In reviewing the dynamics of power and privilege, critical theory provides the theoretical lens to analyse how structures are formed and maintained in order to privilege some in society while disadvantaging others. Within this context privilege offers certain rewards, most notably power. What underpins privilege and power is their relationship with race, class, gender and sexuality (Kincheloe and McLaren 2005). In this way critical theory has been an appropriate medium for interrogating disadvantage. In more recent times critical pedagogy has become 'a kind of umbrella for a variety of educators and scholars working towards social justice and greater equity' (Grande 2008, p. 237). Transformation for Indigenous people occurs through the interrogation of the structures that privilege certain groups and disadvantages others. For Indigenous people the corrosive effects of colonialism adds another layer of complexity (Grande 2008; Tuhiwai Smith 2003).

Critical theory in the context of critical empowerment is about the investigation of the dynamics of power. However, there is still research that is being conducted with Indigenous people that persists with the worst of colonial practices (Battiste 2008). These practices have included the misuse of information that has resulted in interventions that have been both harmful to participants and of no benefit in the lives of Indigenous people (Tuhiwai Smith 2003). Indeed, research with Indigenous people 'must begin by replacing Eurocentric prejudice with new premises that value diversity over universality' (Battiste 2008, p. 503).

There are some critical theorists who argue that there is a move to re-frame the language of critical theory to make it less confrontational and therefore acceptable. They discourage the use of words like 'oppression', 'exploitation' and 'domination' to describe the impact of colonisation and neo-liberalism, not just because of the

stigma, but because there are some who believe these words are too harsh (hooks 1990). Indigenous people understand the words of oppression, exploitation and domination as they are part of their lived experience; these words represent a more authentic voice to their experiences. Indigenous people understand what it means to be oppressed, particularly the de-humanising attributes, of racial discrimination, dislocation, rape, cultural genocide, and murder, as part of the *hegemony* to be identified as the *Other* (hooks 1990).

Indigenous people living in the western society do so within the prism of race and racism, which is 'imposed by a racially coded and constraining society' (Ladson-Billings and Donnor 2008, p. 61). Critical race theory provides the theoretical lens that allows for interrogation of how race is used to continue the oppression of Indigenous people. Indigenous people, globally, have experienced significant losses because of their race, for example, the removal from their traditional country, loss of language, religious conversion and servitude (Battiste 2008; Ladson-Billings and Donnor 2008). They continue to experience colonial racism. Colonial racism is dangerous because at its heart is the extermination or the assimilation of the culture that has been colonised both have the same outcome – the disappearance of a culture and its people (Memmi 1965). The goal for Indigenous people is clear, as Memmi (1965, p. 151) states, '[t]he liquidation of colonization is nothing but a prelude to complete liberation, to self-discovery'.

Critical race theory allows for the interrogation of 'Whiteness' as a racial concept. Indigenous academics and others have argued that the interrogation of race should not just concern for people of colour or Indigenous people but also about White people; about interrogating Whiteness as an ethnicity, and how Whiteness has become a symbol of privilege (hooks 1990). White people live in a privileged space and as a consequence have alienated themselves from themselves; they have no sense of their unique situation (Watson 2004). Indigenous students are challenged in their ways of thinking and their ways of communication, for the academy more often views that which is non-White as the 'other'. The academy has yet to acknowledge or even regard a critique of Whiteness, for White is seen as normal (Marker 2004). Therefore, allowing Whiteness to become part of the ethnicity tapestry makes for greater diversity and inclusion into the 'borderland of difference in which identities are fashioned in relationships to the shifting terrains of history, experience, and power' (Giroux 1994, p. 51).

Critical race theory uses a range of techniques for exploring how power and privilege are determined. It is most effective when used in the analysis of the

narrative. Critical race theory legitimises Indigenous voices and it also challenges the rigid Eurocentric position held within the academy that argues that research can only ever be 'objective', 'neutral', 'elitist' and 'color-blind' (Dunbar 2008). Critical race theory argues that there can be no definitive objective position in research. Dunbar (2008, p. 87) notes 'there is no scholarly perch outside the social dynamics of racial power from which to observe and analyze'. Indigenous scholarship deserves its rightful place in the world of academia and unconstrained by rules imposed by the academy with its Eurocentric values and ideology legitimised by colonialist powers and worldview (Battiste 2008).

It is the responsibility of Indigenous researchers to use their positions as researchers for the purpose of emancipation (Battiste 2008; Cook-Lynn 2008). Unfortunately, in the process of entering and becoming part of the academy, Indigenous scholars become part of the elite intellectualism of universities. The challenge for Indigenous scholars is in upholding their cultural values. As Memmi (1965, p. 151) states, '[c]olonization distorts relationships, destroys or petrifies institutions, and corrupts men, both colonizers and colonized'. There are the expectations and responsibilities by Indigenous communities for Indigenous scholars to work for the collective liberation of their communities. The challenges for Indigenous scholars are in staying connected to their Indigenous culture, upholding the Indigenous worldview that reflects Indigenous cultural traditions and not being influenced by the dominant Eurocentric view of individual liberation (Cook-Lynn 2008).

Indigenous theory is about dismantling the structures that support racism through a process of participatory consciousness-raising, which, in the context of Indigenous theory, is the exploring how racism and colonialism impact on lives of Indigenous people (Bishop 2005). The shared concern for critical social researchers and Indigenous researchers is an understanding of the power differentials between researcher and participant. This presents a challenge for Indigenous scholars as the Eurocentric position with research often contradicts the indigenous view. Battiste (2008, p. 503) notes 'academic disciplines have drawn from a Eurocentric canon, an ultra theory that supports production-driven research while exploiting Indigenous peoples, their languages, and their heritage'.

Indigenous knowledge systems and critical theorists share a common ideal that researchers need to be political activists in assisting in the dismantling of structures that cause and support oppression (Bishop 2005; Grande 2008; Madison 2005). There is the challenge for Indigenous researchers to be more than just one

dimensional, they need to be focused on two outcomes, firstly, dismantling the structures of oppression, and secondly, facilitating a process that provides for conscious-raising (Rigney 2001). Indigenous researchers are usually involved in activism at a grassroots level of when they are engaged in their communities in consciousness-raising activities to challenge the structures of colonisation (Bishop 2005). An Indigenous theory is important for two reasons: it provides a theoretical framework for conducting research in Indigenous settings, and it provides for the legitimisation of an Indigenous epistemology to counter the Eurocentric position of the academy.

This theoretical framework for this study is critical theory and Indigenous theory. As outlined above there is a natural fit between these two knowledge systems that is complimentary to their respective philosophies. Therefore, the theoretical frameworks of critical theory and Indigenous theory are the appropriate tools for analysis of how care-giving is constructed by Indigenous people living with a serious mental illness. The values and principles of critical theory and Indigenous theory will ensure that the researcher adopts a reflexive approach to the research process. This is important so as not repeat the process of oppressing participants which has occurred in the past due to cultural insensitivity and poor research practices.

Indigenous research has its own set of criteria. There are some Indigenous scholars who argue that research with Indigenous people can only be understood fully 'from an Indigenous perspective using Indigenous language; it cannot be understood from the perspective of Eurocentric knowledge and discourse' (Battiste 2008, p. 505). I agree with Battiste, but not entirely, for even though I am not a fluent speaker of Nyungar, because of my lived experience I have an intimate understanding what it means to be Indigenous, and so less likely to engage in practices that may re-oppress Indigenous people. Regardless, there is always a concern with research conducted in an Indigenous setting, and I believe that as an Indigenous researcher I need to heed the words of the Maori academic Linda Tuhiwai Smith (2003, p. 1) who states, 'the term "research" is inextricably linked to European imperialism and colonisation. The word "research", is probably one of the dirtiest words in the Indigenous world's vocabulary'.

4.5 Summary

Given the history of colonisation in Australia it was imperative that the selection of an appropriate theoretical framework was considered a priority for this study. Racism and disenfranchisement continue to impact on the lives of Indigenous

Australians. The chapter reviewed the major theoretical frameworks used for this study, both Indigenous and non-Indigenous. As to be expected, there is no one theory but rather a combination of theoretical positions that fitted the criteria. It is now widely accepted among critical researchers that critical theory and post-colonial theory share a common beginning. Both theories emerged from social upheaval, and they both share a common philosophy of working with and for marginalised and disenfranchised groups. Therefore, it is my view that critical theory and post-colonial theory fit neatly with Indigenous theory, for they all share the common philosophy for the dismantling of structures premised on Eurocentric values that have marginalised and oppressed.

The next chapter, *The Time for Indigenous Speaking*, provides an overview of the method for the study, including the main philosophical influences of the study, including critical epistemology and Indigenous epistemology. It also provides an overview of the method used in the study, critical ethnography, and the study's methodology. The linkages between, epistemology, theoretical perspectives, methods and methodology are all related to the research question for the study: *How care-giving is constructed by Aboriginal people living with a serious mental illness.*

Chapter Five: *The Time for Indigenous Speaking – Methods*

5.0 Introduction

There should be a relationship between the theoretical and methodological approaches selected for any research study and in this study, the combination of critical and Indigenous theories provide the theoretical framework for the analysis of the data obtained in the course of the research. The previous chapter, *Theoretical Perspectives*, provided the context for the study by reviewing appropriate theories which presented the framework for exploring how care-giving is constructed by Indigenous people living with a serious mental illness. In this chapter I discuss how I used the methodologies of critical ethnography and Indigenous research to facilitate more meaningful interpretation of the participants' experiences. The chapter is divided into five sections:

Positioning the study: Locating the Indigenous voice starts by describing the aims and objectives underpinning the study. It also discusses the philosophy of critical epistemology standpoint theory that contributes to the shaping of the study.

Insiders/Outsiders: Conducting research in Indigenous settings reviews the qualitative methods adopted for the study. There will be an overview of the research methods, critical ethnography, community-based ethnography and Indigenous research methodologies adopted for the study.

Challenging the processes of the academy: Issues of power begins by describing the study design, the process for the selection of the participants, and the different stages of the research process. It also outlines the outcomes from the partnership that was developed between the participants and the researcher.

Legitimising the Indigenous voice: Ethical research with Indigenous people outlines the ethics process undertaken for the study. It discusses the concept of research as a path to activism, and the limitations of the research.

Summary: will present and discuss the arguments presented in the chapter. It will conclude by reviewing the main points to be covered in the following chapter.

5.1 Positioning the study: Locating the Indigenous voice

Purpose of the Study

The dearth of research knowledge about the experience of care-giving for Indigenous people living with a serious mental illness was the major motivating factor for this study. There have been a number reports that have detailed the lack of public awareness about the complex underlying causes contributing to the sense of alienation by Indigenous people living with a serious mental illness (National Aboriginal and Torres Strait Islander Health Council 2004; Swan and Raphael 1995). Therefore, an in-depth study of the experiences that could provide understanding of care-giving issues for Indigenous people living with a serious mental illness was warranted.

Objectives of the Study

There is an urgent need for increased knowledge and understanding of the underlying issues impacting on the experience of care-giving for Indigenous people living with a serious mental illness. The specific objectives for the study were:

1. To provide a description and interpretation of the experiences of care-giving for Indigenous people living with a serious mental illness;
2. To provide an account of the underlying socio-political realities for Indigenous people living with a serious mental illness in the context of mental health and care-giving;
3. To offer a framework that supports Indigenous people living with a serious mental illness in the context of care-giving that could be devised and integrated into health services.

Research questions

The research questions that directed the study were:

- *How is care-giving interpreted by Indigenous people living with a serious mental illness?*
- *How do care-givers and care recipients that is, Indigenous people living with a serious mental illness, describe and understand the underlying issues, problems or concerns in regards to care-giving?*

- *How can health services be more effective in supporting and enhancing care-giving for Indigenous people living with a serious mental illness?*
- *What are the wider socio-political implications, in particular, how racism affects the lives of Indigenous people living with a serious mental illness in the context of mental health and care-giving?*

Standpoint/s – Critical Epistemology

The principles of both Indigenous and critical epistemology have contributed to the shape and direction of this study. Chapter One provided the overview of Indigenous epistemology; in this section I discuss the philosophy of critical epistemology that has also shaped the study.

Critical epistemology begins with the premise that any form of injustice, oppression, or abuse of human rights needs to be addressed. As critical theorist Phil Carspecken (1996, p. 3) noted, '[w]e are all concerned about social inequalities, and we direct our work toward positive change'. Farmer, who works with the poorest Haitians found that their plight was not just confined to their race or culture, but was related to the inequities within Haitian society, 'the experience of occupying the bottom rung of the social ladder in inegalitarian societies' (Farmer 1997, p. 263).

Critical epistemology, according to Madison (2005, p. 5), 'begins with an ethical responsibility to address processes of unfairness or injustice within a particular *lived* domain'. The concept of an ethical responsibility, an underlying principle shared by critical theorists, involves 'a sense of duty and commitment based on moral principles of human freedom and well-being and hence a compassion for the suffering of living beings' (Madison 2005, p. 5). Critical theorists are committed to end suffering, as Farmer notes, '[a]lmost all of us would agree that premature and painful illness, torture, and rape constitute extreme suffering. Most would also agree that insidious assaults on dignity, such as institutionalized racism and sexism, also cause great and unjust injury' (Farmer 1997, p. 261).

Critical epistemology, has, as its core philosophy, an ethical responsibility that research should be focused on the cessation of social injustice (Madison 2005). The philosophy of critical epistemology, outlined by the feminist theorist Patti Lather (1991) are contained in the following five assumptions:

1. Critical inquiry is in response to social injustice and oppression, and in particular is an attempt to try and understand the views of those experiencing the oppression.

2. Any critical study should motivate and direct those who are oppressed in the process of a transformative experience. This is mutual relationship, for the transformative occurrence should be experienced by both the researcher and the participant.
3. Critical theory should provide a pathway to the understanding of ambiguities or false assumptions held within society about the dispossessed and oppressed.
4. Critical study should address the need to provide a culturally safe place within the research process for participants to be able to criticise, a place where they feel safe to give objection.
5. The research should have an action based component, that is the preparedness on the part of the researcher to be part of the ongoing program of emancipation.

Carspecken (1996) on the other hand, offers the following five assumptions underpinning the philosophy of critical epistemology:

1. Contemporary society is many ways lacking in its approach to providing an understanding of the situation of inequality.
2. Critical epistemology does not support inequality of any form.
3. There is a need to deconstruct the structures of power and to make them more transparent.
4. All forms of oppression need to be uncovered and dismantled.
5. Critical epistemology supports research methods that do not support or contribute to the structures of oppression.

Furthermore, Critical researchers know that contemporary society, both subtly and knowingly, oppresses its most vulnerable citizens.

All ideas and beliefs are held within power relationships and there is the need to interrogate the underlying tensions of power and research. There is also never a truly 'neutral' or 'objective' space in research; as values will impinge upon facts, and therefore it is critical to be clear where values and facts interact (Lather 1991).

Lather highlights the importance of acknowledging the context of symbolic representations, in particular, perceptions of reality and their relationships to institutions of power, as critical theorists reject the concept of an absolute truth. Critical theorists argue that conditions that support privilege, power and oppression

are not always transparent and as a consequence are often ignored within social science research methodologies (Carspecken 1996). This has been a major omission in the social sciences. The emergence of critical epistemology owes its genesis to the lack of responsiveness by qualitative researchers to the issues of social injustice, oppression, and abuse of human rights which has resulted in what Carspecken has called the 'failure to understand the relation of power and truth [that] has led criticalists, given our value orientation, to interrogate closely the epistemology of mainstream inquiry' (1996, p. 8).

The underlying philosophy of critical research processes is the dismantling of structures that oppress and disenfranchise groups (Fine and Weis 2005), and the assumptions that underpin the framework of critical epistemology include:

1. that society lacks the moral understanding and courage to face the implications of social inequality;
2. that critical researchers do not support inequality in any form;
3. that critical researchers need to deconstruct and make visible the structures of power;
4. that all forms and systems of oppression need to be exposed;
5. that critical researchers need to work with research methods that do not support or contribute to the structures of oppression.

Researchers who apply the principles of critical epistemology will be challenged in their research processes. These principles demand that researchers work ethically as the values of critical epistemology require that participants not be misrepresented or made invisible (Carspecken 1996). Critical theorists Michelle Fine and Lois Weis (Weis and Fine 2004; Fine and Weis 2005) use the term 'compositional studies' to describe their process. A compositional study is one that involves interpreting and analysing the diversity and multifaceted layers of meaning embedded in modern society. Compositional studies involve the three analytic steps. The first step is the recognition of time and space interconnectedness, that is, any critical ethnography needs to recognise that any study and its finding must be contextual for it needs to acknowledge the historical and its interconnectedness to race and economic conditions. Most qualitative research does not recognise the connection of power and social injustice. The second step is a deeper understanding of the philosophy of critical theory, that race, ethnicity, class, gender and sexuality are not just abstract categories but are people's lived realities. The third step includes the recognition

that there are multiple perceptions of reality, and to accept that there will be diverse views and opinions (Fine and Weis 2005).

There is a natural relationship between critical epistemology and the three steps of compositional study, for both have a similar philosophy of research being contextual, relational and organic. Fine calls this approach a 'theory of method', which offers the critical researcher an array of skills and choices. For example, adopting a multiple positioned approach allows the researcher to be 'grounded, engaged, reflective, well versed in scholarly discourse, knowledgeable as to external circumstances, and to be able to move between theory and life "on the ground"' (Fine and Weis 2005, p. 68).

Critical epistemology allows flexibility for the application of multiple methodologies, or bricolage, or the researcher-as-bricoleur (Denzin and Lincoln 2005a). The following section focuses on the concept of researcher-as-bricoleur in the context of this study.

Researcher-as-bricoleur

Denzin and Lincoln's (2005a) description of the researcher-as-bricoleur as a quilt maker provides a beautiful image of creation. When Patricia Hill Collins (1990) recounts the phenomenon of Black women and quilt making, she states that Afro-American women believe that each individual is a unique expression of a common spirit, power or energy. Denzin and Lincoln (2005a) describe the qualitative researcher as a person who can multi-task if required, a researcher who, if need be, will be flexible, but more importantly, assembles images into montages. In Chapter 4, Section 4.3 *On bricolage and critical theory* I discussed the role of bricoleur in research.

The theoretical bricoleur is a researcher who 'works between and within competing and overlapping perspectives and paradigms' (Denzin and Lincoln 2005a, p. 6), while the narrative bricoleur is one who understands the power of the narrative and the importance of honouring and holding the tradition of storytelling. Stories are powerful as they are the containers of traditions and ritual. The researcher-as-bricoleur and political activist is conscious that knowledge is power, and that information can have significant political influence. The values underpinning critical research are political; doing critical research 'will require scholars willing to dip into the waters of history and political economy, while sharpening the skills of case study, ethnography, and autoethnography' (Fine and Weis 2005, p. 80). The

researcher-as-bricoleur and political activist uses his/her skills to empower rather than oppress.

The researcher-as-bricoleur and the philosophy of critical ethnography work with a similar premise that there needs to be reflexivity in the research process. By adopting a more reflexive approach to doing research enables a more multifaceted research process. The combination of critical research with the researcher-as-bricoleur approach is useful in the analysis of the participants' world view. Researcher-as-bricoleur allows the critical researcher to reinterpret and articulate theories and research methods (Kincheloe and McLaren 2005).

The emergence of the concept of researcher-as-bricoleur mirrors the progress of research practices in the postmodern period. Indigenous researchers are the beneficiaries of the researcher-as-bricoleur approach, as the underlying values of bricolage lessen the rigidity of the Eurocentric approach to research. Bricolage allows critical researchers to defend 'what we assert we know and the process by which we know it' (Kincheloe and McLaren 2005, p. 318). Indigenous researchers have first hand knowledge and experience of having to defend what we know; bricolage and critical research are therefore relevant approaches for us.

5.2 *Insiders/Outsiders: Conducting research in Indigenous settings*

Qualitative research methodology

The design for this study is a qualitative research inquiry to explore how care-giving is constructed by Indigenous people living with a serious mental illness. Using a qualitative methodology for this study was considered appropriate because it method facilitates a deeper exploration of the important issues by enabling participants to define the parameters of their responses. This is particularly so in the use of interviews as the primary means of data collection. As Morse and Field state, 'doing qualitative research is an intense experience [which] enriches life; it captures one's soul and intellect' (1995, p. 1).

Qualitative research needs to be conducted within the framework of reflection and responsibility. It provides the unique opportunity for researchers to make sense of the world in providing explanations through the development of theories, using the ideas of the reality as understood by participants (Denzin 1997; Morse and Field 1995). Importantly, conducting qualitative research provides researchers with alternate approaches that can allow greater flexibility in conducting social research. Corrine Glesne (1999, p. 3) describes this process:

Learning to do qualitative research is like learning to paint. Study the masters, learn techniques and methods, practice them faithfully, and then adapt them to your own persuasions when you know enough to describe the work of those who have influenced you and the ways in which you are contributing new perspectives.

Qualitative research has been the popular choice for those involved in research with Indigenous peoples, in spite of the fact that Indigenous people may still have concerns associated with Eurocentric research practices which are intrinsically linked to the reinforcing and legitimising of colonial practices, particularly in the field of health research (Rigney 2001; Tuhiwai Smith 2003; Turner 1997). Qualitative research methods allow researchers to be involved with an inquiry in a more intimate manner, as they are 'more likely to confront and come up against the constraints of the everyday social world...see this world in action and embed their findings in it' (Denzin and Lincoln 2003, p. 16). Importantly, good qualitative research should not be done in a political vacuum, and it should be represented as a contextual experience.

The use of qualitative research methods for this study offers the opportunity for the collection of different types of evidence in order to ensure that the findings are contemporarily relevant (Perakyla 1997). Criticisms of qualitative research have traditionally centred on questions about the reliability of the findings thus derived. Qualitative research findings have been attacked as unreliable and lacking in rigor because they do not rely on statistical analysis to support theory (Guba and Lincoln 1989). In response, qualitative researchers have argued that qualitative research is focused on the discovery of meaning rather than measuring and testing attributes within a population (Morse and Field 1995). Findings are contextualised, grounded and theoretical, and it is these qualities of qualitative research methods that can provide a logical and rational description of participant data (Morse 2004). Another characteristic that differentiates between qualitative and quantitative research is the focus of the research. Qualitative research focuses on the construction of theory whereas quantitative research is about testing a theory (Morse and Field 1995).

An important consideration for this study was selecting a methodology that would work across the political, social and cultural spectrums of Indigenous society (Lincoln 2005; Turner 1997; Tuhiwai Smith 2003). There were two reasons for the choice of qualitative research methods for this study. Firstly, the narrative process would provide greater cultural safety, given the sensitivity of the research question, and secondly, the political dimension of mental health issues required a broader understanding of the issues of care-giving in an Indigenous mental health context.

There is still much suspicion in Indigenous communities about the ethics of Eurocentric research (Battiste 2008; Rigney 2001; Tuhiwai Smith 2003). It was therefore, very important that the selection of methodology did not harm or re-oppress Indigenous participants. As an Indigenous researcher, engaged in research in my own community, I was aware of the importance of not replicating previous research practices, for example, by conducting research that was of no benefit to the community.

The choice of critical ethnography as the qualitative method was based on the values of emancipation of community, as Lincoln (2005, p. 202) states, 'critical theorists, especially those who work in community organizing programs, are painfully aware of the necessity for members of the community, or research participants, to take control of their futures'.

Critical Ethnography

The main aim of critical research is to achieve emancipation and change. It has a twin focus of uncovering the nature of power relationships found in all parts of society and dismantling the structures of power that oppress. For critical research to be effective it needs to redefine the parameters of research and theory and to use our research to refine social theory rather than merely to describe social life (Carspecken 1996, p. 3). Importantly, critical research allows for a deeper exploration of issues. Madison (2005, p. 5) articulates this position succinctly:

The critical ethnographer also takes us beneath surface appearances, disrupts the *status quo*, and unsettles both neutrality and taken for granted assumptions by bringing to light underlying and obscure operations of power and control.

As I have previously discussed in Chapter 4: Section 4.2 *Social theory as praxis*, critical research methods emerged during the 1960s, and the combination of the philosophies of critical theory and post-colonial theory has resulted in a more reflexive research method (Foley and Valenzuela 2005). Postmodernism and identity politics provided the space for critical research to gain acceptance as it was seen as a way to bridge the divide between those with the power and those who were powerless (McLaren ed.1995). Since its inception critical ethnographers have challenged the academy on rigidity in their processes in the production of knowledge and the legitimacy of their so-called ownership of knowledge (Giroux 1994). Critical ethnographers understand the importance of research being reflexive, and that 'in a class society marked by class, racial, and sexual conflict, no producers of knowledge are innocent or politically neutral'. (Foley and Valenzuela 2005, p. 218)

Critical researchers work at the cutting edge of theory development, constantly striving for theory to be a change agent. The researchers involved in 'research as praxis' are those, according to Lather, 'committed to the development of a change enhancing, interactive, contextualized approach to knowledge-building [and] have amassed a body of empirical work that is provocative in theory and increasingly, method' (Lather 1991, p. 53). The point of this approach is to link critical theory to research practices.

The aim of critical research is to be more reflexive, and the concept of 'research as praxis' occurs at the interface between research method and theory development. Research as praxis has a twin focus: the first is to work at the interface between the lived experiences of participants in a society that rewards and privileges some members and discriminates against others, and the second is to raise the consciousness and understanding of this inequality in the wider society (Lather 1991).

The critical ethnographers' standpoint has been to give authority to the historical and cultural positions of participants. Critical ethnographers are 'mere culture-bound mortals speaking from very particular race, class, gender, and sexual identity locations' (Foley and Valenzuela 2005, p. 218). Critical ethnography was one of the methodologies chosen for this study because of its capacity to adapt to a culturally appropriate design framework (Bishop 2005, Rigney 1997, Tuhiwai Smith 2003). A critical research approach would facilitate the investigation of the research question: how care-giving is constructed by Indigenous people living with a serious mental illness.

Community-based Ethnography

Community-based ethnography is about facilitating a more transformative experience for participants. This is achieved through a process that allows participants to gain greater understanding of their own unique situations and by creating opportunities for the development of effective strategies that can offer meaningful solutions within those situations (Stringer 1997). Community-based ethnography is a method that explores the meaning of the lived experiences of people. Community-based ethnography is based on the principles of 'interpretative interactionism', an approach that provides for better understanding the interrelationships between the private and the public and 'works outward from the biography of the person' (Denzin 2001, p. 2). This is particularly relevant for Indigenous people as narrative or storytelling is the container for tradition, rituals

and relationships where there are many layers of meaning held within the spoken narratives of an Indigenous person's life (Cook-Lynn 2008; Roe 2000).

The interpretative interactionism approach challenges researchers to be less subjective in their approach to the research process, to be more collaborative and to position themselves alongside the participants. It directs the researcher to record and write differently throughout the research process, promoting shared ownership of the research project, community-based analyses and an emancipatory and sustained commitment to community action (Denzin 2001).

Community-based ethnography is linked to action-oriented research and can be interpreted as a social response to research. It is intrinsically participatory and not an etic process (it is not an outsider account) but an emic process or an insider approach to the research process. The focus of community-based ethnography is on the importance of relationships. Community-based ethnography is a participatory collaborative approach and it is the learning that occurs in the process of doing research that is its emphasis (Stringer 1997).

Community-based ethnography was one of the methodologies chosen for this study because its values and principles are consonant with an Indigenous worldview (Battiste 2008; Bishop 2005; Rigney 1997). A community-based ethnography approach would adequately facilitate the investigation of the research question. There is a natural affinity between critical ethnography and community-based ethnography; they both reflect the values of bricolage. Both approaches are consonant with an Indigenous worldview, are self-reflexive in their research processes on the issues of inequality and social justice in the research process. The benefits of adopting both these methodologies, by incorporating the values of bricolage, mitigates against the rigidity of the Eurocentric approach to research. Furthermore, the adoption of the proposed methodologies in conjunction with the theoretical frameworks allows for me to function more effectively as an Insider/Outsider researcher in the context of the Western Australian Indigenous community.

Indigenous Research Methodology

The aim of colonisation was to achieve the disenfranchisement and extinguishment of Indigenous culture (Memmi 1965). Indigenous scholars conducting research in their own communities understand their responsibility to use research as part of a healing process rather than reinforcing past experience where research practices have oppressed Indigenous people. Tuhiwai Smith reminds us that 'the ways in

which scientific research is implicated in the worst excesses of colonialism remains a powerful remembered history for many of the colonized peoples' (Tuhiwai Smith 2003, p. 1) Indigenous Australians still regard research with deep suspicion and hostility and therefore research in an Indigenous context is different from non-Indigenous research (Foley 2003; Moreton-Robinson 2000; Nakata 1998a; Rigney 2001). Tuhiwai Smith (2003, p. 15) further states, 'Indigenous methodologies tend to approach cultural protocols, values and behaviours as an integral part of our methodology'. There is a further responsibility for Indigenous researchers to undertake research that is culturally safe (Battiste 2008; Coffin 2007).

Indigenous people are interested and committed to research, and in the construction and validation of knowledge, but not if it compromises or misrepresents Indigenous culture (Foley 2003; Grande 2008; Moreton-Robinson 2000; Nakata 1998a; Rigney 2001). As the Maori academic Russell Bishop observes (2005, p. 110),

[r]esearchers in Aotearoa/New Zealand have developed a tradition of research that has perpetuated colonial power imbalances, thereby undervaluing and belittling Maori knowledge and learning practices and processes in order to enhance those of the colonizers and adherents of colonial paradigms.

The issue of addressing neo-colonial power in a research context is a constant challenge for Indigenous researchers (Humphrey 2001). Bishop proposes a five point model to address neo-colonial power imbalance when engaged in research with Indigenous people. The model can be applied by asking and answering the following critical questions (Bishop 2005, p. 112):

1. **Initiation:** Who determines the beginning of a research project with Indigenous people?
2. **Benefits:** Who benefits, directly and indirectly from the research?
3. **Representation:** Are we ensuring that the research fairly depicts the lived or social reality of indigenous people, and that it is not overly simplified, or appropriated, or that Indigenous knowledge is commercially exploited?
4. **Legitimacy:** Is the Indigenous authority of the texts ensured? Past research practices have devalued and treated Indigenous knowledge with contempt, with the aim of elevating Eurocentric knowledge and
5. **Accountability:** Is there shared responsibility and ownership in the research process including the initiation and design of the study and importantly control over the dissemination of findings from the study?

Combined with the National Health Medical Research Council's *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* (2003), Bishop's five point plan provides cultural safety when doing research with Indigenous people. Marie Battiste (2008) a First Nation woman and researcher, with other First Nation people, has developed a research ethical framework that protects Indigenous knowledge and tradition in Canada. Researchers in Australia, New Zealand and Canada now have ethical guidelines for doing research with Indigenous people that will protect Indigenous knowledge and heritage (Cunningham, Reading and Eades 2003).

Indigenous researchers are now challenging the authority, legitimacy and relevance of the appropriateness of mainstream Eurocentric research processes when applied in an Indigenous setting (Foley 2003; Moreton-Robinson 2000; Nakata 1998a; Rigney 2001). Taking the Maori as an example, the impact of research for Maori, according to Bishop, has been the pathologising of Maori culture. He claims that Maori culture has been demeaned by the 'propositions that Maori culture was and is inferior to that of the colonizers in human terms' (Bishop 2005, p. 110). The negative propositions perpetuated by non-Maori researchers, according to Bishop, continues to undermine Maori cultural epistemology and ontology. The impact of non-Maori views 'have consequently misrepresented Maori experiences, thereby denying Maori authenticity and voice' (Bishop 2005, p. 111).

A major issue of concern for Indigenous researchers is the proposition that research methods should be dispassionate, objective and neutral, rather than subjective, relational and experiential (Grande 2008; Foley 2003; Pidgeon and Cox 2002). An Indigenous research practice has its own unique epistemology, for it is based on values that enhance community, not on the standard Eurocentric approaches to research which value so-called objectivity and neutrality (Battiste 2008; Marker 2004; Pidgeon and Cox 2002). Contrary to the mainstream view that focuses of individualism, an Indigenous knowledge base and worldview is constructed around shared learning experiences, and the focus is on togetherness, community and harmony (Pidgeon and Cox 2002; Weber-Pillwax 2001).

An important distinction between Indigenous and non-Indigenous research methodologies is the importance of relationships. Indigenous research is relational and intuitively grounded on an Indigenous knowledge base and values (Kirkness and Barnhardt 1991). The interviewing process with Indigenous people by Indigenous researchers is unique for two reasons, the first is the close familial structure within Indigenous society, and the second is their shared history of impact

of colonisation (Weber-Pillwax 2001). Indigenous Australians share close familial networks which is often present between Indigenous participants and Indigenous researchers, this offers another important dimension to the research process. These close relationships and networks provide the opportunity for a greater level of trust between Indigenous participants and researchers.

Indigenous researchers do struggle with the academy's position of so-called objectivity in the research process because they know it is important that there be recognition of the importance and value of relationships with Indigenous research. As Weber-Pillwax (2001, p. 169) states,

Unless we realize that knowledge in actuality through integration into our own ways of being and knowing and doing, our studies have no life. They become those empty practices of the teacher who cannot be a teacher but who purports to act as a teacher.

The importance of Indigenous research methodologies cannot be understated, as they are methodologies 'that enable and permit Indigenous researchers to be who they are while engaged as participants in research processes that create new knowledge and transform who they are and where they are' (Weber-Pillwax 2001, p. 174).

Research in an Indigenous health setting is very different from that which is conducted in a non-Indigenous environment (Thomas and Anderson 2006). An Indigenous research approach is valid and it is equally systematic, but its methodology is not always recognisable for Indigenous knowledge is present through a myriad of forms. It involves both the physical and spiritual dimension, it is about space and time, and it is about people, animals and the landscape. All these elements are present in a culture that uses the oral tradition of storytelling in providing and framing cultural references (Battiste 2008; Marker 2004).

In the university system the emphasis is for researchers to gather information and then reflect and process this information into knowledge (theory) in a very highly systematic manner. Indigenous research is equally systematic for it is relational, that is, more time is spent on preparation and, if necessary, on rituals, and on establishing, forming and maintaining significant relationships. This requires a high regard and responsiveness to the community; it means approaching research with 'humility, sensitivity and openness', so that, 'knowledge in this method seeks the student rather than the other way around' (Marker 2004, p. 105). The relational approach to research is an extension of an Indigenous worldview; a difficult concept for the academy to embrace. The Indigenous approach positions the researcher in a

unique position, for the animals, plants and the environment become the teachers in the process of discovery and learning. The relational approach adopted by Indigenous researchers is a core part of their Indigenous worldview, for there is an inherent understanding of not harming their community or themselves. As Marker (2004, p. 106) states 'Knowledge is powerful and potentially dangerous if one is not ready to receive it properly; a deep and sublime sense of relationships is required'.

The relational approach is not something new to some in the academy as feminists, poststructuralists, critical theorists have all adopted aspects of the relational approach in their methods (Denzin and Lincoln 2005b; Fine 2005). They all share concerns about the inherent bias within the academy towards mainstream epistemological values (Denzin and Lincoln 2005b; Kincheloe and McLaren 2005; Marker 2004).

Research with Indigenous people means to take on an activist role; by focusing on being objective, the researcher creates social distance. To be a researcher with Indigenous people is a political act regardless of the intentions of the researcher. So it makes sense that non-Indigenous researchers are prepared for their research to be part of the dismantling of structures of oppression and for their work to be an active part of the process of decolonisation (Bishop 2005; Grande 2008; Pidgeon and Cox 2002).

Writing as Inquiry

There is only narrative – that is, only different genre-defined ways of representing and writing about experiences and their multiple realities (Denzin 2001, p. 7)

It was my goal to write this thesis in a style that was accessible to a wide audience, those in academia and the Indigenous participants and community members. However, I underestimated the difficulty the undertaking of such a task. The academy requires the scholar to present a thesis worthy to be assessed on its academic merit. I therefore had a dilemma, how would I proceed with my goal of the production of work that was accessible to a wide audience. The original intention was that the thesis would serve this purpose. However, academic language, because it is so specific, is often perceived as elitist and therefore alienating to the non-academic community.

To achieve the goal of writing to a wide audience I decided to write multiple versions and to target my writing to suit each of the audiences. For example, the thesis needs to be written in a style that demonstrates academic understanding and grammatical

expertise that produces a document of quality worthy of acceptance. Therefore, because of the use of theory, referencing style, and other academic requirements, the thesis may not be appropriate for the participants, or other community members.

I decided to write a separate report – a *Community Report* for participants and members of the community which will include a summary of each of the chapters, and which will be written in a style that is less academic. The Community Report will be available to a wide audience, and will be written after the thesis has been examined. Writing two separate documents allow for the goal to write in a style that is accessible to a wider audience, those in academia and the Indigenous participants and community members.

5.3 *Challenging the processes of the academy: Issues of power*

Phases of the Study

There were five key phases in this study. The first phase involved the researcher (me) scoping the study through discussions with Indigenous health workers, Indigenous community members and mental health practitioners about the viability of this type study. I had worked for four years in the mental health sector as the manager of an Indigenous mental health service of Derbarl Yerrigan Health Service, the local Aboriginal Community Controlled Health Service in Perth. Due to my previous work experience I had confidence that the proposed study would be acceptable to the local Indigenous community.

The second phase entailed the establishment of the Study Reference Group with which I formed a collaborative relationship for the entire process of the study. The Study Reference Group's involvement extended through all phases of the project including the study design, recruitment of participants and ethics process. Refer to Appendix 1 for the names of the people in the Study Reference Group. Curtin University Ethics Committee granted ethics approval in December 2005. Ethics approval was also granted by the Western Australian Aboriginal Health Information Ethics Committee in July 2006. Refer to letters of ethics approval and letters of support from Derbarl Yerrigan Health Service and Aboriginal Health Council Western Australia (Appendices 2a, 2b, 2c and 2d).

The third stage, the data gathering phase, involved recruiting participants, conducting the first set of interviews and participant observation. Refer to Appendices 3a, 3b, 3c, 3d & 3e for relevant documentation. The production of a newsletter for the study, distributed bi-annually, also commenced in the third phase.

The Newsletter was distributed to key stakeholders, including the Study Reference Group members, participants, and mental health agencies in the Perth area. Copies of the Newsletter are attached at Appendix 4.

The fourth phase involved further partnership activities with participants, including, where possible, a visit to each participant with a transcript of their interview, as well as a summary and critique of the interview for their review. Participants were told that they could change or delete any of their comments from the interview. During the fourth phase a second interview was conducted with six of the participants. Participants for the second interview were selected because of their unique generational or intergenerational relationships, for example, mother and daughter, husband and wife, grandmother and daughter. In this phase an Arts-based inquiry workshop was also held for participants. Of the eight participants who attended the workshop, seven were participants in the study, the other being a partner of a participant.

The fourth phase of the research also involved an exciting proposal, initiated by the participants for the formation of an Indigenous Mental Health Network. The aim of the Indigenous Mental Health Network would be to shape mental health policy so that it better reflects the needs of Indigenous people living in Western Australia. With the participants' permission I contacted a community-based mental health service, Ruah Community Services, to assist the group in the formation of the network.

The fifth and final phase of the research involved giving participants a draft copy of the findings chapter for them to review. Participants were invited to give feedback on the chapter and to have any of their comments changed if they wished to do so. During the fifth phase public presentations of the study were given to groups of key stakeholders, including participants and their families, Study Reference Group members, Aboriginal health workers and other interested community members. I also gave a keynote address to the 'Our Mob, Our Minds, Our Spirit: Indigenous Mental Health Conference' held in Fremantle in November 2008 on the findings from the study. Refer to Newsletters and Appendix 4 where copies of Newsletters are appended.

Data collection techniques

This study utilised the critical ethnography methodology which is based on an emancipatory research approach which places an emphasis on transformation, both for the researcher and the participant. Research that is emancipatory should facilitate inner transformation, promote self reflection and assist for a deeper and

more confident understanding of a person's situation. As Lather states 'the task of a critical social science is to explore the nature of the intersection between choice and constraint and to centre on questions of power' (Lather 1991, p. 56).

Selection of participants

Reciprocity is an important concept that must be considered when doing research with Indigenous people. Importantly, respecting the respective roles of researcher and participant is essential for a successful study (Pidgeon and Cox 2002)

Reciprocity is also important because it is relational. From an Indigenous methodology perspective and that of a critical ethnographer, relationship building is an important cultural concept in forming and negotiating relationships within the research context. The process for selecting participants involved members of the Study Reference Group, Aboriginal health workers, mental health staff and members of the Indigenous community. Aboriginal health workers and mental health workers selected the participants for the study from their networks. The process involved a third party introducing the researcher to a prospective participant. The third party who was a mental health worker, Aboriginal health worker or family member or friend, would discuss the study with the likely participant who, if he or she was interested, would then be introduced to the researcher.

The participation of the Aboriginal health workers and mental health workers assisted the study in two ways. Firstly, it protected participants from feeling pressured into becoming involved in a research project, and secondly, it provided the justification for the involvement of the participant's mental health worker or health worker in the study. Relationship building and authenticating the suitability of the researcher occurs on two levels, the personal and the cultural. At the personal relationship level, the prospective participant is able to check out the suitability of the researcher, and at a cultural level, the cultural placing or checking out of a person (if the researcher is Indigenous) occurs in the context of community connections and family. This is an important cultural concept in forming and negotiating Indigenous relationships. Acceptance by the community of a research project and of the researcher is critical and also essential for the success of any meaningful study with Indigenous people.

Rationale for inclusion of care-receivers

The rationale for including care-receivers was a response to the request of research participants and their families who believed that the story of care-giving provided by the family could not be told without such contextualisation. Originally I was going to

include only those who provide care to an Indigenous person living with a serious mental illness, but almost immediately after starting the interviews I was approached by family members living with a serious mental illness who felt that their story about being cared for by their caregiver was important to the story of care-giving. After discussion with my supervisor and the Study Reference Group we acknowledged that, in fact, participants were telling us that the care-giving role could not be understood in isolation from the context of kinship and care. Participant suggestions for the study design also demonstrated their commitment to the project. The collaborative nature of the research required that their suggestions be acknowledged and, where possible, integrated into the study design.

Family members advised the researcher that he needed to be respectful of community and sensitive to the unique bonding that exists within Aboriginal families. The participants were clear that a holistic understanding of Aboriginal experience of care-giving and mental health required that all members of the family or community who were affected be allowed to contribute their story if they wished. The change in the study design was approved by the Western Australian Aboriginal Health Information Ethics Committee.

Rationale for sample size

The small sample size is considered valid for a qualitative study using in-depth analysis. The number of participants in the study was further rationalised on the basis of three important points. First, the researcher was constrained by the need to use a culturally safe recruiting method within a very small community with previous negative experience of research. Second, the researcher was aware of the vulnerability of this population, the need to protect sensitive kinship systems under multiple stresses and to provide adequate and ongoing relational and community support to those who engaged with the research. Third, the research was based on the case study framework methodology. The study was, in effect, working with 13 cases. Case studies provide the opportunity for analyses which plumb the depth and breadth of a phenomenon as experienced by an individual (or family) longitudinally. They typically involve multiple interviews and intensive sorting of data over time. The sample size could be construed as small if it was based on 13 individual one hour interviews or questionnaire, but in the context of this study the sample size is justified as it represents 13 in-depth cases constructed through time intensive longitudinal in-depth data collection and analysis.

Participants

The target populations for this study were caregivers of Indigenous Australians living with a serious mental illness and those who were recipients of care. There were Indigenous and non-Indigenous participants recruited for the study, but the inquiry was restricted to only Indigenous Australians living with a serious mental illness.

There were 13 participants involved in the study. Of the 13 participants, 12 were female and one was male, 10 were providers of care, nine Indigenous and one non-Indigenous, with three of the Indigenous participants living with a serious mental illness being receivers of care. The participants selected were a representative sample of the Indigenous population living with a serious mental illness. The three Indigenous people living with a serious mental illness were close relatives of their caregivers, as they were husband, granddaughter and daughter respectively.

Initially, the study was to focus on the experiences of care-giving from a caregiver's perspective. The reason for the inclusion of Indigenous people living with a serious mental illness was that the researcher was approached by an Indigenous family member living with a mental illness who asked to be included in the study. This person's request provided the opportunity to add another dimension and perspective on the issue of care-giving. After discussion with my supervisor and with the Study Reference Group, I decided to include in the study Indigenous people living with a serious mental illness in order to include their perspectives on care-giving. The inclusion of both perspectives: those receiving care as well as the experience of providing care added greater depth to the study.

The study was not gender specific; rather, as a representative sample, it was designed so that anyone who presented to be a participant, either female or male, would be included as part of the sample population. It was assumed that the study could reveal that care-giving is predominantly located with a particular gender, but in the early stages of the study design this could not be taken for granted. However, this proved to be the case as 12 of the 13 care-givers were female, with only one male participant.

Participant observation

An adapted version of the participant observation method was used for the study and the use of the method of participant observation was confined to two settings - the interviews and the art-based workshop session. The purpose of participant observation is to learn what is often taken for granted in certain situations, and to discover or uncover the underlying meaning by watching and listening. It is

important to recognise is that any observations by the researcher are filtered through the researcher's own experiences and the journaling provided a method for the researcher to check, analyse and observe his own processes (Morse 2004).

The researcher focused attention on a range of activities and events that occurred within the two specified research contexts, interviews and arts-based workshop. The researcher was observant and sensitive to the periods of silence and reflection during an interview. Entries into the researcher's journal in the participant observation phase included deliberations on a particular event, then a period of reflection before writing up the observations in the journal by the researcher. Entries into the journal occurred within 24 to 48 hours after an interview. Journal entries were used as part of the analysis process, as the observations helped in deepening understanding of the content of the interviews. The observations were also used in providing feedback to the participants in the form of a summary of their interview process. Conducting observations requires sensitivity, as conducting observational procedures can be intrusive if not done in a respectful manner.

Interview process

There were two interviews conducted with participants in the study. The first was in an unstructured form, and the second interview was in a semi-structured style. The interview guide and questionnaire are appended. Refer to Appendix 3d for relevant documentation. All the interviews were conducted in a place selected by the participants which was typically their home or workplace. Both first and second interviews ranged from between an hour to an hour and a half in length. The interviewer was aware that some of the participants were a little uncomfortable with their interview being recorded. To help them overcome their initial nervousness, the interviews began with a general and non-threatening question: *Can you tell me a little about yourself? For example, where you were born, where you grew up and if you are comfortable in talking about it how you came to be living here in Perth?* This approach worked; after participants had spoken for a few minutes about themselves it was enough for them to overcome their nervousness. The follow-up question was: *Can you tell me what it has been like to be a caregiver or someone who is receiving care?*

The unstructured interview worked best for the first interview with participants, as it provided the opportunity for the participants to tell their own story. From a critical ethnography process this is the preferred method, as it is 'a conversational or dialogic style of interviewing, which encouraged the subjects to participate more'

(Foley and Valenzuela 2005, p. 223). This 'free-flowing' approach allows for a greater level of intimacy in the process. Obviously conducting an effective interview requires the interviewer to actively listen and not interrupt unnecessarily, but rather allow the conversation to flow without distracting the participant's stream of thoughts.

Second Interview

A second interview was conducted with six of the participants. The second interview was semi-structured, with six questions focused on care-giving, experiences of mental health services and racism. The aims of the second interview were to deepen the focus of the questions on firstly, the issue of racism in the context of mental health and mental health service delivery, and secondly, the experiences of care-giving, both receiving and giving, in an intergenerational and generational context. There were six participants for the second interview and their relationships were, mother and daughter, husband and wife and grandmother and grand-daughter.

Rationale for second interview

The rationale for interviewing six of the 13 participants twice was for clarification and for deeper exploration of some of themes that had emerged from the first round of interviews. For example, the theme of racism had emerged in the first round of interviews which were more unstructured and open, asking people about their care-giving experience. The format for the second interview was more structured and followed some of the themes from the first interview to enable deeper exploration of the material.

The benefits gained from the second round of interviews were significant. The second interview provided the opportunity for the research to explore significant topics that had emerged from the first interview. For example, the second interview confirmed the theme of racism. The research methodology was an inductive process, not a deductive process of testing a theory; which enabled the emerging theme of racism as related to care-giving and mental illness to be explored more in the second interview. In addition, the second interview provided the opportunity for the researcher to ask specific questions about how people coped with the mental illness of their loved ones (or their own illness) and about specific interactions with caregivers and systems. Explicit questions about care-giving enabled the researcher to gain more data about the personal attributes interviewees felt they had to have in order to deal with the main difficulties they encountered at individual, institutional,

community and cultural levels. These specific questions allowed for a more focused analysis of the data and the themes that were emerging in the research.

Interview process: Characteristics of interviewer

To be an effective interviewer a researcher must have some basic skills which include background knowledge and information on the topic in question and competent interpersonal skills to allay any fears or apprehensions that may be present for the participant. The researcher needs to communicate to participants that there are no right or wrong answers in an interview (Swanson 1986).

There is a growing body of research that details the benefits of engaging in reciprocal research practices. Lather states that reciprocity is important, 'because the researcher moves from the status of stranger to friend and thus is able to gather personal knowledge from subjects more easily' (1991, p. 57). Importantly, reciprocity in an interview context allows for a greater level of intimacy which then allows for the researcher to assist participants in understanding and, if need be, to be able to change their situations.

Interviews require researchers to have good interpersonal skills and an interest in engaging in conversation with others. These characteristics include a lack of pretentiousness that enables engaging with a natural flow. It is the skill of the researcher that determines the success of interviews, for if the researcher is controlled or strained, it is highly probable that participants will not want to engage in the process (Chenitz 1986). The researcher must be able to communicate in a manner that is non-judgmental and non-threatening. Importantly, the researcher needs to exhibit confidence and sensitivity in the course of the interview and to be mindful and reflexive to any change in the situation (Swanson 1986).

A competent interviewer understands a participant's present situation as it is applicable to the participant. An interview is as much about the situation as it is about the person. It is important to understand the key motivational factors that are inherent in every story for these are present in everyone's life. The important thing is to discover, uncover and recover. To do this effectively requires that the researcher be continually mindful and reflexive in his/her approach to the interview for interviewing is a process of self-observation and self reflection (Douglas 1985).

Recording the data

The interviews were recorded on a digital sound recorder, and then saved onto the computer. The interviews were transcribed by a third party and later stored onto the

researcher's computer. The storage of hard data including the interviews complied with the requirements of the university ethics and the WAAHEIC Ethics Committee.

Data analysis

The researcher collated and analysed the data with the aim of identifying the key experiential elements from each interview. The data was organised around the descriptions of the key aspects from each individual participant's experience as well as comparing similar situations provided by other participants in the study. The theoretical lens used for the analysis for this study was critical theory, post-colonial theory and Indigenous theory. In particular, the analytical focus for the study was to identify how racism has contributed to the current health and economic status of Indigenous people. The participants, people living with mental illness and their carers, provided the particular focus for this analysis.

Any analysis of racism requires the recognition of cultural difference (Jones 1997). Racism presents in many forms but 'poverty can often efface the "protective" effects of status based on gender, race, or sexual orientation' (Farmer 1997, p. 279). Poverty is still the main driver of suffering and in most situations is still the main cause of serious illness and premature death in the world. Racism in itself has its own characteristics, but to broaden an understanding it needs to include an analysis of class, gender, sexuality and structural violence. The focus of analysis of the data for this study was to identify the structures of racism and oppression that disadvantage care-giving for Aboriginal people living with a serious mental illness.

As the researcher, I am an Indigenous man who has previously worked in the area of mental health, and I am conscious that my life experiences were similar to the participants' life events, particularly within the context of racism and colonisation. In responding to this situation the concept of 'bracketing' was implemented as a way to mitigate this influence by contextualising the experiences of the participants, and analysing the participants' experiences that emerged from the data for their essential elements and structures. Bracketing involves the researcher allowing the data to have precedence, without it being overly influenced by the researcher's life experiences (Denzin 2001). The key themes that emerged from the individual narratives in this study on care-giving for Aboriginal people living with serious mental illness centred around racism, oppression and cultural resistance.

At each stage of the data analysis process the participants were kept informed. Participants were given the opportunity to respond to the findings from their interviews for their accuracy and appropriateness. In maintaining the philosophy of

critical ethnography I was continually mindful that the lives of the participants when viewed through the lens of critical theory of race, of ethnicity, class, gender and sexuality; were not just abstract categories, but a critical part of people's lived realities.

Empowering participants: Working with interview transcripts

The researcher adopted the method of Lather's 'concept of reciprocity' (1991) which involves working at the moment between the researcher and the participant on the issue of data and theory and the critical ethnographer Douglas Foley's 'deeper engagement'. The concept of deeper engagement involved returning with a transcribed copy of the interview to the participants and allowing them the opportunity to make changes if they so desired (Foley and Valenzuela 2005). Lather's concept of reciprocity also includes the notion of co-authorship of interviews. Lather's focus is on moving to the point of equality in the research process; her approach is for participants to have a greater sense of ownership in the research activity. As she states '[r]esearchers are not so much owners of data as they are "majority shareholders" who must justify decisions and give participants a public forum to critique' (Lather 1991, p. 58). There is a natural relationship with the approaches of critical ethnography and Indigenous methodology because they both work at the interface of equality and social justice in the research process.

For this study I returned transcripts to participants and in so doing provided participants with a deeper understanding of the interview process. The opportunity to see the transcripts and make comments was part of the transfer of knowledge which in itself was described by participants as a very empowering process. Participants also had the opportunity to edit the transcripts, if they felt there was a problem with how they were being represented. This process has a number of benefits, for according to Foley and Valenzuela (2005) it enables the interviewer to be seen as being more human, rather than as often portrayed as the 'other'. Further the process curbed some of the power issues present within the interviewer - interviewee process.

Where there is a method in the research process that facilitates a feedback loop it allows for a more meaningful relationship between researcher and participant. This process builds mutual trust, respect, reciprocity and relevance to the process. Importantly, it provides for the capacity building of research in disenfranchised communities, and begins the process of educating community members about the benefits of research; aiding in the process of decolonisation that has occurred

through past negative research practices with Indigenous people (Pidgeon and Cox 2002).

Empowering participants: Newsletter

A Newsletter produced for the study on a bi-annual basis was a simple method to keep people informed of the progress of the study. Participants had indicated that they felt disengaged with their involvement in other research projects, some in particular mentioning to the researcher the lack of feedback about their contribution to those research projects.

The Newsletter was one initiative to counter this sense of disengagement as it provided participants and other key stakeholders with an opportunity to be kept informed of the progress of the study, and a sense of involvement in the study as opposed to some participants' past experiences in research projects in which they had had no further contact with the interviewer after the interview. The Newsletter was a way of keeping participants informed and engaged in the various stages of the project. The Newsletters are attached at Appendix 4.

Time and research methods

An effective and culturally safe qualitative study needs time. There were many hours spent with families in the pre-interview, the interview and the post-interview stages. When the interviews occurred they would often take several hours as there were often interruptions during the interviews. After the interview participants were also keen for me to stay and assist with other matters as is common in my community. Post-interview sessions returning the transcripts to the participants required time for the transcripts to be read, debriefing if required and further discussion and clarification of data. Each of these sessions involved several hours and the collection and collation of more data relating to each case study.

The interviews were undertaken from the first year of the project and continued over the next 24 months. More importantly, relationships and trust have now been fostered and maintained with the 13 families for over three years and half years. Each case represents many hours of intensive work. Participants were kept informed of the study process through the newsletter; they were encouraged to contact me if they had any concerns or wanted to continue the story. Some participants contacted me occasionally to help with a range of issues that were occurring with them or in their family. Some of the issues included arranging referrals for counselling support, mental health support and accommodation. I also attended funerals and provided loss and grief support to caregivers and their

families. On several occasions I was approached to assist caregivers and their families with a range of problems, and as a trained social worker I was able to assist.

The aim of the data collection and analysis process was to ensure cultural safety, which consequently prolonged the period for analysis. Given the insensitive past practices of researchers working with Indigenous people I was determined not to repeat those same practices. To ensure that the data collection process was culturally safe I designed a framework that offered security to the participants. I had no direct involvement in the recruitment of the participants; this was done through a third party. All transcribed interviews were collaboratively edited between researcher and participants. Participants received a draft of the findings chapter for their editing. The project was supervised by a Study Reference Group of Indigenous leaders who met twice a year over the length of the study. Cultural safety was pre-eminent.

Limitations of the study

There were a number of limitations to the study, some of which related to the methodological tool, that is, critical ethnography. One possible limitation was that there were only 13 people recruited for the study, 12 females and one male. This limitation must be balanced with the methodological strengths which accrue from using an in-depth case study approach when obtaining data from marginalised or oppressed groups. The sample size was partly due to the difficulty of recruiting participants to the study. I was advised by Indigenous community members and my reference group that it would be most culturally safe and appropriate if recruitment of participants was conducted through a third party; such as an Aboriginal health worker or mental health worker. The recruitment process took much longer than expected and was extended because of this arrangement, as often the workers were not always available to recruit participants for the study. Time did not permit a longer period for recruitment of participants. To mitigate for the sample size I interviewed six of the original participants twice. This proved to be successful as I was able to explore further issues identified in the first interview and this provided for richer and more extensive data for the case study approach.

There were also participant limitations due to the criteria of who could be involved in the study, as participants needed to be in a stable living situation and they needed to commit to the study for at least a two year period. This excluded people who were very mobile, who were not linked to any mental health service and possibly those

whose living situation and experiences were even more stressed and negative than that of the study participants.

This was an ethnographic study which used an inductive process with the aim of generating further research questions. This, I believe, has been achieved as there is additional material that could be pursued for both an inductive and deductive study.

The 'snow-ball' technique was used in the recruitment of participants. Once I had recruited some of the participants they were able to act as the third party to recruit others. However, the snow-ball technique could possibly be problematic in regards to the sample not being representative of the urban Perth Indigenous population, in that the participants were more likely to recruit family or friends in similar situations to their own.

Participants were recruited from the Perth area. Perth is the capital city of Western Australia. The Indigenous population living in Perth include the Wadjuk Nyungar (traditional owners of the area) and other Indigenous people from across the state and interstate. As the study was limited to the Perth area, separate issues that may present for care-givers living in remote or rural settings were not accessed in this study.

Even though there is an over-representation of Indigenous people in Western Australian prisons the issue of forensic mental health was not covered in this study. Therefore, a limitation of this study was that it did not include Indigenous people who were either in prison or under the supervision of corrective services.

Finally, there were structural critical theory issues relating to the researcher being male. Most of the participants were female, and there were moments in which my gender (being male) may have been a limitation for the study. While I cannot be entirely sure of these impacts, I suspect that if I were female, some of these disparities may not have emerged, or perhaps different set of issues may have been raised in the course of the interview. In this context there were always issues around particular agendas, interpretations and views that may have impinged on the research process. While I had a sense that this could have been the situation in interviews with Indigenous women, I nevertheless felt that this would not necessarily be problematic as I felt that I could be empathetic because of my own situation as the primary carer for my wife who has a serious chronic illness. I am confident that

the participants felt comfortable with me as evidenced by the tone and range of the comments they offered.²

5.4 Legitimising the Indigenous voice: Ethical research with Indigenous people:

Doing research in Australian Indigenous community

Ethics approval for the study was granted from two sources, the Curtin University Ethics Committee and the Western Australian Aboriginal Health Information Ethics Committee, an Indigenous community-based ethics committee. The Curtin University Ethics Committee provided approval, without raising too many issues. In contrast however, the Western Australian Aboriginal Health Information Ethics Committee was thorough and more robust in its duty of assessing the project. The guidelines for the Indigenous community-based ethics process required the researcher to frame his application on the principles for conducting research with Aboriginal people outlined in the National Health Medical Research Council (2003) *The Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research*. The guidelines required the researcher to frame his ethics application on the six values of *spirit and integrity, reciprocity, respect, equality, survival and protection and responsibility*. These six values have been incorporated into this study. Refer to Appendices 2a & 2d.

Study Reference Group

The establishment of a Study Reference Group to monitor the study reflected the requirements outlined in the six values as outlined by NHMRC (2003) *The Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research*. The Study Reference Group was convened at the outset of the study and its role was to provide cultural advice and technical assistance for the study. The research project was constantly under review by the Study Reference Group so as to ensure that there was cultural, spiritual and social cohesion. The establishment of the Study Reference Group ensured that the researcher worked with integrity, as the Group continually assessed and evaluated the cultural aspects for the study. As the researcher is Indigenous the concept of being an ‘insider’

² During the final stages of the PhD the researcher applied for a NHMRC Post-doctoral Training Fellowship. To assist the application he requested from some of the participants comments on his suitability as a researcher. The comments were very positive, as evident by the following comments, ‘Respectful, honest, good researcher. Knowledgeable, experienced, transparent reliable, doesn’t make promises he can’t keep. Walks the talk. Successful in everything he does, competent, experienced, culturally appropriate, patient, appropriate with Aboriginal women, respects people’s space, established good rapport, a man who respects.’

applied (Tuhiwai Smith 2003). Being in the role of 'insider' can be an issue, for as the Indigenous population in Perth region is relatively small, being Indigenous and having 'insider' knowledge of the community can often be a challenge as boundaries can become blurred (Dickson-Swift et al 2006). The Study Reference Group was able to provide cultural advice, without compromising confidentiality, on cultural and community matters that occurred during the study. Refer to Appendix 1 for the list of Study Reference Group members.

Western Australia is geographically the largest state in Australia. The scope of this study was limited to the Perth metropolitan area. As the capital city of Western Australia, Perth has a diverse population of Indigenous Australians who come from all over the state and from other states and territories in Australia live. In recognition of this diverse population the membership on the Study Reference Group reflected, to some degree, this cultural and geographical diversity. The Study Reference Group included Indigenous people from the South West, the Kimberley, the Pilbara and the Gascoyne regions of Western Australia. The Indigenous people on the Study Reference Group were recognised in their respective communities as well as being acknowledged as competent professionals by their Indigenous and non-Indigenous peers in the areas of Indigenous health, higher education and welfare. The Study Reference Group closely monitored all aspects of the project particularly around the collection of data, and the dissemination of information flowing from the study.

Indigenous Supervisor

There were two supervisors for this study, one of whom was an Indigenous academic with extensive experience in the area Indigenous mental health. This was to ensure another level of accountability as well as providing cultural security for the project.

Research as a path to activism

One aim of this study was to provide pathways for participants to develop a holistic understanding of the underlying issues of care-giving in a mental health context, and to facilitate awareness and provide skills so that participants can challenge and change systems that oppress and marginalise disenfranchised groups. Critical ethnographers, according to Corrine Glense (1999, p. 12), 'seek to do more than understand and describe, they want to transform unequal power relations'. There is a growing body of research, in which critical ethnographers and Indigenous researchers argue that researchers must go beyond description of the issues to

become activists for change (Battiste 2008; Fine 2005; Giroux 2008). Critical ethnographers work in the role of activist, as they recognise the need to expose injustice and to offer pathways to emancipation (Madison 2005).

Arts-based inquiry workshop

An arts-based inquiry workshop was held for participants to further explore the experiences of care-giving in the context of serious mental illness. The arts-based inquiry workshop was attended by eight participants, seven of whom were part of the study, the other was a partner of one of the participants. The purpose of the arts-based inquiry workshop was to provide an opportunity for the participants to explore through the medium of art, the meaning of care-giving for an Aboriginal person living with a serious mental illness. As Finley (2005, p. 684) states, in arts-based research, 'paradigms for making meaning in the contextual realms of art and social science collide, coalesce, and restructure to become something that is not strictly identifiable as either art or science'.

A local artist was engaged to lead the workshop. This artist has previously worked with local Nyungar youth in the Perth area and had also worked with people living with a serious mental illness. The artist used a very innovative and exciting style of art in the workshop called Digital Mandela Process. The Digital Mandela Process is a collage and involves the arrangement of five centimetre square images. Each square picture is cut to size from a magazine using a view-finder (or template) of pre-determined size of the image. The term 'digital' is used because of its similarity to pixels on a computer. A focus of the workshop was to use the production of a collage as a means of consciousness-raising about the issues of care-giving for participants through their individual pieces of art.

An arts-based inquiry approach is useful in the application of qualitative research. In more recent times there has been a growing acceptance of this methodological and theoretical genre among the new forms of qualitative inquiry (Finley 2005; Guillemin 2004). There is now increasing evidence that shows that '[t]he visual arts are more than a palliative – under the right guidance, they can be a vital form of self-help which allows Nature powers to restore balance and harmony to a troubled mind' (Adamson 1984, p. 5). Art has many facets to its healing qualities, but importantly it is a safe method for communication, particularly for conveying inner thoughts and ideas. Art in its purest form allows for enormous potential for healing, and 'gives palpable form to imagination' (Adamson 1984, p. 6).

The use of an arts-based inquiry approach for this study offered art as a path to activism. As Finley (2005, p. 682) states:

Arts-based inquiry, as it is practiced by academics doing human social research, fits historically within the postmodern framework that features a developing activist dynamic among both artists and social researchers.

Painting or any work of creativity is a powerful release for energy in serious illness. The arts-based inquiry workshop provided the opportunity for participants to experience, in a group situation, the shared experiences of the issues of care-giving for Aboriginal people living with a serious mental illness.

Publications: Joint ownership to the of creation of knowledge

The researcher provided participants with documentation from the study, including individual interview transcripts and a copy of the Findings chapter for their comments. Participants were invited to provide comments on their interview transcripts and on the Findings chapter. The concept of reciprocity and reflexivity is a key criterion of critical ethnography and Indigenous theory (Battiste 2008; National Health and Medical Research Council 2003; Weseen and Wong 2000). However, there has been a failure by the social sciences in understanding the relationship of power and truth that has contributed to the lack of reflexivity by qualitative researchers on the issues of truth and justice (Carspecken 1996). Critical ethnographers have argued for a greater sense of mutuality, between researcher and participant within the research process (Fine and Weis 2005; Madison 2005). 'We ask for revelations from others, but reveal little or nothing of ourselves; we make others vulnerable, but we ourselves remain invulnerable' (Behar cited by Weseen and Wong ip. 34).

The focus of critical ethnography should reflect a collaborative approach in the research process at both the methodological and political levels (Madison 2005). Emancipation lies in the design of the study, and for it to occur participants need to have an active involvement in all processes of a study including the design, the construction and validation of its implications and importantly co-creators of knowledge (Foley and Valenzuela 2005). Critical inquiry should motivate and direct those who are oppressed in the process of any transformative experience (Lather 1991).

A strategy adopted by the researcher was for participants to review documentation before any publication. In this study participants reviewed their transcripts and the findings chapter. Allowing documentation to be reviewed 'does not relinquish

authorial authority, [but] it does add a great deal of reflexivity to the data collection and representational process' (Foley and Valenzuela 2005, p. 223). The lack of opportunity for participants to be involved in the analysis of the findings, according to the Lather, 'makes possible a situation where the entire issue of false consciousness is skirted' (Lather 1991, p. 59).

Importantly, when participants identified issues in the documentation, they were acted upon; there was ongoing negotiation with the participants, and, where necessary, changes were implemented that reflected the wishes of the participants. It was the view of the researcher that it was politically expedient for participants to be able to both read and understand the text in this ethnographic study. It is this type of political collaboration which allows for a more meaningful interaction between researcher and participant.

The benefits of adopting the reflexive approach in this study have been evident. The application of critical ethnography and Indigenous methodology, both based on relational values and principles, has resulted in a positive relationship between researcher and participants based on trust, respect and reciprocity.

Indigenous mental health advocacy network

During the data collection phase several of the participants requested that the researcher assist them in organising themselves into a Network for the purpose of advocating on Indigenous mental health issues in Western Australia. The request by the participants was vindication for the choice of critical ethnography as the methodology for the study. The researcher coordinated the process by having discussions with a community-based mental health agency in order to support the establishment of a Network to shape Indigenous mental health policy directions and to ensure that the organisation selected be prepared to enter into a partnership with the Network and be committed in supporting the Network for the medium to long term. The outcomes from this initiative have been notable for there is now an established group with membership from the agency, participants from the study and other Indigenous community people. This group meets monthly with the aim of shaping Indigenous mental health policy in Western Australia.

Dissemination of findings from the study

As was previously mentioned under *Phases of the study* the final stage of the project involved providing feedback on the study. In November 2008 I gave two presentations on the findings from the study, the first, held at a Community Centre, was to the study participants. The second, a week later, was the keynote address to

the 'Our Mob, Our Minds, Our Spirit: Indigenous Mental Health Conference' held in Fremantle. The conference attendees were Indigenous and non-Indigenous service providers, from mental health and welfare organisations. A further presentation to submit the findings will be held with the Study Reference Group in early 2009. It is also planned to provide another presentation to other key stakeholders, service providers and community members, in early 2009.

5.5 Summary

In this chapter there was a further exploration of the importance of identifying the appropriate methodological frameworks for this study. There should be linkages between, epistemology, theoretical perspectives, methodology and methods when constructing the framework to be used in the analysis of the research question for of *how care-giving is constructed by Aboriginal people living with a serious mental illness*. The chapter explored the distinctive relationships of critical ethnography and Indigenous research methodology and that even though each of the methodologies has its own unique qualities, when combined they are provide a framework that enables a meaningful interpretation of the Indigenous participants' experiences of living with a serious mental illness.

The next chapter *Voices of resistance* will provide an overview of the findings from the data on the issues of care-giving and Aboriginal people living with a serious mental health illness. A critical ethnographic approach was used that applied a multi-level analysis by choosing themes that provided an explanation to the experiences of the individual when nested within family, community and society. The linkages between, theory, methodology and methods to the research findings are critical to the findings from this study.

Chapter Six: *Silenced Voices No More!* – Findings 1

6.0 Introduction

In this chapter I present an overview of the findings of what it is like living with a serious mental illness from an Indigenous perspective. In particular, the more global challenges that impact on family, community and society. Caregivers described the multiplicative effects of cultural racism, stigma and discrimination of mental illness, as well as institutional and individual blocks to them providing care for family members. I also discuss the findings from the participants on the challenges of care-giving.

The presentation of the findings from the study has been split into two chapters, Chapters Six and Seven. The findings presented in both chapters are from the collation of the data obtained through interviews with participants. The interviews were analysed using a critical ethnographic approach which applied a multi-level analysis which relied on the choice of themes that provided an explanation to the experiences of the individual when nested within family, community and society. The selection of themes was based on their reoccurrence and frequency within interviews, and on their saliency, that is, the importance participants placed on an issue. The data from the interviews were diverse and topical, insightful and revealing, and made available a rich seam of information for the study. It should be noted that strong language is present in some of the quotes used in the chapter/s.

This chapter is divided into three main sections, each of which provides an overview of the main themes that emerged from the study. The chapter sections are:

Overview of the participants: provides the demographic details of the participants involved in the study.

Living with a serious mental illness details the main issues confronting Indigenous people who are living with a serious mental illness. It also provides an overview of the challenges confronting care-givers and care-recipients within their families, within their community and society.

Experiences of care-giving explores the strengths and limitations of families; working from a strengths perspective and the issue of children and mental illness.

Staying the distance provides the emotional, psychological and spiritual questions surrounding care-giving, particularly the issues of disenfranchisement and marginalisation.

Summary: offers an overview of the main themes that were discussed in the chapter. It will conclude by introducing the main themes for the following chapter.

6.1 Overview of the participants

As outlined in Section 5.3 of the previous chapter, there were 13 participants interviewed for this study, ten of whom were carers and of these, nine were Indigenous people and one was non-Indigenous. The other three participants were Indigenous people living with mental illness and receivers of care. Twelve of the 13 participants were women. I have used pseudonyms to protect the privacy of the participants quoted in this and other chapters to illustrate the issues and themes that have emerged from the analysis of the interviews. The table below provides the demographic information of the participants.

Table 1: Participant Demographic Information

Care-giver			
Pseudonym	Gender	Relationship to cared-for	
Barbara	Female	Mother	
Beth	Female	Aunt	
Cathy	Female	Mother	
Cheryl	Female	Wife	
Ellen	Female	Grandmother	
Gail	Female	Mother	
Gina	Female	Mother	
Jenny	Female	Mother	
Joan	Female	Mother	
Paula	Female	Mother	
Cared-for			
Pseudonym	Gender	Relationship to care-giver	Diagnosis

Andrea	Female	Grandchild	Schizophrenia
Noel	Male	Husband	Depression
Sarah	Female	Daughter	Schizophrenia

6.2 Experiences of mental health issues: Mental illness is a dark scary place

This section reviews the main issues confronting Indigenous people who are living with a serious mental illness and provide a synopsis of the difficulties of their interactions with mental health services. The issues explored include the interactions with family and community, as well as discussion of the myths and perceptions surrounding mental illness.

Living with a serious mental illness

In general, the major focus and preoccupation of participants living with a serious mental illness and their care-givers were issues surrounding mental illness itself. The chronic nature of mental illness makes the reality of day-to-day living difficult. Participants' memories of serious and acute episodes of mental illness included the time spent in hospital and their experiences in the community when they were unwell. These memories were all significant motivating factors for them to remain well.

Andrea described living with a serious mental illness as living in a dark scary place:

It is a dark place, and the main thing of coping with it is to know that you've got the support there, even though half the time when you're in a mental state you don't think there is. You know, and it takes a lot, takes a lot, out of you because its one scary place. That's all I can say, it's really scary.

Ellen, Andrea's care-giver, also described her experience of mental illness in equally graphic terms, as a place that was isolating and separate:

Mental health is a lonely place. We try to understand and I mean we try to understand, but we could never be in that position. But I'd say it's a lonely place.

Sarah, another participant, identified loneliness as a significant issue for women living with a serious mental illness:

People living with a mental illness just want somebody to talk to and people with mental illness I found are really lonely people. And they never shared that with anybody, you know, and I found that a lot of the women, especially women, in their 40s and 50s are lonely women.

Being given a diagnosis for a serious mental illness was difficult to accept, as Sarah noted:

I couldn't accept my diagnosis of schizophrenia, but because I'd had so many psychotic episodes and I also have depression they've now classified me as being schizophrenic. I still argue with my doctor, I don't think I should have that diagnosis; I prefer depression because I find that more acceptable. I didn't know...that there were these big great adverts about schizophrenia but at the same time I was still afraid of this...big word. This scary big word and lots of people, the general public are afraid of that word. With schizophrenia you've got it all the time. Even now when I talk to people I say, 'Well I can cook, or, or I can call myself depressed or I can call myself schizophrenic, what do you prefer?'

Another participant, Noel, described the difficulties of living with a serious mental illness:

A lot people they look at mental health and they think you're fucking 'mad' you know, but it's not like that. I get by day-by-day, but mental health you know, it does wreck your life. There are times when I just want to chuck the towel in and give it all up.

Family and community

Generally, participants were positive in their description of family and community acceptance of their mental illness. They acknowledged the importance of family in the healing process, but there were occasions when families experienced difficulties.

Andrea described some of the difficulties confronting family members:

...sometimes families usually do not always understand what is happening to you and what you are going through...with the family its like, you're not seeing what they're seeing. They think that everyone's at least against the wall. I believe they don't understand where you're coming from but in a way it's true that they don't know where you're coming from.

Andrea's care-giver is her grandmother, Ellen, who has been her main support:

I noticed that when Nan told me what's going on with me and when she said, 'I don't know how to help you but if I can help you it might help me as well. You know, I don't know, I've never been in this position but I want to know how to help'.

Andrea noted the difficulties confronting care-givers of people living with a serious mental illness:

There should be more supports for people to be care-givers for people living with a serious mental illness. To help people who are helping those living with a serious mental illness makes sense. For if you are working as a nurse in a ward it can be difficult because being around people with a mental illness is hard, as I tend to go a bit 'loopy' at times. Some people don't even know how to take me...That can be really draining and that's where they [care-givers] need the support. People need to be aware and have an understanding for as I said people are frightened, because they don't know anything about it, and they can get very frightened when they are around people with a mental illness.

The situation is further compounded when families are separated. Cheryl who is the main care-giver for her husband, Noel, described the difficulties in being separated from her siblings, some of whom live interstate:

Since we've been in here we feel like we've got a big balloon and our house is in that big balloon. We can touch it, we can live in it. I'm a carer for my husband as I'm his strength. He's my strength with my four kids.

Barbara is a care-giver for her daughter who has a serious mental illness, but lives interstate. Barbara's daughter has two children, but because of the severity of her mental illness the children have been fostered to other families. Barbara has been a significant support to her daughter despite the separation:

[Barbara's daughter] doesn't see her children very often because she has delusions about them and they're not safe around her. This is one of the problems I've been sorting out for years now. The children are now eleven and fourteen and all those years they've never lived with her so over this period of time I try and make sure there's been as frequent access to them and access visits as she can have. Either when she came out of jail or through other difficult periods including homelessness or just her whole life as it has been quite chaotic. It's either been in jail, homeless or in a mental hospital or in some institution somewhere. So she hasn't sort of learnt or experienced being, I hate the word responsible, but she's never been able to support herself in any way, and then with her mental illness the illness is they don't want to be around other people either. It's a very lonely type of illness they don't take on advice of carers. I've tried to organise for a carer but she just thought I was trying to tell her what to do.

At times Barbara has had to be quite resourceful in her efforts to support her daughter:

So what happened is that every time she's had to deal with the bureaucracy, I've done it, I've sorted it out from here. I've organised dental work over the phone; I've organised most things. She's had that many problems I've just been able to find whoever [whether] she's needs a hospital or whatever of [or if] her health needs fixing; I have just sent an email, fax or a phone call.

The experiences of most of the participants who were living with a serious mental illness were similar; they all spoke of the importance of family as part of their healing, but were saddened and surprised at how mental illness can fracture and distance some family members. Sarah described of her sometimes strained relationship with her siblings:

Sometimes I find it really difficult to explain it to my brothers, you know, that this is the situation. And they say 'Well snap out of it!' Well I wish I could 'snap out of it' [laughs]. You know, I wish 'I never snapped into it' [laughs] ... Mum's the primary carer, all my brothers and sisters, even though they care and they support me and we do social things together and all that sort of stuff, they're still there on the side saying, 'Well snap out of it. Get your life into gear.' And all that sort of stuff.

The lack of awareness and acceptance in the community for people living with a serious mental illness is a concern, for as Andrea noted, a person living with a serious mental illness can be perceived as a threat:

I remember that people just give me this vibe. It was like we as people are different and that they then become distant, for instance ignoring me and not talking to me as much. Sometimes I can feel that they are a little bit scared of me because I am different. That does change your attitude towards them when they start doing that. Because I mean why do they act like that? It's confusing because I don't feel different so when people start acting different around you do start feeling funny.

Ellen's comments supported Andrea's views about the sense of fear that is present in the community directed at people living with a serious mental illness:

People are frightened, and because they don't know anything about it, they're very frightened. It's the aggressiveness I think, they're scared of something they don't understand. They just don't understand how it works they just think people are being aggressive. Or violent. They don't want to but you know they're still that person and that person needs help and is still fighting for somebody to help them.

Noel believes that there are some in the Indigenous community who are in denial of their mental illness and as a result are not seeking help for their mental illness.

A lot of Aboriginal people won't admit they're they got a problem, you know. I feel that there is a lot of shame about the problem. Especially when it comes to mental health but I sort of just grin and bear it. I would like to just tell people, you know, that there is a problem in the community with mental health. But a lot of them keep hush, hush about it too, you know.

Managing a mental health crisis

When a mental health crisis occurs it can often have a destabilising and traumatic effect on the family. The family responses to a mental health crisis varied, ranging from the proactive to the reactive. For Joan, whose son needed hospitalisation for his first episode of a mental illness, the intervention from the mental health providers exacerbated an already tense situation. The family were exhausted from trying to manage her son's mental health crisis over an extended period of time without any support. They eventually were able to convince her son to go to the hospital to be assessed. What occurred at the hospital was, unfortunately, an example of unprofessional clinical practice. Sadly, it nearly ended in tragedy for the family:

It began at the hospital, for when we did finally see the psychiatrist she came to see him and she started the conversation asking how he was, and then her phone rang and she said, 'I have to take that, I should be only about ten minutes'. And he said to her, 'I will go out and have a smoke', and she said, 'No don't go because I will not be long, I'll only be ten minutes'. Well, in fact

she was more than ten minutes and that agitated him no end and we couldn't get him to stay and he wanted to go home there and then.

And then he said, 'You see, I told you this would happen and they are not going to help me; they can't help me and I'm going home'. It took us all our time to keep him there until the psychiatrist came back. When she finally did come back he let her have it, he called her a liar and he said that she was supposed to come back in ten minutes but she didn't come back and what did she think he is and that he had to wait all of this time. He was really, really agitated. So then the psychiatrist said that he could go home, because I said we had to go and pick up the children from school at 3.00pm. So we needed to go and I said that he was not going to stay at the hospital, so we went home, but in the meantime the psychiatrist arranged to send the Psychiatric Emergency Team (PET) who came with the police to their house.

We had no knowledge of this; she didn't ring to let us know or anything. We were home before they arrived and he had locked all the doors because he said to us that they were going to come for him, he believed that they would be all lined up out the door. We tried to calm him down by telling him, because we believed this to be true, that no-one was going to come as we had earlier been to the hospital and that would be the end of it, until we went in again. What we did not realise was that because he had refused to go into hospital the psychiatrist had organised for the PET to come out to bring him in. So it was exactly how he predicted for they really were lined up there for him, but he had locked all the doors beforehand and we weren't allowed to open them. When the police arrived they were trying to get him or us to open the door or the window or whatever and we said no we can't because he doesn't want us to and we don't want to upset him and lose his trust and if we can get him out ourselves we will. That is what we wanted to do, we didn't want to agitate him more, because he was starting to blame us for taking him to the hospital at this stage, and that we were dobbing him in. So we asked the police to just hold on as we would try and get him to come out. But because he continued to refuse to open the door they smashed the door down and came in. Even after they had entered he was still being cooperative as he was talking to them and we were all talking to him. All the while this was happening he had a drink in his hand until at one point one of the police tried to grab it off him, the policeman told him to put the drink down, you know how they get, and I just said to them, 'Hey, he is not violent and he doesn't need you to be like that with him because he is not violent', so I said that you can stop right there he will come with you. They did stop and they didn't go any further with it, and he did eventually go with them in the end, and his wife went with him. But if I hadn't been there, to me, they would have got more aggressive with him and he could've been quite...you know, it was horrible for us at that time because the kids were at home watching, they were trying to get the kids to open the door, but there was no way that the kids were going to open the door.

This experience could have been avoided, according to Joan, if the psychiatrist had been more sensitive and skilled in working with a young Indigenous man who was mentally unwell and psychotic. If the intervention at the hospital had been more respectful and professional, with the psychiatrist completing her assessment, Joan's son would have been admitted and the serious incident at their home could have

then been avoided. As it was, an even more serious incident was avoided primarily because of the intervention of Joan, not because of the state professionals sent to 'help'. This incident reveals the fragile nature of independence that exists for people living with a serious mental illness and the volatility of their interactions in times of crisis with the mental health system and the community.

Loss of control

Most of the participants, those either living with a serious mental illness or caring for someone with a mental illness, talked about their sense of powerlessness when mental illness descended into their lives. Gail, a care-giver described how her daughter's behaviour, being bizarre and totally out of character, left her both confused and bewildered as to what to do:

It was at that point that I recognised that it was beyond the realms of my capacity to be able to deal with or make sense of what was happening. And I thought, 'This is really bizarre, this is beyond my control, this is something I don't have a grip on. What the hell is going on here!' I actually thought I was perhaps losing my mind.

Loss of control and feelings of powerlessness in varying degrees were a constant feature the experience of most of the participants. Ellen described how she and Andrea were afraid of the future in the early stages of Andrea's mental illness:

But I tell you that it's a powerful thing this mental illness. Fear like 'Are they ever going to get better?' And they feel like, 'Are they always going to be like that?' My grand daughter talked about it and she would ask, 'Nan am I ever going to get better?'

The fear and confusion in the early stages of mental illness were often experienced, as Sarah noted, prior to her diagnosis of her fear and confusion of her symptoms:

I knew I was still sick because I was hearing all these voices in my head. I knew there was something wrong but I was too scared to tell anybody because this wasn't right, if I told somebody then they would know about my little secret.

Given that mental illness is a serious chronic disease it is not surprising that participants felt helpless and confused, and described a deep sense of loss and powerless. The adjustment to the diagnosis of a serious mental illness for care-givers and those living with the illness is a significant one.

6.3 Experiences of care-giving: Knowing the role

This section reviews the main issues confronting care-givers who are providing care to Indigenous people who are living with a serious mental illness. In this section I explore what it means to *Stand Tall* as described by one participant, the strengths

and limitations of families, working from a strengths perspective and the issue of children and mental illness.

Knowing the role

In determining the role of care-giving, participants offered varied responses which were generally fairly consistent with the theme of 'being attentive'. Gina noted how she was conscious of the any change in circumstance that may destabilise her daughter Sarah:

I need to be very watchful of noticing every move so as to keep an eye on her. To see, you know, what she was doing all the time was important. Trying to, not being in control I think you could easily try and control the situation by watching and saying don't go there, don't do this, don't do that. Not controlling that person but allowing them to do whatever they have to do but just be watchful. And I wanted to say something about the difference in this kind of care; of caring for somebody that you know is your child with a mental illness, as opposed to mental illness in the community because in the community you can go home from it. You leave it behind at work and you know, you learn to do those things, but with your child it's different as it's there with you all the time. It doesn't matter where you are you could out doing recreation or something like that just out and about but you still wondering what if. I think every one out there should know that caring for someone means keeping an eye on it.

Staying with the theme of 'being there' but not controlling was also stated by Ellen, who felt that there was a careful balance in being a good care-giver, to be respectful and not too controlling:

I suppose we have to have a lot of understanding and lots of love because you got to really care about what you're doing, I think. Like if you try and boss them they're just going to get their back up. It's hard to explain, I suppose, but anyway it takes a lots of understanding.

An issue that was discussed was the fragility and uncertainty for people living with a serious mental illness. Gina noted how she and other family members were very vigilant and alert to any change in Sarah's behaviour that could be initiated due to stressful circumstances:

Don't leave them, well you can leave them but just be watchful. To be alert to certain things that might be happening in their life. Because what we know, like when my son died and we knew as it caused us all great grief and heartache, so somebody with a mental health problem and who needed medication may suffer more, but in fact, my daughter did really well, even though it was quite heartbreaking and a period of grief. We were all keeping an eye on her to make sure that she was ok and she came through it pretty well, as well as can be expected.

For many of the participants they were quite prepared for the unexpected, as Sarah noted:

And you can get frustrated; it's not always easy, like I talking here today is not easy. We've had arguments and that sort of thing. And other members of the family will jump in, well that's how we are anyway. But in the end you come back to your plan and this is what you remember...so pull them back sometimes to the plan it makes them realise, 'Yes I've got somewhere to go, I'm not out here suffering by myself'. Come back to that normal procedure.

Standing tall

The issues confronting care-givers could be complex and demanding but, as Ellen noted, certain qualities of strength often emerged during times of crisis:

You have to have strength otherwise you know. It doesn't matter like every day of our life, every hour, you've got to believe that it doesn't matter what ever you do you've got to believe you're going to come through, and that it will be okay. Every little hurdle regardless, it doesn't matter how big or small you can still go over it

Ellen's grand-daughter, Andrea also acknowledged the importance of the support of her grandmother in her recovery, hence the phase *Standing Tall*:

It was really scary for everyone. It was like they all stood down from it and it was more like Nana just stood up and its like, 'Well we're either going to be here to help, or otherwise we're just going to stand back and bicker amongst each other and nothings going to get done'. They were scared because they didn't know what was going on. And it took for Nana to stand up and say, 'No now is time that we stand together so who's going to stand with me'. It took a while but they all stood up in the end.

A constant theme was the belief that strength was always present and that it would emerge if people remained strong and stood together, as Ellen noted:

I've said that if we work together we can we can conquer. We can do anything. If we all stand strong that's what I keep telling them and all the family. You can get over anything.

There is a cost in this process that is not always acknowledged by community and mental health practitioners, for as Ellen stated,

I mean sometimes I get a bit tired but I don't get angry because as I said if I don't help them who's going to help them?

Family issues

A strong theme with most of the participants was the diversity of responses to how mental illness was perceived in families. In most situations family were always supportive, but there were occasions as noted by some of the participants where there were adjustments required or in coming to terms with the reality of the chronic nature of mental illness in their families, for as Ellen stated:

It can be very stressful as it can pull a family apart, if you let it. If you're not strong enough to hold your family together it can cause people to split up.

Ellen further noted how families living with mental illness are often placed under great stress, and as a result it does require families to undergo significant changes:

Well I suppose there wasn't a lot of help for me or Andrea because we it was just the two of us. They have eventually come on board now so we're got their support. I think there is, and it's like, and I think a lot of families you know I don't want people to think that my children are mad.

When families are placed under tremendous stress because of mental illness the situation can be made worse if there is little or no support from the community.

Sarah commented:

When I was working in mental health, I found that there was no specific agency that looked after the carers and what they were doing, and giving them support in how they were actually approaching, you know, caring for the person living with mental illness. I found that my family, when I first got sick, they have no information. There was nothing out there for them you know, they didn't know what was going on with me. There was nobody for them to go to, because mental health, the issues that I was facing, was they thought, 'This isn't the same person'...They knew that something was wrong but they couldn't put their finger on it. They took me to doctors and doctors turned me away virtually and said, 'She needs a lifestyle change'.

Gina, Sarah's care-giver, described her situation as being confusing and coupled with the family being in denial, as they were trying to come to terms with Sarah's diagnosis of a serious mental illness:

I think it's different when you're a carer of a family member and in this case, my daughter. In her early thirties or late twenties she started having psychotic episodes. The first thing me and my family did, the ones close to her, was to try and deny that it was happening; we realised this later, what we were doing. But at the time it was like, 'Don't be silly', or 'Why don't you do this, or do that, or try this, or try that', and 'Please can you take her to live with you', and all this sort of thing.

Families can be complex, as Cathy described when talking about how her son's mental illness was made more complicated because of his insecurity and confusion with his Aboriginality.

My son was beautiful child, his Aboriginal father though didn't have much to do with him. He left when he was about 18 months old; I was a single parent. My son had huge identity issues; he identified with his peer group who were sniffers and chronic solvent abusers.

Being a sole parent and non- Indigenous, Cathy felt that she was not able to assist her son with his identity issues about being Indigenous. The lack of positive Indigenous male role models in her son's life made it difficult, which Cathy believes also exacerbated his situation:

I mean he's always had enormous identity issues because he was brought up with a white wadjella mother. He really didn't have any male role models. His role models were his co-sniffers. I know he was hanging around with a Koorie guy who was about 24 when he was about 14. No he's was 19 or 20 and he was like this 2pak tough but he was a sniffer and that was his role model. He was older than he was and I couldn't battle with that. That was out of my hands, being fair skinned and having had no contact with his Aboriginal family.

The issues confronting Cathy are not necessarily unique, but it does expose gaps in the provision of services by the mental health system; mental illness in families can be complex, and should not be seen just as a clinical issue. Therefore, any approach to mental health intervention should address the underlying issues of co-morbidity, drug and alcohol misuse, accommodation, poverty and underlying psychological issues. To just focus on clinical intervention and not the bio-social-psycho-physical aspects is a failure in duty of care.

What about the other children

The children of parents or families where mental illness is present are often invisible, both to service providers and within families. Participants in this study told of the issues within their own families of how mental illness has impacted on their children. Gail commented on the difficulties of one child being ill and still being a parent to the other children:

Gail: I think when your child is hurting like that you...its very hard not to feel that some how you might be somehow responsible for all of that. Even though I would quite logically spell it out in my head that this is a result of a sequence of events that gets the person to the point where they're crying out to get some help on how to redirect where they're going with their lives. But yeah, I was feeling very exposed, very vulnerable quite physically exhausted by the whole processes. It was making me incredibly tired.

R: How was your relationship with the other children?

Gail: Fortunately I had my eldest still at home who was, and I suppose it was a little unfair of me to lean on her so heavily, but she was so capable, but she was able to pick up the slack when I wasn't there. Because it was about the time when I re-entering the workplace, re-establishing a home base for us and because we, you know, when the relationship dissolved the house went and I was homeless and the kids...I was trucking around the place with five kids and having to live under relatives' roofs where cramped quarters and all the chaos that that creates, and it was just chaotic.

There are issues for children when a mental health crisis occurs. Joan described the experience of her son's involuntary admission to hospital being witnessed by his children:

Yeah, you know how children are, they can take things or leave it, but some little things every now and again would come out where you think, 'Oh goodness me!' You know, 'Maybe the kids should have had some counselling', so you had a little talk to them and they would say, 'Nah that's fine, Dad's just this person, that's just Dad'. You know...they sought of handled it really, really well. Maybe we had put more of our focus on my son and forgot about the children and what they shouldn't, maybe they should have had some counselling. Mainly how the police had to break the door down and their Dad had told them not to open the door, you know, that type of thing just gets to the kids a little bit. And maybe we forgotten about the kids and they should have more or less had some counselling, maybe.

When a serious mental illness impacts on a family there are on occasions serious repercussions, including separation. This often means another layer of stress for the person living with mental illness, as noted by Gina whose daughter Sarah had a serious mental illness.

The hard part I suppose is knowing that my daughter couldn't be happy because [her partner] had the kids but there was one good thing...[we] knew that he was a good father, and he cared for the kids, and because when she moved over there they were just around the corner. So every now and again when he gets silly over something 'cause my daughter might have been late or something, she will come back and we we'd plan on ways of dealing with his attitude. They were the sort of things that can make it hard. What was being hard for her or being hard for my other daughter' then it does make it hard for you. You know you just [put] a bit of extra time and effort in and we got through.

Working from a strengths perspective

The participants were all aware of the challenges of the practice of care-giving; they were open and honest in their discussions about care-giving. For example, one of the participants, Gail, described how being a care-giver was definitely at times challenging and therefore that having insight into your strengths was really necessary:

I suppose...there were times when I actually kicked myself and thought to myself, 'You're not super woman! Nobody actually said that you had to wear this huge generous S across your chest to prove your infallibility in order to be considered to be of any worthwhile value to anyone'. So you do that whole self analysis stuff and think, 'Well what the hell am I doing this for!' I think carers aren't alert to some of their own crisis that they're going through, and it's not directly related to the other person that's in crisis. Or the person that their caring for that's in crisis. Some of it has to do with their own shit that they're dragging along.

Gail recognised in herself an inner strength that she had not realised or previously recognised or acknowledged. It was the crisis with her daughter that revealed these strengths:

I thought, 'If I don't get through this I'm going to die!' It was interesting because I went to and I considered her not so much a confidant but at least a friendly face to be able to understand where I was coming from. I was in absolute tears about all of what the circumstances were in my life at the time, how important this was for me, and why I needed a second chance, which was going to be, and it wasn't going to be, an issue anyway. But when she heard my woeful story she was like, 'Well, why didn't you tell me sooner? Why didn't you tell me that you have this huge burden on you? I could have done something a lot sooner made the transition a whole lot easier for you'. I was like, 'Well why didn't I?' And part of me was saying, 'Well I don't want you to make me into a charity case. I don't want you to think that you need to hold my hand through this because this is as much about me having to make this journey for my own personal growth and development as it is about testing how capable I am. What is my capacity to do what I have [to] do [to] be able to take all of this on'. I found that I was incredibly resilient through all of this, surprisingly enough.

As Gail stated a crisis can also be a positive experience, as it was in her case for she believes that this encounter with her daughter's mental illness has had a positive effect on her and her daughter:

I mean I draw great strength from the fact that during my process of healing and dealing with all of my past traumas that you do actually develop some coping skills. And you do get healthier and stronger because you're able to talk about it and by the more you talk about it the less inclined you are to conceal it so that it does not start to fester. The fact that she has had it exposed and been in the situation where she's gone off and got some treatment and recognised that there are things that she needs to be conscious of so that she doesn't fall down and get you know, beat herself up and get into a point where she thinks that you know, the whole world is against her sort of thing.

Gail's mental illness provided some surprising results, as she discovered, her resilience with coping with the challenges of her daughter's mental health issues was a revelation. Mental illness, although at times difficult and traumatic, can be transformational for both care-givers and those receiving care.

6.4 *Staying the distance: The emotional, psychological and spiritual dimensions of care-giving*

This section explores more deeply aspects of the emotional, psychological and spiritual questions surrounding the care-giver role, particularly the participant's perspectives about dealing with loneliness and isolation, overcoming fear, with rejection. It discusses how love has an enormous capacity for healing.

Knowing your strengths

All the participants displayed amazing agility and resilience in their ability to cope and manage difficult situations. Despite their difficulties they not only coped but were

optimistic about their own lives and the lives of others in the community. Reflecting on her situation and on living with the uncertainty of mental illness on a day-to-day basis, Cathy stated:

I think you learn to live with it but some days are certainly a lot harder than others. If you're having a good day its good, if you're having a bad day it makes it difficult. When you're a sole parent I think it's worse because you haven't got a partner to fall back on, who can share half the load so that you can go out and do something for yourself sort of thing. Your life in a way stops for yourself because you've got to...I mean I can't like put him out in the street and say go fend for yourself because he wouldn't be able to. It's not really normal when you speak to other people you know it's not normal. But in your own head you've got to normalise it I think because you go mad, you've got to build some normality around it.

Being a sole parent means being very resourceful and focused as Cathy recounted of her experiences:

It was difficult having to balance work in all of this. Having to sometimes feel guilty for working thinking I shouldn't be working I should be at home looking after him but not having any choice in that.

Even when faced with these difficulties Cathy described how she believes she has been transformed through the experience:

I think that mental illness when you're a carer it pushes you beyond yourself. And that's the only way I can describe it, and that it can be a really scary terrifying experience. Especially, you know, if you've had some post trauma stuff happening throughout it all like depression which inevitably I've had. But its pushes you beyond yourself and you don't know where that's going to lead. It could be either down or it could be...[I] have [had] times when it's [been] down. You can have times where you can actually see that it's made you a richer and stronger person, which it does but it's not something generally out there in society that most people would say could be the case.

Loneliness and isolation

The issues of loneliness and isolation were a common theme that was present for most of the participants, as Barbara noted:

My daughter has always lived in NSW and she didn't always have my support but she didn't really want it. She is very strong headed, strong willed and stubborn like me. That sort of personality type and she got mixed up with drugs at a early age and there was a drug culture and stuff. I go over about every year; last time I was there was two years ago, after I painted her house I brought her furniture cleaned up the backyard. I got CDEP [allowance] I did everything. I did a whole lot of, you know, domestic stuff to help her and I had just had a knee reconstruction so I wasn't in a very good mood. But I did all that and I just thought, 'Oh well', this was sort of not a farewell but like a I'm not doing very much because I've got little kids now. Sort of like, I can't be worrying about the big kids because I've got the little kids and if I'm worrying too much about the big kids well, how am I going to go? There's only enough time in a day or money in the bank. It's just the energy and time

and money to be able to sort of worry about it. I don't really have enough for everybody like I used to because I'm not working myself. So she doesn't want to have anything to do with anybody that's part of the mental illness

Cheryl also noted a similar situation, as she and her family are not originally from Western Australia, but from interstate and the separation from their respective families reinforces a sense of loneliness and isolation:

My husband's father comes from Queensland and his mum comes from NSW. We moved over here 12 years ago because of family violence, domestic violence. My in-laws tried to separate my two eldest boys by getting them to fight against each other and pick on each other. And I didn't agree on this so I moved myself, my husband and my two kids over here to WA. We've been over here in the twelve years; I now have two more children...I've been with my husband for 20 years. Through those 20 years I've given ten years to his family living with them. Having my two eldest boys and then when I seen that they tried to separate my boys I said to my husband its time for me to move over here to be near my family to give my family a go with my kids. But since we did that my husband's fallen into a depression for one, moving from one side of Australia to the other side, and for the fact that his family don't want anything really to do with us. In the 12 years that we've been here we've been home I think four times. No sorry, three times we've been home. We buried my husband's mother seven years ago, we buried her on the Friday and on the Tuesday, four or five days later, Noel's family came into the house and told us to piss off. Told us they didn't want us near them. They didn't want us to have anything to do what ever. Today my husband only speaks to his baby sister and his dad and they're three brothers and two sisters. He only speaks to his baby sister

Overcoming fear and powerlessness

Fear is a powerful emotion, and for several of the participants they spoke of their own fear and of a sense of powerlessness. The experience of witnessing a mental health crisis for the first time can be a frightening experience, as Ellen noted:

It's a lot better now but when I first had encounter with anything like that it was very frightening. And people are frightened of things they don't understand so and it was many years ago it must been about 16 years ago or something [my] first...encounter [with mental illness] was [with] a niece and I've never seen anything [like it] she just had a baby and it was like postnatal depression but she actually had some a mental illness at the time but we didn't know then...but, I suppose, it just got easier and easier...but to understand, I suppose, it's easier until it's actually on your doorstep then it's like you face it, you know.

Cathy spoke of her sense of powerlessness and her sense of helplessness and fear for her son because of his extreme behaviour:

The main feelings were fear, powerlessness, grief and loss, a lot of guilt a lot self blame. Basically from age 13 to 15 and half he sniffed solvents, glues, everything, chronically. He was playing chicken with trains; I was constantly told to go to town to collect him. I'd come home and I'd have mobs of kids in my house. One time I had holes punched in all the doors, spray paint all over

the floor, all the curtains ripped off, and he was basically close to dying because he was putting himself in the most...he was so off his face when he was solvent intoxicated he was wobbling in front of train lines. I used to have the train men come and say come and get your son. I bring him back and then he'd be gone in ten minutes. So I would have sent him to Saturn if it would have helped.

A sense of fear and powerlessness was also evident for Cathy for her son's uncertain future because of his mental illness:

He won't be able to work. It's been hard because, I mean, on this journey people have disagreed with me. I've recognised his chronicity, 'Oh if he just went out and got a job everything will be fine'. And that's just so frustrating. And I don't know, I don't really know if I'm fully reconciled with it. It's like, if I look at it realistically, I don't know how the hell his girlfriend manages him, I couldn't. Or how long that will be for before he's back on the street, and where to from then? There's not really a lot supported accommodation services for him. So I reconciled to the fact that he may not be able to work... I don't know if I'm fully reconciled yet. I don't know.

Dealing with rejection

There are many issues that confront care-givers, not least is the issue of being a 'good parent'. Pressure from judgments made by friends, family and the wider community was a prominent theme in interviews. Cathy noted:

...even before the onset of his mental illness with the solvent abuse there's this stigma. It's like I remember a guy next door saying, 'Are you aware your kids sniffing? Are you aware he's hanging around with those Nyungar kids?' I said, 'He's Aboriginal too you know'. Because he's fair some people presume. And it's almost like, well, 'What are you doing about it as his mother?' And you know and I tried to say to this neighbour, 'I've done everything, you know'.

The issue of rejection by family and friends was also raised by another participant, Paula:

But it's changed the way I think about him and probably because I'm leaving work and I'm getting a pay out I'm able to now look after him. But society and your friends and families have a lot of messages and I always get defensive when I say I'm going to do this for him and do that for him because we probably may have spoilt him or I spoiled him a bit, and society frowns upon that. It's quite deep and I've noticed that even if you tell people the whole story, 'Oh he's got a mental illness, I'm going to buy him a car', and this and that, they will you know, one of my friends turned around and said, 'Oh look at my children, I never brought them a car or anything anytime'. And it was almost like I felt like saying, 'Well fuck! Your children don't have a mental illness! Hello, what have I just been saying for the past fucking hour!' You know, so it's still like it's almost one upmanship. 'Good on you! Go and fucking take money off them, don't give them anything that's your shit! I just told you why, you know it makes me angry actually'. So I get wild with that because, I don't know, there's something about our society, it's about we have to raise our children to be independent and kick them out of the nest.

Sink or swim, which my son's father and I did have that attitude. My son's father used to have little meetings with me and say, 'Come on, back me on this, lets cut him off'. And yeah, I mean, we could cut him off and he could end up on the street or in jail or something and I'm not doing that. Everyone can get fucked basically. I don't care if I spoil him I'm still going to do it. So yeah, there's a lot of tension; there's no one who says, 'No you're doing the right thing'. Everyone says, 'You're spoiling him', or you know, or even if they listen to you sympathetically at the end it's, 'Yes, but I never did that for my children'. Oh good on you, yippee, you know, go and fucken blow it out your arse. It's just weird, it is seriously weird. My sister-in-law is the only one who understands, and you know maybe I did spoil my son. But it's all spilt milk maybe my son's father and I should of been proper parents stay at home and not pursuing careers and he would of been a different he mightn't of got sick who knows.

Give them love

All of the participants expressed their concern and care for either the care-giver or the person living with a serious mental illness. Some of the participants used more descriptive language in translating their feelings, as Cheryl noted:

Love, only one word mate love; love overcomes everything it over comes evil it over comes everything. And if you can show someone that you've got love in your heart they can either take it and run with it or they can take it and just stand still. Is that wrong? That, that's how I feel. I've shown my husband so much I'll give him all my heart whereas if I keep a little bit from him he's not getting the full effect.

Care-giving is both constant and demanding, so the love of a parent cannot be understated as a compelling reason for staying with the sometimes arduous task of care-giving as Gina described of her situation:

You can't send them back to where they came from can you? As much as you'd love to sometimes, but yeah. Well it is the duty of a carer, as a lot of people would get up and walk off. I know that but I wouldn't do that to them, because I love them I wouldn't do it to them. I've sat there and thought it would be really nice to lying on a beach or on a boat or something away from them all where they can't hear that stuff, but you'd never do it. I mean I wouldn't do it. But yeah, it's just a nice thought.

Finally, as Gina described of her situation, even though care-giving is at times a demanding role her love and commitment to her daughter's health cannot be understated. This was the case for the other participants who were also care-givers, for they were also committed to the task of being a care-giver; they would be there to the end.

6.5 Summary

Three main themes emerged from the findings. The first was the *challenges of living with a serious mental illness*; the second, *knowing the care-giver role*, and the third, *staying the distance*.

The first theme, *challenges of living with a serious mental illness*, included the personal, for example, a participant's fear of receiving a diagnosis, the experiences of alienation, loneliness and stigma due to their illness. The other challenges related to the participants in relation to others, for example, the lack of understanding and sensitivity by mental health practitioners and in some instances their families of their situation, or the challenge of living with a serious mental illness in the wider community for they are perceived as a threat to the wider community.

The second theme, *knowing the care-giver role*, revealed the stresses involved in the care-giving. The participants spoke of being constantly watchful for any changes in behaviour that may indicate a person becoming unwell. The pressure of daily living that adds another layer of stress to an already fragile situation because of the participant living with a serious mental illness. They included the break-up of a family, the resulting custody issues, the stresses of being a single parent and care-giver, and the lack of understanding by mental health practitioners of these participants unique situation is stressful and a constant challenge. Regardless, the participants spoke of the positive outcomes because of a mental health crisis; they spoke of finding their resilience and coping skills in dealing with a stressful life situation.

The third and final theme, *staying the distance*, was about the impact on the emotional, psychological and spiritual of being a care-giver. For the care-givers it was important for them to feel that they had some control over their lives. They spoke of how being a care-giver can be as basic as seeing life in the context of having a good day or a bad day, of the importance of being able to participate in all of life activities including having and keeping a job, and of the importance of knowing your strengths because care-giving for someone with a serious mental illness pushes you beyond yourself. The sense of isolation because of geographical distances, which arose because some of the participants had relocated from interstate, and not being close to family, was stressful. As a care-giver there were times were times of feeling overwhelmed, powerless in the face of living with uncertain futures for the care-giver and the person living with a serious mental illness; there was a constant sense of loss and grief. Care-givers noted the

importance of cultivating relationships that engender love and acceptance both for the care-giver and the person receiving care.

The three themes that have emerged from the findings from the participants show that there are serious unresolved issues of society's understanding of the unique issues of care-giving for Indigenous people living with a serious mental illness. The next chapter presents further findings from the study, and it will focus on the issues of care-giving but in the context of racism and exclusion, including the participants' negative experiences of hospitals, of hearing the voices of resistance and of how there is pressure to silence those voices.

Chapter Seven: *Voices of Resistance* – Findings 2

7.0 *Introduction*

This is the second chapter on the findings of the study. As in the previous chapter the themes presented in this chapter emerged from the data and they reflect the issues identified in the literature review on racism, mental health and care-giving. The participants were specifically asked questions on racism, and similar to the issues identified from the literature, the issues of racism and exclusion were a constant presence in the lives of the participants. The selection of themes of racism, exclusion, stigma and alienation and silencing of voices was based on their recurrence and frequency within interviews. As was mentioned in the previous chapter it should be noted that strong language is present in some of the quotes used in this chapter.

The chapter is divided into three main sections, each of which provides an overview of the main themes that emerged from the study. The chapter sections are:

Why are you not listening? presents the experiences and perceptions of the participants' interactions and experiences with psychiatric hospitals. It explores how the misuse of power can marginalise and disenfranchise Aboriginal people living with a serious mental illness.

Voices of resistance reviews the systemic issues in mental illness and care-giving that was evident in this study. This section provides insight on the critical issues that underpin the power relationships that are present within race, class and gender.

The politics of silencing explores the global issues experienced by the participants, both care-givers and care-recipients, of their experiences of collusion and silencing in the context of mental health. It also discusses the systemic issues of stigma and alienation that revolve around mental illness and care-giving as articulated by the participants.

Summary presents the main points discussed in the chapter and concludes with a review of the main themes that emerged from the Art Workshop that are explored in the following chapter.

7.1 Why are you not listening? Experiences of mental health services

For most of the participants mental health services had become an integral part of their lives, either willingly or unwillingly. Stories provided by the participants offer insights of their experiences with the mental health system. These insights range from their experiences with hospitals, authority figures, the difficulties of pursuing the role of advocate, and the collusion against patients rather than collaboration with them that they experienced from the health system.

Hospitals are scary places

Hospitals were generally viewed by participants as places of importance but also as places of a last resort. Given the integral part they played in peoples' lives it is disconcerting that for most of the participants their interactions with hospitals were not pleasant experiences. There is a genuine fear by Indigenous people of Graylands Hospital in Perth as it has considerable historical 'baggage' or background with regard to involuntary incarceration of people with mental illness; Graylands hospital is the specialist Psychiatric Hospital in Western Australia. There is quite a strong negative perception of the hospital in the Western Australian Indigenous community. The very name of the hospital elicits fear, as Sarah described when she was told that she was going to the hospital.

I lied as soon I knew I was going to Graylands hospital, I lied and talked my way right out of getting a bed in there. The fear of being diagnosed with a mental illness and to be, you know, crazy people go there and it was like the fear was just...Ok I knew once I was in RPH [Royal Perth Hospital] I thought 'Yeah all right then I'll go there'. You know it was just that there was this fear. And I just thought, 'No way in on God's earth am I going to go in to this place tonight'. And I was ok to go into RPH but when it came to having go into Graylands hospital it was a whole different matter. I would go to any other place rather than Graylands hospital. I think it's the stigma attached to the place, and I think that's the same with a lot of other people they think that when they have to go to Graylands hospital. They go 'No No! I don't want to go there!' and when you talk about Bentley Clinic or some other clinic, 'Oh yeah, okay I'll think about that', you know. So even other people that I've spoken to have a problem with Graylands hospital.

Psychiatric hospitals in general were perceived as unfriendly and scary places as Andrea notes of her first experience in hospital:

It was very scary, I think I cried for the whole two weeks I was there for the first time.

The issue of the competency and sensitivity of staff working within the hospital was an ongoing issue raised by participants. Joan, her son and his family experienced a

second incident of poor practice by hospital staff, which placed Joan's son at some risk and which could have resulted in tragic circumstances:

There was another incident where he was on this medication and he came back from interstate very ill. We took him to the hospital and there was another bad incident where they were negligent. His [situation] we believed was urgent and I had said to the staff at the hospital, 'He needs attention right now because he is starting to get agitated, so can you please attend to him immediately?' While we waiting for an assessment my son started to lie on the floor as he couldn't physically sit up. He wanted to just lie down. I asked if they could find him a bed as he was beginning to get more and more agitated. They did take him into a room, but alone, and I told them that someone needed to be with him as he would not stay in there on his own as he would get up and leave. They assured us that it was not necessary that someone be in the room with him as he couldn't get out. I did ask if they were sure of this, because we were willing to stay in the room with him until he was seen. They told us that we need not worry as he was secure. The next thing we know he has somehow managed to get out of the room and left the building. His leaving got everyone into a panic prompting all of the hospital security staff out looking for him. It was the police who eventually found him, unknown to the mental health staff at the hospital, and they took him back to the hospital, but rather than admit him they gave him some Panadol and discharged him because he told them that he was okay. So then we had to go looking for him and we found him down the street so we brought him back to the hospital. The hospital in the meantime had alerted the police and they were all there, this was after the hospital had let him go earlier. The police and the hospital were there but no-one was actually out looking for him, they were just standing around in the likely event that he might become violent. I told them, 'Excuse me, but you let him go earlier when the police brought him into hospital, and now you have all of the police here in case he gets violent'. I got a bit cross about that.

The above illustration is quite disturbing for it shows that when major psychiatric hospital is put under pressure it can fail dismally when responding to a crisis situation. Joan's family, who had previously had a traumatic experience with this same hospital, experienced another inappropriate intervention and insensitivity from hospital staff. This episode reveals the tentative and fragile relationships between community and the mental health system. If members of the Indigenous community are ever to trust the mental health care system it will require mental health providers to be more responsive to their needs.

Abuse of power

The use of authority is a contentious issue, as some of the participants noted. If authority is abused, particularly in a hospital context, it can have quite negative implications. Andrea described her experiences in hospital with authority figures particularly who were being too authoritarian and patronising.

I had a problem with authority, particularly when the person didn't act like my friend or like they were acting like someone over the top of me, I would lash out at them. If the person acted in an authoritarian way, like above me, I would lash out. But if they acted like they listened to me down at my level I was perfectly fine with them. The problem is they do talk down to people and then they wonder why people lash out at them. It's like if you don't come down to our level, we feel that they're just saying you've got a mental illness and it is a mental disease. People with other types of diseases they don't get talked down to like we get talked down to, because we have a mental illness. They feel threatened and they shouldn't feel threatened because we can sense it.

Sarah spoke of her experience with a young and inexperienced psychiatrist who was quite insensitive and judgmental in her assessment of her situation:

I was putting off from going to the clinic and then when I finally went I saw a really young psychiatrist for the first time and seeing a young person, probably younger than me, in there I found a little strange. The thing that she said to me was so upsetting that I just couldn't believe that she was a psychologist or psychiatrist. I just got such negative feedback from her. Things she said to me were like, well you know, because I lost my kids my kids with their father, and all that sort of stuff, and he was putting me through court at the time to get custody of them, and then the way she spoke to me was like she really put me down. Like she said to me, if I was a good girl then I...I can remember the sort of words she used she said, 'If you be a good girl then you might get your kids back'. I was shocked and I was thinking she doesn't know anything about me or where I've come from or experienced. She didn't ask any questions of my background or anything like that. That was the first couple of interviews that I had with her and I thought, 'I'm not going back there'. You know I just thought, 'No way am I going back there'.

Advocacy and mental health

One issue raised by family members acting as advocates for the person with a serious mental illness was that they felt that when they tried to mediate on behalf of the person with a mental illness they were discouraged from doing so by mental health staff. Cathy, a care-giver, recounted her experiences of the difficulties with mental health providers when trying to advocate about her son's drug issues.

What I'm looking at is with drug and alcohol abuse you can set these sorts of boundaries and people talk about boundaries, but when they're delusional the whole concept of boundaries just goes out the window, because they don't know about boundaries. It's ludicrous, absolutely ludicrous! I can see it from both perspectives, but when you're told that it's a drug issue and it's like...I know you cannot assess someone's mental state if they're not straight. But when you've got a kid that's never straight or there is limited opportunity to find them when they are straight so you can do a mental health assessment is rare, I must admit that I found that really unhelpful. I just wish I had of been believed more in terms of my assessment because as his mother I was around him 24 hours a day, seven days a week. But by just plonking him in a hospital for a couple of weeks hoping that he might settle down and then doing an assessment does not always work. In the end it took

a real crisis, it took him harming himself quite seriously, before it actually led to some intervention. I found that frustrating, really frustrating.

Ellen, also a care-giver, recounted an experience with the mental health system as also being difficult, particularly when trying to come to terms with a system that is neither flexible nor sensitive to the issues of families coming to terms with mental illness. Ellen believes that the workers in the system are inflexible in their approach to families, and that there is the expectation by workers that families should have an understanding of mental health issues, which is often not the case:

So it was new to us and we were supposed to know what was happening. It was sort of, well you know this is our first time being here and we're trying to learn and trying to cope and to make her better.

For some of the participants trying to get help for a family member is almost a full-time activity, as Jenny, who is a care-giver for her son, noted:

For each organisation it is very difficult to get anyone to actually come to the house. For my kids it's been hard to get someone to come to the house until it's actually a crisis. Like I've got three kids all with disorders and I can't even get anyone to come out to assess the younger one. I've been to eleven different places and each one has sent me onto another and then the next one. We've ended up back at the beginning again with no one coming. Its been the same with my 19 year old, a Catch 22 situation; you just keep getting passed over from one to another to another and actually you end up nowhere, because unless he goes to them it's not going to happen.

Exclusion or inclusion

There was a perception by some of the participants that the current level of bureaucratisation of the mental health system operates on the basis of administrative considerations and not on the basis of need of the individual or family.

Jenny recounted a disturbing experience with a mental health worker:

I had advice given to me once...by a psychiatric nurse who was working with my youngest son. [The nurse] was running a behaviour program and his advice to me was, 'Here's a trailer', he said, he gave me the address of a place out in the middle of the bush somewhere. He said, 'You tell your kids nothing,' he said, 'get in the car and go'. That was his advice for me and that was from a psychiatric nurse from, I won't say who or where, but that was the advice given to me, after he was trying to help deal with the family. That happened quite a few years ago and it was just sort of behavioural thing and that was his advice. 'Run away from it. Take your daughter and run', was what I was told, yeah. Which, I mean, as a sole parent you certainly can't do that! Anyway, I could but I wouldn't. I think he got a bit annoyed with me because I wouldn't do it.

The worker revealed the pressures and difficulties of the system in providing intervention and, according to Jenny, the worker's words have been prophetic for all her efforts have yet to produce any positive outcome for her son.

Beth, recounted her experience in trying to get a mental health assessment for her nephew which she believes was compromised because of collusion between several agencies, including the school, welfare and mental health services:

When he was in primary school in Year 7 there was a meeting of about nine people, I don't know which department they were all from but, I think, there was one person from the Child and Adolescent Mental Health Service, but there was nine of them. I was the only Aboriginal person sitting in the room, and there were nine of them but none of them had seen him or assessed him before the meeting. They just wanted to have a meeting and they said they're going to do this and they were going to do that, but they didn't do anything so nothing was done. I said I wanted it all done before he got to high school, and I was crying and shouting, but nothing came from the meeting.

As is often the situation agencies can walk a fine line between collusion against clients when they try to collaborate with one another. Several of the participants experienced what they felt was exclusion for they believed that there was collusion between agencies that disadvantaged their situation.

7.2 *Voices of resistance: Letting the silent speak*

In this section I review of the systemic issues that are evident around mental illness. The section provides insight into some of the critical issues that underpin the power relationships in race, class and gender that reinforce the systemic marginalisation and disenfranchisement of Indigenous voices on issues of mental health and care-giving. The section is divided into two parts: part one reviews participants' personal views and critical insight into the issues of care-giving and mental illness. In part two the discussion broadens to include the societal or systemic issues that underpin the critical dynamics of race, class and gender. Among the issues explored are the proactivity created by having some prior knowledge of mental illness; the difficulties in being an advocate, particularly when the role is not supported by health providers; how remaining silent only reinforces problems; the importance of identifying strengths in families in times of crisis, and finally a focus on dealing with mental illness and uncertain futures.

Knowing means you can act earlier

Having some knowledge of mental illness was seen by participants as a way of being empowered to act earlier, giving them a sense of having greater control of their situation, particularly in the event of a crisis. This is evident in Sarah's description of living with a serious mental illness:

Before I went through the illness or before I got ill I didn't know and I didn't understand anything about depression, or schizophrenia or bipolar or any thing like that...so if I had an understanding before, of even depression and what that did to people, I may have been able to pick it up with myself and what I was going through a lot earlier than when I did. Because I think I had postnatal depression and it wasn't picked up until two years later. So in that period, if I had some knowledge before then I think would have been able to cope a lot better. I would have been able to go and see a doctor...about that issue because I was going to the doctor for my physical not mental stuff... when there was a problem. Acknowledging that you've got a problem and being able to share that with somebody, that's really important to be able to share that there are issues going on in your life and you know, not covering them up.

Sarah also discussed her emerging awareness and the process of coming to a deeper understanding of her situation:

Not lying about your mental illness because you tend to lie about it, so being honest with yourself is really important and then being honest with other people. Because if you don't, it could...just go on being on a rollercoaster with the illness. I think it isn't a form of coping I think it was a form of denial of the illness and if you're denying something then how are you going to cope with the actual issues, you know.

Gina, Sarah's care-giver, stated that there is need to look further and be vigilant when being a care-giver for a person living with a serious mental illness:

Act immediately and do not leave it till tonight or tomorrow. You may not have a daughter or son there if you do that or, you know, brother or what ever. That's happened on many occasions and I suppose the other thing I could say here is that I've seen people, not necessarily my daughter, but I have seen others who come with other things wrong with them, like an illness like a sore foot and that sore foot is worse than it looks. They are trying to tell you something and I suppose that sort of thing about looking beneath what's there, you need to look beneath what they're saying or what you see is important.

Discrimination with mental illness: Fact or myth?

The issue of being accepted was a recurring theme raised by participants. Andrea, stated that even when a person is prepared to acknowledge they have a mental illness there are no guarantees that they will not be rejected or discriminated against because they have a mental illness:

I mean I'm not, I don't go to every place, but it is not easy if you are being constantly asked questions like, 'Do you have a job?' It's like, 'Well, I've done a bit of schooling and I do a bit of volunteer work but I haven't got a job yet'. It's like, 'Well, how are you doing this?' And, 'How are you doing this? like, but I know I will get there in my own time'. When it comes to the crunch and they ask me continually questions I say, 'Oh yes, I do have a mental illness and I'm still trying to cope with it'. It's like, 'Oh well, how did it happen? Explain it to me'. But they do feel intimidated when you say you have a mental illness. You get excluded because you're considered a social risk.

Ellen, Andrea's care-giver, added to the discussion about the rejection of people living with a serious mental illness:

In one way you're an outcast really, sort of an outcast. I know a person that went to go to this place to an anger management course, and when he applied they wouldn't take him because he had social behaviour problems because of his mental illness. That set him back for awhile but then he picked himself up. I said to him, 'There are lots of people out there who are going to treat you like that, but you just need to snap, not snap out of it but you know take a step back, shake yourself off and get on, you know, and look ahead and work it out.'

Participants described their own or others' resourceful ways to control their environment and or situation, as Andrea describes:

'Well if they expect me to be like that well I'll just be like that.' I've heard a few people say that so I thought well let them. Like when I was in the Adolescence Unit in the psychiatric hospital and like all of us in there, they looked at us really oddly because we were young and were in a mental health hospital. It was hard for us because everyone in there just looked at us differently and acted differently towards us. A few of the young people came to me, and even though I was trying to deal with my own mental illness, I tried to help people in there. Like as I said, when I stood tall at that place I helped a few people and even though they did go back a little bit, they did begin to start standing tall. But it was hard because it was the way that they would look at us and everything. We would sometimes sit down for a whole hour and talk about how people treated us when we were in that place. And it was like, 'Oh well what are you going to do today?' 'Well I'm going to go see if I can stir up my social worker because she thinks I'm a mental case so I'll run amuck with her today. 'It's like I had [done] that a few times as well. For instance with my doctor I would hope she didn't say the wrong thing that day because she knew how unstable I could be. It's more like sometimes they do know we have a mental illness but it's just like we are encouraged to be like that. How are we supposed to get better if we are encouraged to be that way because of our mental illness?'

Rocks turn into mountains

Silence and shame surrounding mental illness is endemic and entrenched and as a result many of the participants believed that their voices were not being heard. One of the care-givers, Cathy, spoke of what she believed were the inconsistent social expectations of society for someone who was a care-giver for a person living with a serious mental illness:

I think we live in a society where parents are very much seen as locus of blame or whatever and it's very hard as a carer to not unconsciously take that on, but it's also part of the grieving process as well. So it has been a real struggle for me and probably still is on and off. Because your emotions often are different to what your rational mind is because you know one thing but your emotions can be quite different to that.

Cathy also spoke of her frustrations at not coping, and of searching on her own for answers, without support from either family, health care professionals or friends:

The conditions for him [her son] living with me were that he did not sniff but it doesn't work. And desperation, too I mean I got to the point when he was up north and every time the phone would ring or even when he was in Northbridge before he went and every time the phone would ring it might be one o'clock in the morning and I've got to get up for work, I would know it's was another disaster. At one stage I picked the phone up and hurled it across the room and it smashed into a thousand pieces because I didn't want to know anymore.

Power and authority were a constant theme, particularly for participants living with a serious mental illness. Andrea recalls her interactions with mental health practitioners and how she experienced difficulties with their authoritarian manner:

They do talk down to us and then they wonder why they get lashed at...People with other types of diseases don't get...talked down to like we get talked down to. I think they've got to have some people with authority because they do get people to settle them down. But not me, it just makes me worse. They figured that out in the end and then they were just like, 'Ok, we'll just leave her alone'.

The issue of communication was viewed as an essential component to strong relationships particularly when living with a family member with a serious mental illness. Cheryl noted:

I believe to be a care-giver and to be a carer you have to have love, you have to have self-esteem in yourself, and you have to have good communication throughout your family. Because if that communication stops that's when mole hills build up inside your heart and you get rocks that turn to mountains. If there are mountains there's no way you're going to move them. The only way to move them is with love. Love can over conquer everything.

Resilience and mental illness

Participants and their families were often placed under a high degree of situational stress. The fact that these families survived not just one crisis, but several, is evidence of their resilience and character to withstand the shocks and stresses of living with a serious mental illness. Ellen, Andrea's care-giver noted the importance of inclusion of the family for dealing with the issues around mental illness:

I think in one way her [Andrea] getting sick helped a lot of other people around her. Not that she got sick, you know what I mean, but how we coped with her and people can see what happened.

Andrea described her first episode of a serious mental illness which resulted in a crisis:

It was explosive, just explosive and just putting all them pieces back together and actually helping each other, the constructiveness of the family just holding that tighter and tighter and coming back close. How can you explain that? It's like all of a sudden just everything just goes smash and it crashing into nothing, you know, and then slowly putting all pieces back together building it back together. It's amazing how families can work together.

Cheryl also described how important family is in overcoming difficulties and that working together as a unit is their strength:

If you're the head of the house and you're a care-giver, as I'm a care-giver to two – I care for my husband for his mental health problems and then I'm a care-giver for my daughter. She's ADHD and the difficulties with that is sometimes I feel at times that I can't do any more. I can't. It's like I...run into a brick wall especially with my daughter. But it's good because if I didn't have my husband with me, my daughter would run all over me. And it's good as well that I've got like, an older family and a younger family because my two big boys they help me with the little fellas especially when there's time that I've got to give to their father...But I'd be nothing if I didn't have to look after my kids and see...what I've achieved with my bigger fellas to make it work for the little fellas. It's not the same but yeah, I've achieved what I had to with my big fellas I gave them everything I could.

Uncertain futures

An uncertain future was a theme for several of the participants and the severity of the person's mental illness related to the concerns about their future. Paula shared her fears for the future for her son because of his mental illness:

Doing this interview has been good because I realise two things: one I am fortunate and my situation not too bad. There is a small sense of grief about you know, my son could have been the next Aden Ridgeway, whatever... [but] when he was 15 I think I did my grieving back then a long time ago. That he was this perfect son and then everything changed...And you know...he was a real go getter, assertive, and got on well with people. So to see him now...[is] like looking at two different people. I've always blamed the gunja...who knows, gunja could of [have] caused his mental illness or maybe it was him self medicating. Anyway its happened. I think that having this interview has been good because I didn't realise how defensive I am about protecting my son...but society actually has this thing that if your not absolutely 'loony tunes' and going mad, that you're ok and you should be working, doing this and that. Its all about being normal but in a different way I mean I never subscribed to normality. I think we have imaginings or stereotype, even if we're generous about it, [of] what constitutes someone with a mental illness and what doesn't. Because my son is borderline where he's not a raving lunatic so people aren't sympathetic, or they get scared too. I know my brother was actually institutionalised and I had a childhood friend who rang me up and said, 'Oh he's ok he won't attack me?' and stuff like that and I said, 'No just treat him like normal'. But usually I think we can understand if someone has got a mental illness. My son isn't fitting that kind of stereotype and that's why I get anxious and defensive because I think and I wonder too probably I have a bit of self doubt whether I'm helping him cop out from life and using mental illness as a reason. But personally, and this is

maybe...why I'm not so good...I mean I want him to be happy and well but I don't want...so he can be like a rat running around in a wheel you know?

7.3 The politics of silencing

This section reviews the more global issues experienced by the participants, both care-givers and care-recipients, and how they articulated their perceptions and critical consciousness about the activity of giving care to Indigenous people living with a serious mental illness. These issues include the stigma and alienation of serious mental illness as experienced by the participants, the phenomena of collusion and silencing – what it means to be an Indigenous person and have a serious mental illness, duty of care myth or reality, and finally the question of whether there is fatalism or hope for participants after their experiences of mental illness.

Stigma and alienation

All of the participants spoke of experiencing stigma and alienation either directly or indirectly because of mental illness. Cathy spoke of the difficulties she experienced with mental health services and drug and alcohol agencies which resulted in a crisis for her son:

That was a relief that he was diagnosed...I know a lot about mental illness and I knew he had symptoms of schizophrenia and what I found unhelpful was when I called the Psychiatric Emergency Team, and I'm not criticising the Psychiatric Emergency Team, but being told it is not a mental illness. I understand the system, I work in the system, so I can see it from both perspectives. But when you're told that it's a drug issue and it's like, I know you can only assess someone's mental state if they're straight...I found that frustrating, really frustrating. I think it's because of the stigma related to drug psychosis.

The issue of alienation was raised by some of the participants, as Cheryl noted when asked how she, someone living with mental illness, coped in her interactions with mental health services:

Not very good, not very good at all; by not seeing Aboriginal people working in the hospital when I was going through my illness was hard as I needed to see a black face, an Aboriginal face. I needed to be able to sit down with this person and talk to this person about my issues, but they were putting people from other nationalities in front of me instead of an Aboriginal person, a black face.

Cheryl also spoke of the lack of Indigenous workers in the system, and she recalls how she and other local Indigenous people had previously lobbied successfully for the hospital to employ Indigenous workers:

Through our local Aboriginal women's group, there were 15 women, there were grannies, some men, mums and cousins we argued for and now have black faces at the hospital. We now have two Aboriginal workers working at the hospital which is a major improvement particularly from when I was first admitted, that was really frightening.

Andrea, spoke about how people living with a serious mental illness continue to suffer alienation in the general community:

I mean even though people didn't tell me, I could sense when they used to treat me differently. Like a few times when a couple of the ladies at the op-shop where I used to always go and buy stuff, I felt they were intimidated by me when I would go there. They would treat me different, a lot different, and I would feel it...I kept thinking that they thought that I was a threat to them you know. A lot of people look at us that way. That's why when I did come out of hospital I didn't feel safe walking on the streets. Because I thought people were looking at me differently. It did hurt, because I feel that they're not only hurting themselves but they are also hurting the person who has a mental illness and they don't know it.

Silencing voices

The issue of silencing about mental health issues was raised by several of the participants. Their concerns related to the lack of appropriate mental health information, particularly in the event of a mental health crisis. One of the participants, Joan, talked about her son's mental health deteriorating and his situation becoming increasingly desperate and stressful until she was asked to come and stay to support the family. Joan believes that the situation was exacerbated because there was no professional mental health support offered to the family to assist them during this crisis:

His wife was feeling very frightened because that was why I was there but I was feeling like, 'Goodness there's got to be some way to deal with this', but we did not know what to do or what was going on. It was really strange to us and we felt powerless. Let me put it this way, we felt powerless, we felt the need to go and find out where we can get some help. It was beyond us it was bigger than us you know.

Certain work practices by mental health professionals are used as strategies to cope with burgeoning case loads and these practices invariably silence or mute the voices of the participants. As Jenny noted, when discussing her experiences of trying to access someone to visit her son at home there were excuses given for why they could not see her son, usually because they were 'too busy' to do a home visit:

I am desperate for some support because he won't leave the house. I am having trouble with him leaving the house, I need someone to come to my home and do an assessment but the hospital will not visit you in your home. You have to go to them you can't get a psychologist to come and sit at your house to do an interview. You have got to go to them. In my son's position

his major problem is leaving the house, getting out of the door. Because all these places say that you need to go to them it makes it impossible. I'm sure he could be helped in a lot ways, maybe not one hundred percent better but somebody to just come and teach him to go outside of the house because I suppose somebody from outside the family is better than a family member who is stuck in the middle, it where [it] quite often it ends up in fights. I get frustrated I can sit in my car outside Centrelink for two hours trying to encourage him to walk in and put in his dole form. He thinks everyone is looking at him so I'm his nominee I try to encourage him to do it but after two hours I give up and just go and do it myself.

Jenny has been told that because mental health services do not consider her son's mental health concerns as an emergency, she is unable to access their services.

We've had a couple of appointments but haven't been able to get there because I couldn't get him out of the house. Because [he] is not violent and he's not trying to harm himself or anything like that and in order to call for a mental health emergency he would need to be showing some signs of that behaviour. At this time he's stuck in a house all day. He doesn't have any friends because he's not out there meeting people so as to make friends. Over the years [his] condition has gradually gotten worse I can see from where it all began to now it's gradually, it is slowly getting worse.

Being Aboriginal and living with a serious mental illness

The issue of being Aboriginal and living with a serious mental illness was a critical one for these participants. Participants spoke of racism, alienation and social inequalities as Andrea highlights in her description of her experience:

I mean its is bad enough living with a mental illness but they look at you because you're Aboriginal anyway you're getting the look and its ten times worse if you've got a mental illness. I mean people look at you like you're lower than low and you're not, it's not right! It's badder than being low but then you're lower than low. You can't win! I think it's really, really bad and I think really serious, and sometimes you see it in the mental health clinics as well. There have been times when I have been in at the mental health service with other Aboriginal young people especially in the adolescent unit and we have felt it. I mean its bad enough they think badly of us because of we are Aboriginal and because we do things differently. But having a mental illness on top of this makes it worse because people feel that they can't even go near that person so they will walk around the person.

Ellen, Andrea's care-giver, added the following account of her observations of the inappropriateness of hospital staff in supporting Indigenous people in their care:

The sad part is I recall a couple who came down from up North, they had been brought down and they were scared and just said nothing. They had nobody to help them, there was no one in the hospital who could support them; there was no one there. It was shocking, absolutely shocking. The hospital was so out of touch with the needs of Aboriginal people. I mean they literally had to have some Aboriginal people from their family come in and talk to them, because there wasn't anyone in the hospital who could talk to them. You know, that's why I think we need to have someone at the hospital

that can support Aboriginal people. A couple of the patients could hardly speak English which made it worse. So they really should...have an Aboriginal worker working in the hospital.

Many of the comments from participants revealed their perception of a deep sense of alienation from the wider non-Indigenous community, as Sarah noted:

I think people think that we, Aboriginal people with a serious mental illness, are all criminals to some degree. The perception is that Aboriginal people with a mental illness commit crimes more than other people.

On the negative attitude toward Indigenous mental illness, Gina stated:

There's a problem here for we are still hiding mental health. People hide it until it's too late. When you've been caring for somebody with a mental illness for a while you know the worse thing you can do is to hide what's going on. But people are still, I suppose because of the stigma because they don't want...any one in their family, to be called 'mad'. They don't mind them sometimes being on drugs and drinking but being 'mad' seems to be a much worse thing. So I think we need to get a lot of awareness out there and say, 'Don't chuck a blanket over it'. You know, get out there in the open and well, it doesn't matter where you go. I mean it's important to get awareness out there and tell people, 'Mental illness is not a bad thing. Its something just like any other health issues it has to be cared for and maintained so that person can be nurtured to health'.

Cheryl's husband, Noel, was more abrupt in his analysis of how society perceives Indigenous people with a serious mental illness:

That you're a lazy black bastard, that's all they've got to say about you. You're a lazy black bastard and you're 'mad'. But why are we 'mad', you know. You know people have to realise that just because you're Aboriginal it doesn't mean that you're bad. Because you've got a sickness it doesn't mean that you're 'mad'. You're the same as any other person on the street but we do have problems, and we have to face our problems.

Duty of care: myth or reality

The participants involved in this study spoke of the breach of duty of care by mental health providers and, in some instances, of the lack of responsibility and even compassion toward their situations. The reality for many of the participants was that both mental health and primary health providers were not always proactive in their responses to the needs of the participants. If intervention was provided it invariably came at some cost to the participants.

Jenny spoke of her difficulty with her son's general practitioner's approach to client confidentiality, specifically his response to her request for information about his mental illness:

[If] I can get him to a GP and they don't give him anything. I go in with him, the doctor won't let me in, he takes him in by himself. I don't know what I'm

meant to be doing because I don't get told. My son wants me to go in but the doctor has told me no you can wait in the waiting room so that's the end of that. I went in there the first time because every time we had made an appointment quite often we couldn't get there and after making seven appointments in a row I think the doctor was probably beginning to wonder what is going on here. So I made an appointment and went down and spoke to the doctor and explained the situation and could he spare a moment for a visit. The arrangement was that we had to check whether anyone else was in the waiting room because he wouldn't sit in the waiting room if there are others in there as well...But even when my son says I'd like my mum to be there, they decide that I will not go into the room with him. I have found that doctors or GP's they like to get their money very quickly so you're in and out of the office rather quickly. They don't allow for time to just sit there and talk one-on-one with the person as part of the consultation with the patient. It's sort of like, in and out of the room in less than ten minutes.

The lack of professionalism displayed by some mental health practitioners was a concern for some of the participants who now mistrust the mental health system, as Joan noted of her son's first contact with a psychiatrist at the hospital:

[At the] very first interview...why, answer another phone call? Can it be so important...when...doing the assessment was also important?...feel that it is really bad for a mental patient to be sitting there all ready to tell his story, what's wrong with him, and the person's getting these phone calls...it's a stop start thing the person cannot handle this. If they really experts on mental illness then they must know that a person hasn't got the patience or ability to sit there. I believe that she [the duty psychiatrist] did not care about what was happening because he was an Aboriginal person that's the feelings I got.

Fatalism or hope

There were many examples of both a sense of fatalism and of hope in the responses of the participants. This final section reviews some of the relevant comments as cited by the participants. It is understandable that there was a sense of fatalism expressed by a number of the participants; including a sense of hopelessness for the future, as Cathy noted, due to the physical and emotional costs for her in being a care-giver for her son:

It's like being torn sorry [pause]; it's like knowing you can't sorry [pause]. You know for your own survival you've got no choice you can't have your kid back. But the cost, and you know I've been there a hundred times before, I sort of let go and I've thought, 'If he dies he dies'. I imagine being at his funeral and its like, 'Well, it's out of your control let it go in the hands of the Gods or whatever'. But you just go there and you go there and you go there again and again so. Because...he's always, I mean at this particular time he was drinking and drugging a lot so his mental state was such that I thought, 'How the hell is he going to survive on the street?' But surprisingly enough, he survived.

Cathy's story shows her desperation and the vulnerability of her situation in the role of care-giver:

It's exhausting, absolutely exhausting, particularly when you have to get up to go to work and having to deal with a pretty tough job. Not knowing what you're coming home to, thinking I've got to get up in the morning so I've got to be refreshed and I could get a phone call at one in the morning or two in the morning and have to deal with it. And where to from here then? Because I know I can't have him back with me. I've been through too much and he's too out of control. I think I've got to the point where I think I've got a right to work. I don't want to be a fulltime carer and I can't be because he tries to bully me and control me. It's a dilemma.

There were also examples of hope in Cathy's story, regardless of the difficulties:

I think I've been pushed and pushed. I just think that the only thing that I can really draw on as my strength now is just this sense of letting go. Because its all out of my control its that I can only give so much and then I've got to a point now where I have to give him boundaries. I think that mental illness when you're a carer it pushes you beyond yourself. That's the only way, I can't describe it. It can be a really scary, terrifying experience especially you know, if you've had some post trauma stuff. But it pushes you beyond yourself and you don't know where that's going to lead. It could be either down or it could be...times when it's down. You can have times where you can actually see that's it's made you a richer and stronger person. Which it does but it's not something generally out there in society that most people would say could be the case.

For some of the participants, their Aboriginality and culture were a source of strength, as Cheryl noted:

Our culture we love to bring our culture in especially when our minds start racing and our hearts starts racing. We will go and get our wool and make our headbands and our armbands and our belts. We are concentrating on our colour we're concentrating on our culture and we know that at the end of the day the things that we make will be handed out, to share as part of our cultural experiences. We like to go out to the schools and do our cultural teaching and coming from the other side Australia, we teach a lot of the Koorie and the Murrie ways. We have learned a lot of Nyungar ways since living over this side.

And as Gina noted that it was the influence of her parents and of being Indigenous that was her source of their strength:

I think learning we were brought up as Aboriginal people; that we were Aboriginal. We were also taught the white man's way as well, as we were taught to cope with the white man's way because my parents knew that you couldn't survive by just being Aboriginal it wasn't going to help us fully. We had to cope with both sides. And that's what they taught us really.

The final point on hope and optimism was the remarks by Ellen, Andrea's care-giver, spoke of the difficulties she has encountered:

I suppose we have to have a lot of understanding and lots of love because you got to really care about what you're doing I think. I was very emotional but I had to put that aside cause I knew that, like getting emotional wouldn't help. I mean you do have your moments that are emotional, but I draw strength when you see how much they're trying. It doesn't matter like every day of our life, every hour, I suppose it will be how you've got to believe that it doesn't matter what ever you do you've got to believe that you're going to come through, that it will be good.

Cathy offered an insightful moment she experienced with her son and how this was initially shocking, but also reminded her of the stigma and attitudes towards mental illness in the community:

Well, people with mental illness are stigmatised. I remember when he was on the open ward in the hospital there was a social worker who worked in mental health and they took him out on day leave. He did this big rain dance because he was down on the foreshore where the fish and chips shops are, and he stripped off his shirt and he was down to just about his jocks and he was doing this big fancy rain dance thing. I thought, 'Oh my God', and I hid and I thought, 'Why am I hiding?'...Rationally mental illness is a part of society but if you are out in public and they're behaving and especially with acquired brain injury they can just react and go, 'Fuck, Fuck', and have a tantrum and its just like, it's a reflection on you...but it's not. If you're out with a client and they behave like that its fine but when it's your own child its really insidious sort of stigma thing. I've learnt to laugh at that now. I really have learnt to laugh at that, you have to.

Finally, Cathy's account reveals how profound the experiences of mental illness can be. In her example, Cathy was prepared to step back and reflect on her reactions; in doing so she demonstrated maturity, wisdom and compassion. She realised that her embarrassment was only her 'ego', and in the moment of reflection her resilience and inner capacity provided her with her strength, where she was reminded that there was no reason to feel ashamed, for society may judge you, but not every person.

7.4 Summary

In this chapter there were two main themes that emerged from the findings, as well as the theme from the previous chapter *Challenges of living with a serious mental illness*. The two themes from this chapter were *Voices of resistance* and *Confronting racism*. The main issues for the theme *Challenges of living with a serious mental illness*, relate to the experiences of the participants' interactions with the mental health system, mainly hospitals but not exclusively. It included strong negative perceptions of Graylands hospital, the largest major psychiatric hospital in Western Australia, of inept professional practices that almost resulted in tragic circumstances, lazy and inept professional practices where a participant was told

not to expect any support because her situation was deemed to be too difficult, and instances of where parents of young adults were marginalised from assessment process, their input considered unnecessary. This was both insensitive and poor practice.

The second theme, *voices of resistance*, emerged from participants talking about the need to have an understanding of the issues of mental illness; by knowing what to do in the event of a crisis is empowering. Unfortunately, participants spoke of their experiences of the stigma and discrimination of living with serious mental illness, they felt alienated from society. Care-givers who were parents spoke of the lack of understanding of mental illness and compassion in society as they felt society blamed them, the care-giver, for the behaviour of the person living with a serious mental illness. Participants spoke of defying the conventions within the hospital, they deliberately would become defiant as an act of resistance toward the mental health system.

The third theme, *confronting racism*, was more personal, and I recall the interviews when the questions were asked about the participants' experiences of racism. The participants became very animated, angry and at times distressed when they were telling their experiences. This was both revealing and confirming, as I had a strong intuition that this would be the case, it also substantiated the literature on the topic of racism. The participants experienced the three types of racism, individual, systemic and cultural, as identified in the literature, in regards to the personal, people spoke of being treated disrespectfully, at the systemic level participants spoke of being frightened of the system and of the system ignoring their pleas for support, of how the system was unresponsive to the needs of Indigenous people, of the lack of respect and compassion shown by the mental health practitioners. The experiences of cultural racism by the participants included their remarks that they felt that Indigenous people are viewed as criminals, and that they are lazy and bad.

Finally, when asked of the future, the participants offered a range of comments, but I was struck by Cathy's response. Her son has a serious mental illness, and for her, being a care-giver at times felt like she 'was being torn'. Such a graphic illustration of her experiences is a salient reminder of the demands on those who provide care to the mentally ill. An analysis of the multiplicative effects on the health and wellbeing of caregivers from the third theme *confronting racism* will be discussed in more detail in Chapter 9.

The next chapter analyses the findings from the art workshop. It discusses the workshop in the context of Art as performance, Art as a performance of possibilities, Art as language and identity, and finally Art as activism. Art as performance compliments the methodologies critical ethnography and Indigenous research.

Chapter Eight: *Art as Performance* – Findings 3

8.0 Introduction

In this chapter *Art as Performance* there is a review of the findings from the arts-based inquiry workshop held with participants. The workshop was held after the interviews had been conducted with the participants. There were three aims for the art workshop: first, to provide the space for participants to explore their perceptions of care-giving through the medium of art with an artist with skills in art therapy; second, to provide an opportunity for participants to meet in a safe environment; and third, as some of the participants had discussed the possibility of forming a support group, Ruah Community Services were invited at the request of the participants to discuss the concept of the agency supporting the participants in the formation of an advocacy/support group.

Some of the participants had requested that they be able to meet with other participants involved in the study. All of the participants were invited to the workshop, but not all attended. For the purpose of the study the participants who attended the workshop were given an instruction to produce a collage that was an expression of their perceptions of care-giving. This chapter presents the findings from the workshop as expressed through their art produced at the workshop, contextualised with the literature on critical ethnography and art. The chapter provides an account of the voices of the participants and a commentary provided by critical ethnographers who use art as part of their research methodology. Included in the chapter are examples of the artwork produced by some of the workshop participants. The discussion in this chapter is focused on the three areas: firstly, art as a form of performance ethnography; secondly, art as performance of possibilities; and thirdly, art as a form of activism.

The chapter has been divided into two main sections:

Arts-based inquiry and performance: This section will discuss and critique the key findings from the arts-based inquiry workshop, around the three themes of art as a form of performance ethnography, art as performance of possibilities and art as a form of activism.

Review of the chapter which will provide an overview of the chapter as well as a preview of the following chapter.

8.1 Arts-based inquiry and performance

Performance ethnography

Performance ethnography relates to the everyday experiences of people. The emergence of performance ethnography as a method of qualitative inquiry occurred in the late 1980s and early 1990s when, 'sociologists began to turn their ethnographic field notes into performances and theatre artists and academics in performance studies began to produce or adapt ethnographies in order to perform them' (McCall 2003, p. 116). Ethnographic performance is theatrical because of its visual aspects and because of the movement and props involved in a performance. As Alexander (2005, p. 411) notes, performance ethnography is 'literally the staged re-enactment of ethnographically derived notes'.

The process of art production has the potential of moving participants from the passive to the active. Art as performance describes the process that occurred in the arts-based workshop which was part of this research because the researcher relinquished control during the workshop process. The participants were given freedom to select their individual images, and then provide an interpretation of their art (Madison 2005). This interpretation is not always clear in everyday language because people use allegories and metaphors to describe life events. The use of art provides a safe and familiar space for people to give expression to their experience (Adamson 1984; Guillemin 2004).

The benefits of an arts-based inquiry approach for this study was that it provided participants the opportunity to engage in an expressive and descriptive activity in a safe and nurturing environment. The purpose of the art workshop was to give participants the opportunity to create their own story through art, as art provides for the personal expression of narrative. 'Making art is a passionate visceral activity that creates opportunities for communion among participants, researchers, and the various audiences who encounter the research text' (Finley 2005, p. 685). The arts-based inquiry workshop provided the opportunity for participants to experience in a group situation, similar to experiences of care-giving for Indigenous people living with a serious mental illness.

The use of performance ethnography for this study was adapted to suit this particular situation (Carlson 2004). The principles of performance ethnography were

used for the arts-based workshop as a means to interpret movement in the activity of art. As Alexander (2005, p. 411-12) notes:

The collaborative power of performance and ethnography utilizes an embodied aesthetic practice coupled with the descriptive knowledge of lives and the conditions of living, to stir up feeling and provoke audiences to a critical realization and possible response.

The arts-based inquiry workshop was about creating what McCall (2003, p. 122) describes as 'scenes on the page'. The scenes on the page, in this instance, consisted of art produced by the participants to describe their experiences of care-giving. Most of everyday life is repetitive and routine. As Madison (2005, p. 151) notes, life as a performance is the act of 'moving inconsequentially through the daily, colourless activities of our lives, [when] we flow through moments of ordinariness, non-reflection, and the mundane. But then something happens, and we move to moments of experience'. Moments that are considered mundane can be points for transformation when an experience triggers realisation. Ordinary everyday moments can be the catalyst for transformation, the combination of reflection and conscious realisation can produce change (Alexander 2005; Madison 2005).

The purpose of using art as performance in this study was to explore the links between racism and care-giving in the context of mental illness. The following section explores the narrative of the participants who attended the workshop and were involved in the performance of arts-based inquiry.

Art as performance

The arts-based inquiry workshop used the medium of art to add another dimension to the meaning of care-giving for an Aboriginal person living with a serious mental illness. The aim of the arts-based workshop was to create the space for reflection using pictures that could inspire and transform (Collie et al. 2006). The artist who facilitated the workshop had worked both with Indigenous youth, and with people living with a serious mental illness. Participants were instructed to produce a collage about their perception of mental health care-giving. The artist utilised a method of art/collage called the Digital Mandela Process. (Refer to Chapter Five for a more detailed explanation on the Digital Mandela Process.) For this workshop participants cut out 25 images from a selection of National Geographic magazines and then arranged them in a grid formation on a A4 size page. The artist explained that people will arrange the images in a particular fashion, reflecting their own preference or hierarchy of importance. The usual method for representation on a collage is in a chronological manner, events over time.

The arts-based workshop was an organic process, other than the instructions provided to the participants by the researcher that their images should describe their own experiences of care-giving, they were free to choose images that held their own individual meaning. The process involved choosing and cutting individual images, and then positioning the images on the page. The performance aspect of the arts-based activity was the process of creating a story by moving from an idea, to the production of the visual and then to the creation of the narrative. Finley (2005, p. 684) states: 'In arts-based research, paradigms for making meaning in the contextual realms of art and social science collide, coalesce, and restructure to become something that is not strictly identifiable as either art or science'.

Art as a performance of possibilities

Painting or any work of creativity is a powerful release for energy and the possibility of healing of serious illness. Art can have the effect of diminishing inhibitions, so people can be less self-conscious about their creative work and in some instances can become even more sensitised to their environment. The expression of art has tremendous applications, both on an individual and group level.

The participants used very explicit and figurative language when describing the representation of their images. For example, Sarah described her experience of a period of silence and introspection during her illness as a building with windows. 'The windows here remind me this is a building of all the windows and where do I go? what do I do?. It was just confusion back then. I stopped speaking for a long time to a lot of people, so that mouth resembles silence.' Cheryl, described her feeling of experiencing two contrasting emotional states through an image of a horror film character: 'I've got Freddy Kruger and Jason. There are two faces because sometimes I can be mad. My husband can be mad and that's one face and then you turn it over five, ten minutes later he could be good'. Refer to Figure 1.

Cathy, whose son has a mental illness, described her own sense of powerlessness in the face of the illness with an image of a set of arms 'This is a set of arms that I could cuddle. Might of just been one set but there was always someone there who could hold me when I was in pain and this is the web we weave'. Refer to Figure 2.

Cathy's partner, Daniel, described himself as being disengaged through the image of a hand. 'For most of my life I had to be an island or a rock and I shouldn't of. So I keep a lot of things bottled up inside'. Importantly, the expression of art can result in moments of healing. Refer to Figure 3.

Adamson (1984, p. 5) states, 'a great deal of unconscious material can be brought to the surface. Paintings (or any other form of creative experience) can be a window through which we can see a person's submerged thoughts and feelings'.

Figure 3: Daniel's Artwork



Art as language and identity

An arts-based inquiry approach is a useful tool for qualitative research, in particular, because performance is a means to access language and identity. Performance ethnography can trace its beginnings back to the late 1980s and early 1990s. It was, as McCall (2003, p. 116) notes, when 'sociologists began to turn their ethnographic field notes into performances, and theatre artists and academics in performance studies began to produce or adapt ethnographies in order to perform them'. In the

creation of an art work, '[t]he experience now made into expression is presented in the world; it occupies time, space, and public reality' (Madison 2005, p. 152).

Using art as means of creating space for moments that offer transformative insight is not new, but for the purpose of the workshop the researcher was keen to identify the cultural nuances that are present in the activity of care-giving for an Indigenous person living with a serious mental illness. Cultural performances, Madison (2005, p. 154) notes, 'are therefore understood as more conventional forms of performance because they are framed by cultural conventions'. The importance of cultural performance cannot be understated for cultural performances 'show ourselves to ourselves in ways that help us recognize our behavior, for better or worse, as well as our unconscious needs and desires' (Madison 2005, p. 154). Indeed, the potential of performance ethnography to influence positive change for the individual and community, according to Alexander (2005, p. 412) is significant; 'performance ethnography uses theatre to illuminate cultural politics and to instil understanding with the potential to invoke change and have a positive effect on the lived conditions of self and others'.

The participants who attended the workshop used a cultural framework to describe their experiences. The narrative of the participants was imbued with cultural symbolism and representations, including family, ritual, cultural activities and connection to country. For example, some of the participants recalled the support of family in their moments of crisis and recovery. As Sarah noted when she reflected on the image of a pair of hands in her collage, 'these hands resemble my mum's hand, sorry. Because that was it, she was so strong; she was there for me'. Refer to Figure 4.

Nature and Indigenous culture was represented in the collages of most of the participants, for example, Gina spoke of her connection to her Aboriginality through bush tucker, '[b]ardy grub, I used to eat when I was a child so I recognise that it is a bardy grub, it looks like a bracelet or something but it's actually a bardy grub and I've eaten many of them'. Refer to Figure 5.

Daniel spoke of the global issue of inequality. 'Free trade is killing the world, we live in our materialistic world but there's a lot of things that we don't need to survive'. (Refer to Figure 3).

Importantly, for a critical ethnographer, the workshop provided an opportunity for the exploration of the moral and political issues involved in care-giving to Indigenous people living with a serious mental illness. As Finley (2005, p. 681) states:

Social science inquiry is always moral and political, and I further interpret this is a timely proclamation that its practitioners should, therefore, be purposeful in performing inquiry that is activist, engages in public criticism, and is resistant to neoconservative discourses that threaten social justice.

The arts-based workshop provided a safe space for participants to explore the issues relevant to them. It provided the space for critical reflection where participants could consider care-giving of Aboriginal people living with a serious mental illness in the context of their daily lives either as care-givers or recipients of care.

Art Workshop: Analysis of participants' experiences of the multiplicative effects of stigma, discrimination and racism

The aim of the art workshop was to provide a safe space for participants to explore, through art, their experiences, perceptions and knowledge about care-giving for Aboriginal people. The intention for the workshop was that it provided a safe communal space that would encourage discussion and support between participants.

The headings in this chapter relate to the methodology of performance ethnography which uses art as performance of possibilities and art as a form of activism. For some of the participants Art included their experiences of racism which has been an intrinsic part of their experience with mental illness and care-giving. For example, Cheryl depicted in a photo of a Gollywog to depict her experiences, 'And I've got little old gollywog there cause I was called a gollywog when I was little'. Barbara was more explicit and linked her comments to the wider cultural and institutional racism that she considered had an impact on her care-giving, 'And I blame colonisation for every thing – that's big Ben over in England colonisation for every thing'. The art workshop was held for participants to further explore the experiences of care-giving in the context of serious mental illness in a safe environment using the vehicle of art. In turn, the data which emerged from the workshop was relevant to the understanding of cultural, institutional and individual racism which impacts on the care-giving experience for Aboriginal people.

The inclusion of the art work into the thesis was because art is visual data – a graphic representation of experience rather than a verbal representation. A purely verbal representation of the data was therefore not possible. The art was included along with a synopsis of the discussion to provide a complete data set of the findings so the conclusions that were drawn in the thesis could be linked to the data that had emerged from the research.

A major finding from the analysis of the workshop discussion data was that culture may act as a protective factor against racism. One of the levels of racism in Jones' model is internalised racism (2000). Jones' definition of internalised racism is the 'acceptance by members of the stigmatised races of negative messages about their own abilities and intrinsic worth' (2000, p.1213). The characteristics of internalised racism, according to Jones, include a rejection of racial identity and the denial of or 'rejection of ancestral culture' (2000, p.1213).

Using Jones' model of internalised racism as a guide for analysis, the findings from this research were that the participants did not express a high level of internalised racism. Indeed, all the Aboriginal participants identified strongly with their racial identity of being Aboriginal and with their cultural experience and expressed high valuation of their culture. Their art (and subsequent discussion) was all framed within and around positive Aboriginal cultural images and symbolism. Even though for many of the participants everyday racism was a constant challenge, the findings from the art workshop demonstrate that positive Aboriginal culture and identification with culture may act as a protective barrier to racism. All of the participants identified culture as a source of positive identity.

The art workshop provided the space for introspection that allowed participants to explore within their experiences and perceptions of care-giving. Racism is an everyday experience for these participants, and it is possible that the effects of racism are mitigated for them because of the strong belief in their culture and their confidence in their racial identity.

8.2 Summary

This chapter discussed the findings from the arts-based inquiry workshop, with the focus on the concept of art as performance. The discussion included the integration of the concept of art as a medium to explore the meaning of care-giving as a performance of possibilities. The chapter acknowledged how art can be utilised as a form of activism. The aim of the chapter was to explore through art the other dimension of meaning of care-giving as understood through the voices of the

participants. The combination of the participants' voices and the literature by critical ethnographers who use art as a research method to uncover meaning provides another layer of understanding to the experiences of care-giving for Indigenous people living with a serious mental illness.

Care-giving is still very much an under-valued activity. The next chapter *Moral Boundaries: An argument for an Indigenous model of care* critiques the issues of the characteristics of care-giving and the concept of an Indigenous model of care. It examines and discusses the critical issues of care-giving in the context of an Indigenous person living with a serious mental illness as experienced by the participants. It will explicate some of the Indigenous voices of resistance and dissent against the institutions and structures that have marginalised and disenfranchised Indigenous people living with a serious mental illness in Australia.

Chapter Nine: *Moral Boundaries – An Indigenous Model of Care*

9.0 Introduction

This chapter includes the discussion of an Indigenous model of care-giving and an examination of the critical care-giving issues for an Indigenous person living with a serious mental illness. This discussion is framed under the three significant themes that emerged from the research as key concerns for caregivers. These are, *Challenges of living with a serious mental illness*, *Knowing the care-giver role* and *Staying the distance*. The sections on *Voices of resistance* and *Confronting racism* are developed through the voices of the participants synthesised with the current academic literature in relation to their experience. The chapter presents some further broad justification for an Indigenous model of care-giving.

The five sections in this chapter are:

Mental illness a dark scary place: Experiences of mental illness

explores the main issues confronting Indigenous people who are living with a serious mental illness, including the impact of deinstitutionalisation. It also provides an overview of the challenges confronting care-givers and care-recipients within their families, within their community and society.

Knowing the role: Experiences of care-giving examines the issues confronting care-givers involved in providing care to Indigenous people living with a serious mental illness and places care-giving and mental illness within the context of racism and colonisation.

Voices of resistance: Awakening critical consciousness explores the relationship between mental health, care-giving and activism. There are still challenges for Indigenous people living with a serious mental illness because of an oppressive and uncaring mental health system.

Confronting racism: Awakening voices discusses the issue of racism in the context of care-giving for Indigenous people living with serious mental illness. The experiences of the participants reflect the discussion on racism previously identified in Chapter two of the thesis. This section also provides

an analysis of the topic of racism as experienced by the participants and linked to the literature.

Standing tall: The morality of care-giving reviews the political dimensions of care-giving and the critical elements required for the activity of care-giving

Summary provides an overview of the arguments presented in the chapter. It will conclude with a review of the main topics to be covered in the concluding chapter.

9.1 *Mental illness a dark scary place: Experiences of mental illness*

Setting the scene: Prevalence and the policy of deinstitutionalisation

Identification and treatment of mental illness has had a turbulent history, dating back to the Middle Ages in Europe. It began with the practice of ostracising people with a mental illness from towns and villages. The treatment of people living with a serious mental illness in Europe only improved marginally from the late 1800s, with the focus being on containment or of making invisible (Foucault 1989). As Foucault noted, '[c]onfinement hid away unreason, and betrayed the shame it aroused; but it explicitly drew attention to madness, pointed to it' (Foucault 1989: 65). The current treatment of people living with a serious mental illness has improved and confinement or of making invisible is not common practice.

In Australia, the policy response to the growing mental health concern has been enacted through the release of four Mental Health Strategies, beginning with the first with a timeframe from 1988 to 1992, the second, with a timeframe from 1992 to 1997, the third, with a timeframe from 1997 to 2003, and the last Strategy released in 2003 with the timeframe from 2003 to 2008 (Henderson 2005). Each of the four strategies has taken a particular focus with the aim of addressing the key mental health concerns impacting on the community.

An issue of concern, both globally and in Australia, has been the implementation of the policy of deinstitutionalisation. Deinstitutionalisation, as it was discussed in Chapter three, refers to the concept of reducing the number of people with a serious mental illness being confined as long term inpatients in mental hospitals. The underlying principle of the deinstitutionalisation policy focuses on reducing the number of mental health interventions being provided by hospitals to community mental health settings (Biegel and Schulz 1999).

In Australia the second National Mental Strategy released in 1992 was targeted at addressing the issue of deinstitutionalisation (Henderson 2005). The strategy had two key aims to firstly reduce the demand on public mental health facilities and secondly, to provide for opportunities for people living with a serious mental illness to become 'productive members of the community' (Henderson 2005, p. 245). Even though the policy of deinstitutionalisation has been regarded as a positive initiative, there is growing concerns in Australia with the implications in regards to the allocation of resources to meet the need of services provided in community mental health settings. *Not for Service*, the report published by the Mental Health Council of Australia in 2005, indicated that the policy of deinstitutionalisation had failed because of insufficient funding being allocated to community mental health services that could offset the increasing numbers of people with a serious mental illness moving from hospital to community. As a result of deinstitutionalisation the burden of care has fallen on family members and 'high expectations have been placed on families to provide care to ill and disabled relatives' (Williams and Mfoafo-M'Carthy 2006: 27).

Although there are many benefits of deinstitutionalisation, these are often outweighed by the detrimental effects of the policy in the long term. The 1993 National Inquiry into the Human Rights of People with Mental Illness, known colloquially as the 'Burdekin Report', highlighted the inadequacies of funding to the mental health system for the needs of people with serious mental illness living in the community (Human Rights and Equal Opportunities Commission 1993). Overall in Australia there is a massive shortfall in the expenditure on mental health. The situation is that 13 per cent of the Australian population experience mental illness, but only 7 percent of the entire health budget is allocated to mental health. This equates to a six per cent shortfall in the funding that is required for an appropriate level of mental health services (Hayman-White, Sgro. and Happell 2006). This means that families have to carry the extra burden of care.

Consequences of mental illness: Families, stress and coping

As a condition that mainly manifests in adolescence and young adulthood, mental illness interrupts and hampers a key developmental stage, the transition into adulthood and independence. For this reason there is a fundamental difference in the relationship of the care-giver and the care-recipient; in mental illness the care-giver being typically a parent, and in some cases spouses or siblings (Biegel and Schulz 1999, p. 348). The close and intimate relationships between care-givers and the care-recipient can often be problematic. Care-givers interviewed for this

research shared their concerns about the future prospects for their children.

Barbara, who spoke of her daughter's difficulties in coping with the demands of life because of her mental illness, stated:

She hasn't sort of learnt or experienced being, I hate the word, responsible, but she's never been able to support herself in any way. And then with her mental illness...they don't want to be around other people either. It's a very lonely type of illness; they don't take on advice of carers.

Mental illness is a chronic condition and it is also cyclical, which means that people living with a serious mental illness can have long periods where they have no symptoms of illness, but it can change suddenly and unexpectedly. This tenuous situation is both stressful and problematic for both the caregiver and care recipient, as Beigel (1999, p. 349) states, 'by definition, mental illness is a mental disability that affects cognitive but not necessarily physical functioning'. For Cathy the experiences with her son's mental illness were profound as she shared that her main feelings were 'fear, powerlessness, grief and loss, a lot of guilt, a lot self blame' in not being able to cope with her son's erratic and risky behaviour associated with his mental illness.

A critical issue for care-givers and people living with a serious mental illness has been their fractious and difficult relationship with mental health professionals. People living with a serious mental illness are often treated in the community and families as 'adult children' who contribute little to their families or others. The attitude held by some mental health practitioners is that people living with a serious mental illness are incapable of making their own decisions. These attitudes were reflected in the stories of the participants and care-recipients who felt disempowered for they believed that they were viewed by mental health practitioners as incapable of being actively engaged in the 'shaping [of their] care relationships' (Williams and Mfoafo-M'Carthy 2006, p. 41).

The current care-giving models often portray the person with the mental illness as the source of family distress, and as William (2006, p. 27) states, 'existing models focus on care-giving as a unidirectional transfer of emotions and instrumental labour between caregivers and a recipient of care'. This model has its limitations for it does not acknowledge that the activity of care-giving is a partnership with both the care-giver and the care-recipient having a shared investment in the activity. The participants noted the importance of this shared investment in the care-giving arrangements. Sarah spoke of her concerns that there was little or no support for her family in understanding the issues of mental illness: 'I found that my family,

when I first got sick, they [had] no information. There was nothing out there for them, you know, they didn't know what was going on with me. There was nobody for them to go to'.

The moment of receiving the diagnosis is a critical point in the relationship between care-giver and care recipient. Before the person living with a serious mental illness has received a diagnosis the care-giver has often experienced an extended period of not knowing what was happening. Joan recalled the onset of her son's serious mental illness and of the long period during which both she and her daughter-in-law felt isolated and alone in trying to understand his illness. This situation can lead to 'heroic efforts to save or cure the sick person' (Karp and Tanarugsachock 2000, p. 13).

Research has shown that care-giving is stressful and, as Williams and Mfoafo-M'Carthy (2006, p. 27) notes, there are concerns about a range of things including 'symptoms, caring activities in the home, seeking community resources, emotional distress, emotional fulfilment, effects on family functioning, mobilising coping methods, caregiver psychiatric morbidity, beliefs about causes of illness, and needs for professional assistance'. This often results in intense emotional and stressful experiences for both care-giver and care-recipient as the illness progresses. In particular for the care-giver, it often provokes feelings of intensified sorrow, anger, and resentment (Karp and Tanarugsachock 2000, p. 15). The concerns of care-givers are often not acknowledged by mental health professionals and studies have shown that as a result stress experienced by family members associated with care-giving is similar 'to being exposed to a severe, long-term, chronic stressor' (Biegel and Schulz 1999, p. 346).

Exclusion or inclusion

Despite many reports that state that the objective of health services is to provide a service that is designed to meet the needs of the client, this is not always the case. The failure by these systems is often in the implementation or delivery of services (McCavanagh et al 2000; Mental Health Council of Australia 2005). The participants in this study expressed the view that the mental health system, like most Western based health systems, is highly regulated and hierarchical and as a consequence does not always consider the unique needs of the individual or community. Two participants in the study, Andrea and Sarah, both living with mental illness, articulated their experiences of rejection, alienation and fearfulness. Andrea

described her experience of living with a serious mental illness as one of rejection and alienation:

people just give me this vibe. It was like, we as people are different, and that they then become distant, for instance, ignoring me and not talking to me. Sometimes I can feel that they are a little bit scared of me because I am different.

Sarah described her experience of living with a diagnosis of a serious mental illness as alienating and fearful: 'I was still afraid of this, you know, this big word. This scary big word and lots of people, the general public are afraid of that word. With schizophrenia you've got it all the time'. The situation described by both Andrea and Sarah is common and care-givers too, have similar experiences. A report commissioned by Carers Western Australia identified that half of the care-givers involved in their study felt that mental health service providers should improve their communication with patients and patients' families. The report concluded that improvement in the communication skills of mental health staff should be a priority (McKeague 2003).

Participants who were living with a serious mental illness all reported that they had encountered difficulties with the mental health system. They complained of poor healthcare practices and lack of communication skills of mental health professionals. This is reflected particularly in Sarah's comment about the lack of empathy and lack of professionalism displayed by a senior mental health practitioner: 'the thing that she said to me was so upsetting that I just couldn't believe that she was a psychologist or psychiatrist. I just got such negative feedback from her'. Living with a serious mental illness is challenging, and as described by Andrea, is 'one scary place'. It is only reasonable to expect mental health practitioners to be professional and compassionate in their interactions with people living with a serious mental illness.

Failure by mental health providers

Since the 1980s there has been a major shift in the provision of health services with the introduction of a market based approach on the delivery of health care services (McCavanagh et al 2000). The market based neo-liberal approach to health care is now focused on the individual being more financially accountable for their health needs (Henderson 2005). The shift to a more market based approach to health care has seriously affected and impeded the delivery of health services to Indigenous people. The impact of this is highlighted in the experience of Jenny, who reported that it was almost impossible to get anyone to visit her at home except in a crisis

experience,: 'for my kids it's been hard to get someone to come to the house until it's actually a crisis, like I've got three kids all with disorders and I can't even get anyone to come out to assess the younger one'. Jenny further added that in her view, 'mental health services are more concerned with the costs of operating a service and that personalising programs were too expensive'.

One focus of mental health providers in Western Australia is to market their services as safe, effectiveness and timely. Mental health administrators in Western Australia spend considerable resources promoting the view that mental health services are safe, stable and non-threatening and that the community can be confident that good quality mental health services are provided (McCavanagh et al 2000). What is not acknowledged within the system is that some people's experiences of the system are neither safe nor non-threatening, but rather people do suffer because of an insensitive and difficult-to-access health services (Hazelton 2005). For example, some patients and their families can be sent from one agency to another and still not receive the assistance that they are entitled to. Jenny reported: 'I've been to eleven different places and each one has sent me onto another and then the next one. We've ended up back at the beginning again with no one coming'.

A major concern for participants is the lack of response to a mental health crisis because of the constraints due to the narrow definition of a mental health crisis. Cathy spoke of her frustration at the lack of response by mental health workers to her son's mental health crises because he did not fit neatly into a mental health category. Her argument was that there is no neat mental health category if there is the co-morbidity of mental illness, drugs and alcohol. A drug or substance abuse crisis has its own characteristics, but an indifferent response by mental health providers is not helpful to a mother whose son is at risk of self harm. As Cathy stated, 'with drug and alcohol abuse you can set boundaries and people talk about boundaries but when they're delusional the whole concept of boundaries just goes out the window, because they don't know about boundaries; it's ludicrous'.

Cathy's son's situation is not helped by the fact that the mental health system is based on a medical model with a very narrow interpretation and is therefore often patient focused rather than family focused (Biegel and Schulz 1999, p. 350). Cathy's son's situation is yet to be resolved; it has become a protracted and ongoing issue for mental health and drug and alcohol service providers, which only adds to the confusion and stress for the patient, their family and for the community. Vacillation by alcohol and drug and mental health service providers is one example showing how bureaucratisation can result in minor difficulties or even angst, becoming a fully

blown crisis often resulting in tragic consequences: Cathy indicated that it took a real crisis and an incident of serious self harm before some intervention from the mental health services.

9.2 Knowing the role: Experiences of care-giving

Defining care-giving

The Australian Bureau of Statistics definition of a 'primary carer' is a person of any age who provides the most help or supervision to a person with one or more disabilities (Australian Bureau of Statistics 1998) (Refer to Chapter three in Section 3.2 *The paradox of modernity* for the full definition). I argue that the Australian Bureau of Statistics definition for care and primary care is inadequate as the term 'care' can be problematic, for as Fine (2004, p. 224) suggests, it is 'easily capable of being conflated and confused... [and] the potential for confusion may owe something to the disputed origins of the word'; the word 'care' has its origins in both the ancient Greek and Latin languages. Joan Tronto (1993) offers a less formal definition and posits the notion of 'caring about' and 'caring for' Indeed, according to Tronto (1993) caring almost always involves some form of ongoing commitment and responsibility. So, she believes, it is necessary to distinguish between the two; 'caring about' 'refers to less concrete objects: it is characterised by a more general form of commitment' and 'caring for' 'implies a specific, particular object that is the focus of caring'. Care-giving is still deemed to be a family responsibility and an activity that has been predominately consigned to women. It thereby reinforces gender roles, and as Tronto puts it, 'traditional gender roles in our society imply that men care about and women care for' (Tronto 1995, p. 103).

Care-giving

Care-giving can be stressful. The locus for the stress and burden affecting families living with a serious mental illness is often environmental (Lefley 1997) and includes the stress evoked by experiences of stigma and discrimination. Stress increases in families when their interactions with health, legal and welfare service providers are difficult and frustrating. Families living with a serious mental illness often experience unnecessary additional stress because of negative social attitudes which can include, but are not limited to, 'hostile cultural attitudes towards loved ones; public presumptions of violence; negative expectancies of recovery; underfunding of research and services' (Lefley 1997, p. 212). Further stress occurs for families when they experience iatrogenic stigma. Iatrogenic stigma involves both the stigmatisation of patients by clinicians (Sartorius 2002) as well as the pathologising of families

when a family member has a mental illness and can include blaming parents as the cause of illness (Lefley 1997).

Care-giving is often ignored and undervalued as an activity, and '[t]he world will look different if we move care from its current peripheral location to a place near the center of human life' (Tronto 1993, p. 101). Care-giving as a practice is better understood when viewed as an integral part of life. Tronto (1993, p. 106) believes there are four phases to the care-giving process, which are 'analytically separate, but interconnected phases'. These four phases are 'caring about', 'taking care of', 'care-giving' and 'care-receiving'. 'Caring about' involves the recognition that there is a need to provide a person with care, it is both cultural and personal. 'Taking care of' involves the decision in to assume responsibility for responding to the person's care needs; it requires a cognitive shift for it involves a commitment to the responsibility to engage in the caring process. 'Care-giving' involves the direct response to the need for care; it requires the commitment to the task of directly addressing the needs of care. 'Care-receiving' assumes that the care-receiver is responsive to the care that is being provided. 'Care-receiving' is an important component in the phases of caring, for it allows for an evaluation on the care provided.

The participants in my research understood the complexity and demands of the care-giving role, as Cathy described her experience, 'I think you learn to live with it but some days are certainly a lot harder than others. If you're having a good day it's good, if you're having a bad day it makes it difficult'.

Indigenous care-giving

The findings from the study demonstrate that the experience of care-giving in an Indigenous context is intricately connected to family and community and is a less individually focussed concept than reported in mainstream literature. The concept of 'the individual' is therefore not necessarily the appropriate model for Indigenous model of care-giving. The concept of 'individualisation' in the context of care-giving in Western society is divided between the individual, the family and paid care (Michael Fine 2005; Allen and Ciambone 2003).

Racial comparison of burden of care-giving provides an insightful picture. Three studies were conducted in the United States investigating and measuring ethnic differences in the burden and stress of care-giving which had similar findings (Pickett et al 1993; Horwitz and Reinhard 1995, Stueve, Vine and Struening 1997). These included the findings that: African American families scored higher in coping with the stress and burden associated with care-giving for a loved one living with a

serious mental illness than White families; African American families were psychologically and emotionally more competent in coping with the loss of expectations with a loved one living with a mental illness; and African American families displayed a more pragmatic approach in their preparedness for the duties of care-giving for a family member living with a mental illness (Pickett et al 1993; Horwitz and Reinhard 1995; Stueve 1997).

The reasons for these differences were primarily social and cultural. Horwitz and Reinhard thought that these results might be partly attributable to the cultural practice of 'intergenerational care-giving for grandchildren, extended kin, and the disabled' (1995, p.146). They hypothesised that this might normalise the practice of care-giving thereby making it less stressful. Horwitz and Reinhard also stated that White parents are more affected by the stigma of mental illness, which in turn makes them perceive care-giving as more stressful. Stueve and his co-researchers noted that the social practice of the presence of a supportive network was a protective factor that could mitigate the effects of stress and burden on caregivers (Stueve, Vine and Struening 1997). All three studies clearly demonstrated that African American families living with a serious mental illness perceived lower levels of stress and burden associated with care-giving, despite the presence of poverty and other socio economic indicators of disadvantage in these families (Pickett et al 1993; Horwitz and Reinhard 1995; Stueve, Vine and Struening 1997).

Another protective factor for coping was the presence of religious activity. Often, the Church was an integral part of family life and was also seen as a source of support. Stueve (1997) stated, 'Church members are potential sources of emotional support and tangible assistance; participation in a valued institution may enhance self-esteem; and religious beliefs and prayer may provide adherents with inner strength to tackle life problems' (p. 200).

The findings of my research were similar in terms of coping capacity and the mitigating effects of positive culture and kinship practice on caregivers. Even though most of the study participants were experiencing financial disadvantage and difficulties associated with stigma and discrimination, they did not see care-giving as a burden. The caregivers in this study saw their care-giving role as complex; with individual rights having a place, but not at the expense of family, community and culture. Indigenous participants in this study considered family, community and culture as the most important aspects. Caregivers conceptualised the family member with poor mental health as co-existing within this kinship system of support. The sharply demarcated boundary between the role and identity of being a caregiver

or a care receiver as explicated in White western literature did not emerge strongly in this study (Pickett et al 1993; Horwitz and Reinhard 1995; Stueve, Vine and Struening 1997).

The concept of reciprocity was a much stronger theme in the findings in this study, and this was reflected a different and distinctly Indigenous approach to care-giving. Both the family member who had experienced poor mental health and caregivers, stated that they felt that the care-giving experience could not be accurately reflected by simply focusing on one extreme of the non-Indigenous binary concepts of 'Individual caregiver and care receiver'. This finding was behind the decision to include all family members' experiences of care-giving in the research.

The ecological context of Indigenous families is an important factor in care-giving experience. Studies on the ecological effects of social support on families have identified that the positive recognition of kin, community and work is necessary for any healthy family system (Bronfenbrenner 1986; Elder, Nguyen and Caspi 1985; Scarr and McCartney 1983). Conversely, when systems and institutions in society adopt an approach that is too rigid and judgemental towards individuals and families without considering the wider ecological context, they can become oppressive (Bronfenbrenner 1979, 1986, 1994). The case study of the Hmong family further illustrated the impact of ecological influence on the complexity of care-giving practice within distinct and unique cultural contexts.

Irrespective of the stressful life situations they face, many families have, within their cultural ecological context, incorporated protective factors of resilience (Pickett et al 1993; Horwitz and Reinhard 1995; Stueve, Vine and Struening 1997). Even though confronted with the burdens of poverty, chronic health issues and discrimination they still manage to live a satisfactory life (Werner and Smith 1982). This was true also for most of the participants in this study. Despite their difficulties the participants were living an enriched and meaningful life and they wanted a mental health service that was culturally safe and respectful, not paternalistic or judgemental.

The interviews with family members with poor mental health focused on their understanding of care-giving within their family as well as the levels of stress they observed impacting on their caregivers who had responsibilities not only to individuals within their family, but also to kin and families within the wider community. Individuals who had a mental illness were aware that their mental illness and need for the individual caregiver depleted the wider levels of social support available within the kinship system for others and often felt concerned about this.

Thus, the Aboriginal experience of care-giving for an individual's mental health must be nested within the ecological context of the family, kin system, community and must also reflect the reciprocal care needs of the caregiver and the community. The study sought to define this full scope of care-giving by including multiple perspectives on the care-giving experience.

Defining Indigenous care-giving

The Australian Bureau of Statistics (1998) definition for the term 'primary carer' is:

a person of any age who provides the most help or supervision to a person with one or more disabilities. The assistance has to be ongoing, or likely to be ongoing, for at least six months and to be provided for self care, mobility or communication. A small proportion of primary carers (less than 1 per cent in 1998) are younger than 15 years of age.

There are significant limitations in the Australian Bureau of Statistics' current definition for a primary care-giver which become apparent when applied in an Indigenous context.

Barbara identified herself as a caregiver for her daughter, who has a serious mental illness, regardless of the fact that her daughter lives in another state. According to the Australian Bureau of Statistics definition Barbara would not qualify as a primary carer. This disparity highlights one of the anomalies in how Aboriginal people conceptualise care-giving. Barbara identified herself as a primary caregiver because she believed that her Indigenous familial responsibilities were not restricted to either a geographical location or context. Her case provided important data on the unique Indigenous perspective of being intricately linked to family regardless of time, space and distance. Barbara's case is, in fact, an example of the need for a definition of care-giving to be more inclusive and flexible when applied to Indigenous people. The fact that Barbara's daughter was living in another state was not an issue for her. She stated explicitly that as an advocate for her daughter she was willing to do whatever her daughter required when it was needed, including helping her to have contact with her children. For this reason Barbara identified herself as a primary carer, not strictly to the Australian Bureau of Statistics definition of a primary carer, but from her perspective as an Indigenous woman fulfilling her role as caregiver and mother in a culturally appropriate manner.

I did not question Barbara's self definition as a caregiver, or interrogate the authenticity or authority of her self-identified position. For the purposes of this study, because she did identify herself as her daughter's primary carer, and because she had a range and depth of care-giving experience, she fitted the criteria for inclusion and was a suitable participant. Barbara's data demonstrated that the role of

caregiver from an Indigenous perspective may be more about responding to need when it is pressing, irrespective of difficulty or barriers than about physical proximity and daily provision of help. Barbara's perspective was that, as an Indigenous person whose life and family were severely affected by mental illness, and as an Indigenous person who had cared for a family member with mental illness, she had a right to be included in the study and to tell her story.

After reviewing and then integrating these findings with those available in the literature it is possible to synthesise a more appropriate definition for Indigenous care-giving:

Indigenous care-giving should be viewed as a whole of life experience and seen in the context of an individual nested within their family, and their community. Care-giving includes all of the social, emotional and cultural support that enhances the well-being of the individual, family and the community where a member has a disability.

Confronting the contradictions of mental health for care-givers

The findings of this study reflect Henderson's observation (2005, p. 249) that 'the families of the mentally ill were largely viewed as a source of pathology, necessitating professional intervention to allow them to care effectively for mentally ill family members'. Care-givers involved in a study in Queensland identified four key issues relating to the inadequacy of mental health providers in responding to their needs: firstly, the inability to provide adequate care and treatment information to care-givers; secondly, the failure to allow care-givers to be involved in the treatment and care program for recipient of care; thirdly, the inability of the service providers to support caregivers in crisis situations; and fourthly, the inability to provide care-givers with appropriate information about emerging and relevant information related to mental health care (Hodgson, King and Leggatt 2002).

Care-givers of family members living with a serious mental illness reported having to continually challenge the dominant views held by the medical professionals, and that often their challenge did not meet with success. Cathy's experience with the mental health system when trying to get an assessment for her son was frustrating given her understanding of the complexity of the situation. She observed, 'I just wish I had of been believed more in terms of my assessment because as his mother I was around him 24 hours a day, seven days a week'. Cathy felt that not only was her voice not heard but her pleas for help were also ignored.

Other participants shared similar stories which portray a system that is both negligent and uncaring. The failure to recognise the role of care-giver as a partner in

the treatment and care process was both disrespectful and, in the long term, could have negative outcomes for the person living with a serious mental illness (Hodgson, King and Leggatt 2002). There is obviously a disconnection at the interface between the mental health system and families of relatives living with a serious mental illness. While the mental health system has adopted a market-based approach to health care rather than a service-orientated approach for the public need, families are working from the position of genuine care and compassion. Cheryl, a participant, very eloquently and passionately stated: 'Love, only one word mate, love; love overcomes everything, it overcomes evil it overcomes everything'.

The feminist theorist Nel Noddings (1995) proposes that care-giving is more than just a one dimensional experience, it is about being human with our sense of connectedness and relatedness. As Noddings states, '[t]he source of my obligation is the value I place on the relatedness of caring...[which] itself arises as a product of actual caring and being cared-for and my reflection on the goodness of these concrete caring situations' (Noddings 1995, p. 13). Those who argue the neo-liberal view forget the value of connectedness and relatedness to others, and of the importance of fostering a sense of community. It is unfortunate that what we are witnessing in contemporary times is a more punitive approach to health provision. The expectation that people will be more responsible for their health is leading to the punishment, neglect and denigration of those who are unable or do not have a means to 'make choices, seek knowledge and adopt health-promoting behaviours' (Henderson 2005, p. 244).

Care and inequality

Critical theorists have long argued that the structural formations of institutions are premised upon race and privilege. Fine argues (1997, p. 64), '[i]f institutions refuse to dismantle the filters which limit opportunities for intellectual and economic work, such analysis (and interventions) may ultimately boomerang and punish victims'. If Fine's argument is broadened to public health, then the image presented by health administrators that health services are safe, responsible, caring and accessible to all in the community needs to be interrogated. What is not acknowledged here is that beneath the surface of this supposed safe and responsible environment another world exists. Indigenous Australians know that because of systemic racism health services are neither safe, caring or accessible. The reality is that mainstream mental health services have clearly not been responding appropriately to the mental health needs of Indigenous people (Martin 2006).

The emergence of consumer advocates in recent times has improved the standards of some services; the advocates' actions have ensured that there is now some level of accountability and transparency in the sector (Michael Fine 2005). Unfortunately, there is still a degree of angst directed to the consumer movement by service providers, who often view advocates as a disruptive influence (Hodgson, King and Leggatt 2002). An alternative to the current impasse between consumers and service providers is suggested by Kim Hopper (2006, p. 221) who offers an alternative for service providers with the use his concept of 'committed work' which he defines as 'labor preformed under the auspices of a service contract or salaried job that goes beyond the call of duty'. Such a notion strikes at the heart of the so-called professionalism of the healthcare relationship and the ideal of maintaining distance that is considered sacrosanct in the care industry. Those practitioners who do committed work do so at some personal and professional cost, not least of all criticism from colleagues, but also the presence of personal scars from difficult interactions. It is not easy, but those do committed work discover their efforts are not without appreciation, and that, 'practitioners tend to slip easily into the discourse of kinship, caring, labors of love; not uncommonly, too, they bears the scars of their dedication' (Hopper 2006, p. 221).

The notion of 'committed work' was present in this study. Cheryl described how the support of a mental health worker who performed committed work while working on behalf of her and her family has been a positive experience.

I've got lots of support but with J [support worker] behind me, you know, I tell him a lot of my problems. It's good to have the support there really. It's good to know you've got the support, know you've got people out there who are willing to help you, help you overcome your problems.

According to Hopper (2006, p. 221), '[c]ommitted work can take the simple form of unremunerated labor: providing unbilled clinical services, visiting sick clients or running errands for them on one's day off, working unpaid overtime, trading on hard-won social capital to arrange an otherwise impossible referral'. However, Hopper also acknowledges the limitations of individual caring on society, '[n]or can genuine caring do much more than blunt the impact of oppressive structures' (2006, p. 221).

The consequences of care-giving

The activity of care-giving and of how society values it as an endeavour is linked and enshrined in the concept of respect. Hopper (2006, p. 222) states, '[r]espect cuts so deeply to the core of what it means to hold ourselves and others accountable as moral agents that some political philosophers have made that act of

recognition the core affirmation of equality'. Respect is a core attribute for a caring and compassionate society. It 'finds focus as a vital force at the heart of both legitimate social order and its sometime mutinous offspring as well' (Hopper 2006, p. 223). The issue here is one of affecting change within economic and social structures, for if society is serious about addressing racism, social injustice and poverty, then institutions charged with this responsibility must be held more accountable. We need to 'force service bureaucracies out of their own comfortable confines and into that unruly terrain, alternatively contested and abandoned, known as the de facto mental health system' (Hopper 2006, p. 223). For several of the participants it was apparent that their situation was seen by mental health providers as being too difficult for them to handle. Cheryl recounted her experience with hospital staff, '[b]efore J [mental health worker] was around you would go and ask them fellas in there [hospital] for help and they look at you as if you were stupid'.

Studies of both care-givers and of persons living with a serious mental health concerns and their relationships with the mental health system have shown that there is a general dissatisfaction among care-givers about their relationships with mental health professionals. Care-givers were primarily concerned with the failure by mental health practitioners to recognise their critical involvement in the relationship between the care recipient and the mental health system. Conversely, when there is cooperation and support people will respond, as Cheryl reported how her experience with a mental health worker transformed her and her family's life:

It took me three years to get the mental health issue resolved and to meet J [mental health worker] and ever since I've met J I haven't looked back. I try not to, [look back] but sometimes I do, but I try not to. J has been my anchor and I use him as my anchor, you've got to as a way to uplift your family.

Participants believed that there was a lack of recognition by both society and mental health workers of their care-giving role. The failure to recognise the role of caregiver as a partner in the treatment and care process is both disrespectful and in the long term could have negative outcomes for the person living with a serious mental illness (Hodgson, King and Leggatt 2002). Recognition of care-givers will only be achieved if we have a committed action to change the current situation, for the mental health system continues to pursue the path of individualisation regardless of its failures, as Hopper states, '[a] battered system keeps chugging along, secure in its "institutional bad faith" riddled with tensions and antagonisms that work against collective action, and propped up by the secret ministry of its own reluctant agents'. It will be challenging work to change the 'battered system', for '[f]iguring out what to

do next will not be easy. Madness can be unruly, disconcerting, and recalcitrant' (Hopper 2006, p. 223).

The participants in this study, I believe, were and are committed to their care-giving responsibilities and to finding solutions. However, the question needs to be asked: are mental health care professionals similarly committed?

9.3 *Voices of resistance: Awakening critical consciousness*

The politics of care-giving

The need to situate care-giving in a political context should be a priority for governments and their citizens. Care-giving is a political issue and as such it should be linked into the political framework. Citizens are in a democratic political system in which 'the content and meaning of "care" and "justice" are continually under discussion, particularly in the context of the restructuring of the welfare state and the revision of the legal system'. (Sevenhuijsen 1998, p. 4) Indigenous Australians are disadvantaged in this political system mainly because of their minority status. Indigenous Australians' cultural values are also disregarded and often treated with disdain (Altman and Hinkson 2007). Indeed, Eurocentric values that exist in Australia privilege and respect individualism, autonomy and self-sufficiency and as a consequence those in need of support in the form of welfare are not valued in this society. Recipients of welfare or care-giving have limited options, '[i]t's classic Hobson's choice: one can accept the aid and swallow the humiliation, or one can relinquish the aid but salvage self-regard in the bargain (Hopper 2006, p. 219). Care-giving is a natural activity, although it is often performed in extraordinary situations, and surprisingly, care-givers were often nonchalant about their role. Ellen, a care-giver for her grand-daughter Andrea, as well as a foster mother and mother, was unflustered in speaking about her role as a care-giver,

You have to have strength otherwise, you know, it doesn't matter; like every day of our life, every hour, you've got to believe that. It doesn't matter whatever you do you've got to believe you're going to come through, and that it will be okay.

It is an unfortunate reality that when care-giving is critiqued through the lens of critical theory it often reveals the stark inequalities of power and privilege. In Western societies it is the disenfranchised, women and the poor who are disproportionately represented as primary care-givers (Jaggar 1995). This situation was reflected in this research study as all of the care-givers in the study were women. Cathy described her experiences of being a sole parent and the primary

care-giver, '[w]hen you're a sole parent I think it's worse because you haven't got a partner to fall back on, who can share half the load so that you can go out and do something for yourself sort of thing. Your life in a way stops'.

What colour is resistance?

For Indigenous people resistance has been a constant theme since colonisation, though Indigenous resistance has not been recognised for what it is and the nuances of acts of resistance are not always acknowledged as such. Many of the participants described acts of passive resistance, which is often the preferred method of disenfranchised groups. In *Mission Girls*, Christine Choo (2001) explores the issue of resistance in the context of Indigenous women in the Kimberley region of Western Australia. Her use of the concept of resistance was influenced by James Scott's (1979) theoretical perspective on resistance. Choo (2001, p. 11) refers to the two types of transcripts proposed by Scott that can be applied to analyse the different forms of resistance. They are the 'public or official transcripts' which reflect 'respectable performance' and 'hidden transcripts' which are 'the rules of subversion or offstage responses and rejoinders to the public transcripts'.

Participants in this study were more inclined to acts that resembled 'hidden transcripts'. For example, Andrea recalled how, when she was hospitalised, she and other patients would deliberately be non-compliant in response to the authoritarian behaviour of hospital staff. Another example is Cheryl's husband Noel taking the action of walking out of a hospital meeting convened to discuss her long term care, leaving the meeting angry and disillusioned because medical staff wanted child protection authorities to become involved by having Cheryl and Noel's children removed from their care. A third example is that provided by Joan who told of how her son became increasingly angry and left mid-way through an assessment because of the psychiatrist's insensitivity, unprofessional and disrespectful manner. These actions provide examples of both passive and active resistance.

The medical profession is preoccupied with compliance and when there are instances of non-compliance with medical directives those who do not comply are at risk of being labelled deviant and ostracised (Roach Anleu 2005) Such was the situation with the Hmong family in the US state of California who resisted the western medical system and chose to treat their daughter with traditional Hmong methods. Because the medical professionals were unable to reconcile with this situation they blamed the parents for the child's condition and, rather than working

with the family, they chose to bully the family (Fadiman 1997). (Refer to Chapter 2 for a fuller discussion.)

Resistance took many shapes and forms for the participants of the research for this thesis. For some it entailed confronting practitioners in the mental health system, while for others, it was to offer a more passive response, for example, Sarah's refusal to accept a diagnosis of a serious mental illness. Confronting mental health practitioners is challenging, but Jenny noted that in her experience with a mental health worker she felt she had no choice, the mental health worker's comments in advising her to abandon her family were so outrageous she felt compelled to challenge his authority. As she said '[a]nyway I could but I wouldn't, I think he got a bit annoyed with me because I wouldn't do it'.

Handmaidens of control: collusion and fear

There is a long history of human rights abuses directed at those living with a serious mental illness (Foucault 1989; Roach Anleu 2005). From the 1770s people deemed to have a mental illness were held in 'asylums'. During this period psychiatrists were given increasing authority to detain people diagnosed with a mental illness in a 'mental hospital' or an asylum. Being detained in an 'asylum' was not always for medical reasons and psychiatrists often colluded with the State to punish non-conforming or problematic citizens. The rationale for separating the mentally ill from society was often social and economic, not medical, because of the inadequacy of government to address issues of poverty (Roach Anleu 2005).

The situation in 2008 still reflects the government's incapacity to deal with poverty, particularly since the decline of the welfare state in the 1970s, and the rise of neo-liberalism in Australia with the concomitant shift in focus to individual rights and minimal state intervention (Henderson 2005; Roach Anleu 2005). The increased relocation of state provision of welfare from the public to the private sector has meant that the poorest and most disenfranchised in society have suffered the most (Henderson 2005; Turner 2005). Governments now require health services to be market driven rather than based on a philosophy of public need. No longer is the design or delivery of services based on the diversity of need determined by issues of ethnicity and class (Henderson 2005). Citizens, it seems, can no longer expect public health services to provide for their needs. Participants reported how they felt constrained and disturbed by the economic factors that are often used to explain or excuse the lack of services. Jenny recounted a disturbing event in her encounter with a mental health nurse when the nurse advised her to abandon her child

because her situation was considered 'too difficult' by mental health services. While some of the advice given to Jenny might be correct, what is insidious and disturbing is that the worker used fear and collusion to make his point by telling Jenny she was unlikely to get support, and then offering to assist her if she were to take his advice and leave her family and her child who were in need of mental health support. This raises serious ethical questions about this professional's approach to service delivery.

Unfortunately, the provision of services is now being measured within and through the lens of the economic paradigm; the market is now seen as the final arbitrator in determining how services will be provided. As Henderson (2005, p. 243) states, 'to govern in the modern liberal state involves creating the appropriate political, legal and institutional environment for the operation and existence of the market'. The greater expectation for citizens to be responsible for all their health costs, including prevention and clinical needs, results in a huge burden being imposed directly onto the family and indirectly onto the community. It could be argued this approach is a form of systemic and invisible racism, because there is a direct link between ethnicity and ill-health, and poverty and ill-health. Those most affected by the neo-liberal reforms of the market-based health economy are the poorest and the disenfranchised, with Indigenous Australians being among the poorest and most disenfranchised in Australia (Council of Australian Governments 2003).

Provocations

'Provocations' in the context of this study refers to the mores and values that underpin Western society, and in particular where those values are imposed onto individuals and groups who are not necessarily part of the dominant group. Kim Hopper, a research scientist at Columbia University, provides an excellent example of provocation in the context of health and welfare in the United States by describing an instance of a homeless woman and her struggle against the state. This woman, who had been homeless over many years, had been denied assistance from the State, but in the final weeks of her life, and still homeless, the state wanted to remove her from the streets because she was in need of urgent medical attention, but she was resolutely refusing their efforts to move her off the streets. The story has an unhappy ending, for the woman died homeless and still living on the streets. In the final days of her life the state had been forced into an embarrassing position of having to get the court to issue an order which would have allowed workers to forcibly remove her from the street. The aftermath of her death is interesting for her defiance to the State drew a range of responses. Her death was reported in the

media as stupid and irresponsible; it was reported that her refusal of help 'was suspect because she didn't have her wits about her' (Hopper 2006, p. 219). Another view is that perhaps her refusing assistance from the State was her final act of resistance.

Homelessness and ill-health are difficult issues in which to find resolution. For the workers engaged in the struggle on the street, homelessness is a matter of social justice. For them the focus was to ensure that the woman received the care she needed; for them the ends justified the means. For the woman, the State had contributed to her situation of poverty and she was then being forced into a situation, so she resisted. The State, through the workers, was persistent in intervening in the woman's life without her consent. The struggle ended with the woman persisting with her belief in her own freedom to have the right to choose, and in her final act of resistance, refusing the State's support. It is hard to comprehend that perhaps the act of provocation occurs more often than we like to acknowledge, the State with all their good intentions intervenes into people's life without their consent (Hopper 2006).

I believe that most mental health intervention is often based on similar principles that could be construed as acts of provocations like the situation of the homeless woman in the United States. In this study, participants were confronted with a mental health system concerned more with outcomes than with good process. For example, the experience of Joan, and of the unexpected and unannounced arrival of the police and mental health practitioners to forcibly remove him to hospital, is an example of an extreme act of provocation, as the situation could have ended tragically. Did Joan's son have a choice? No, because it was determined by the authorities that this action was for his own good. For Jenny it was being told by a mental health nurse to take her daughter and run away from her family (two of Jenny's sons had a serious mental health condition) because the system would or could not respond to her needs. This is another example of a mental health system that is bound up so tightly in its bureaucracy that it is now so inflexible and constrained that it has become almost irrelevant to families. The example of Cathy who challenged the competency of mental health workers, as they continued to ignore her pleas regardless of the impending crisis also illustrates this point. The mental health system is abound with stories of neglect and inattention, yet they and other bureaucracies endeavour to rationalise and justify, often by blaming the patients and their families for the failures of the system, with the message that it is their fault that they are not getting the service that they need.

The system is layered with these contradictions, and as I have already discussed, there are always conditions attached to the provision of services. Compliance to these conditions is necessary if one is to receive support and care. Care-giving is more than just a one-dimensional activity, it is multi-dimensional, relational and interdependent, and so there is an important distinction that needs to be made between the public and private spheres of life (Tronto 1993).

An act of provocation becomes even more significant when race is a factor. Indigenous Australians understand the notion of an act of provocation. As a community, Indigenous Australians experience racism at higher levels than non-Indigenous Australians. Living in a country that does not recognise or value Indigenous culture and history is the supreme act of provocation.

9.4 Confronting racism: Awakening voices

The difficulties in measuring racism are challenging because racism is not always overt and can be layered with other forms of oppression; and these cumulative effects can have long term health consequences (Larson et al 2007). Racism is both corrosive and endemic within western societies (Weis and Fine 2004). In Australia, racism or racial exclusion has been central to the structure of society. As Lake and Reynolds (2008, p. 352) state, 'Australia had pioneered the vision of a white men's country and was one of the most reluctant to change'. Australian society has been based on the notion of White superiority. In the 1950s when the United Nations was arguing for the dismantling of global racist policy, Australia dissented because the White Australia policy was considered sacrosanct and 'it was considered "un-Australian" to question the White Australia Policy. It was a key part of Australia's heritage' (Lake and Reynolds 2008, p. 352-53). Cultural racism was enshrined as part of the Australian fabric in the 1950s, and its remnants can still be detected, therefore it is critical that racism be challenged wherever it appears.

The implications of stigma and discrimination for caregivers

Indigenous Australians experience stigma and discrimination that has consequences for their health, often on a daily basis (Larson et al 2007; Paradies, Harris and Anderson 2008). Health systems, like other systems, reflect the values of society, and institutionalised stigma and discrimination is intricately linked to power. The issues of stigma and discrimination confronting Aboriginal families living with a serious mental illness are similar but also distinct from, those experienced by non-Aboriginal people. The distinction must be clearly made. It is clear that the stress of stigma and discrimination can result in poor health outcomes (Stuber, Meyer and

Link 2008) and that people living with mental illness experience stigmatisation and discrimination (Thornicroft et al 2009; Schulze 2009; Hocking 2003; Thompson, Jeffrey and Campbell 2005; Corrigan and Penn 1999). A global study on stigma and discrimination showed that 'by comparison with other [health] disorders, mental illness are typically more stigmatised, and this has been called the ultimate stigma' (Thornicroft et al 2009, p. 408). In addition, it has been recognised that culture plays a role in the understanding of mental illness. Bass et al (2007, p.918) state 'The recognition of the effect of culture on the understanding of mental illness cannot be an after-the-fact consideration'.

The global study on stigma and discrimination identified two main areas where stigma was either experienced or anticipated: work and personal relationships (Thornicroft et al 2009). Globally Indigenous people experience poverty and poor health due to oppression and dispossession, both of which affect work and relational opportunities (Stephens et al 2005) and, for Indigenous Australians marginalisation causes under-representation in the workforce. Stephens et al state (2005, p.11) 'The health of an adult is similarly poor, particularly for communities whose original way of life, environment, and livelihoods have been destroyed and often replaced with the worst of western lifestyle – i.e., unemployment, poor housing, alcoholism, and drug use'. An Indigenous person living with a serious mental illness will often experience dual discrimination on the basis of both identities: Aboriginality and having a mental illness. This experience of dual discrimination can have a compounding effect in terms of the stress placed on the family, the person living with a mental illness and the caregiver.

The politics of silencing

Silencing can have a profound influence on a person's place in society. It signifies a 'terror of words, a fear of talk' (Fine 1991, p. 32). Silencing is an insidious process; it has cultural, social and political implications. When we interrogate silence it is critical to consider, firstly, who is being protected by the silencing, secondly, the frameworks in society that formalise and legitimise silencing, and third, how silencing certain voices can further undermine the voices of communities (Fine 1991). Silencing is intrusive and corrosive to what Fine calls the 'reification of single truths'. This involves the separation of the community into those who 'know' and those who 'do not know'. This is a strategy used by those in power to raise doubts over authority of the less powerful, which in the long term only reinforces the position of the privileged and powerful.

There is a form of 'systemic silencing' which to Fine (1991, p. 33 citing Cummins 1986) is about 'who can speak, what can and cannot be spoken, and whose discourse must be controlled'. This type of silencing occurs at all levels of bureaucracy to ensure that there is no interrogation of the system in terms of discrimination in the critical areas of race, gender, sexuality and class. Silencing by mental health providers is systemic as there is collusion within and across systems, beginning with the administrators. The outcome is that individuals, families and the wider community are continually compromised in their quest for a fairer and more equitable health system. While many state controlled social programs are being privatised in the name of a free market economy, for too long, policy and practice have been separated. Therefore it is critical that there is social research that interrogates health systems in order to highlight instances of social injustices, racism, and inequitable service provision.

Racism exists within the context of silencing. Racism persists because

people with 'white skin privilege' benefit from a system that accords them more opportunity. But people who are the beneficiaries of white skin privilege need not recognize that privilege, and by not thinking of the needs of people of color, they may ignore the existence of white skin privilege (Tronto 1993, p. 121).

Oppression and mental illness

Societal and institutional forms of oppression deny Aboriginal people access to resources and services that would help them succeed; this means increased vulnerability to poor mental health. Difficulty in accessing resources and services can prevent and/or assist people to recover from mental illness. This study explored how oppression impacts on the health and wellbeing of caregivers by,

1. Identifying the sources of oppression at the social level that create barriers for Aboriginal caregivers and care-recipients in accessing mental health services.
2. Identifying the barriers at the institutional level for Aboriginal caregivers and care-recipients in accessing mental health services.
3. Identifying how Aboriginal caregivers and care-recipients experience oppression in accessing mental health services.

Everyday Racism: Rationale for including racism in the study

Everyday racism is a common experience for Indigenous Australians (Larson et al 2007; Paradies 2006a, 2006c; Paradies, Harris and Anderson 2008; Paradies and

Williams 2008). Self-reported experiences of discrimination and racism are the most common form of measuring the impact of racism on the health and well being of racial and minority groups (Williams, Neighbours and Jackson 2003). Although the self-report method is important and useful, some caution should be taken as context should also be taken into consideration (Guerin 2005).

Originally the focus of the thesis was to explore the issue of care-giving for a specific racial group (Aboriginal people). The case studies examined respondents' experiences of being Aboriginal, care-giving or receiving, living with a serious mental illness and interacting with mainstream mental health services over time. Racism emerged as a strong and central part of Aboriginal participants' experience. After the first round of interviews a fourth research question was included that specifically related to racism and was stated as:

What are the wider socio-political implications, in particular, how racism affects the lives of Indigenous people living with a serious mental illness in the context of mental health and care-giving?

A specific question: *What does it mean in this society to be Aboriginal and to have a serious mental illness?* was added to the second interview on the basis of the data that emerged from the first interviews. Thus, while the first round of investigation did not ask specific questions about racism, the second round of investigation followed this issue more deeply because it had emerged from the initial data as a defining theme. Racism may have emerged as a primary theme because of the lack of Aboriginal community controlled mental health services in Western Australia. Racism emerged explicitly within the discourses of the participants' experience and this may be because experiences were determined by services provided by the mainstream public health sector.

Institutionalised levels of racism

Camera Jones, a health researcher and lecturer, has offered a framework for understanding racism. She states that racism is found at three levels, institutionalised, personally mediated and internalised. Jones describes institutionalised racism as endemic, and more insidious because it is structural and therefore has 'been codified in our institutions of custom, practice, and law' (2000, p.1212).

Applying Jones' theory for classifying racism, medicine has failed spectacularly, both at the institutional level (Cunningham 2002; Hall et al 2004; Coory and Walsh 2005; Larson et al 2007;), and at the personal level (Krieger 1993, 2003; Williams 1999; Williams, Neighbours and Jackson 2003; Paradies, Harris and Anderson, 2008;

Bhopal 1998; Jones 2000; Harris et al 2006; Snowden 2003). Researchers have argued that medicine as a discipline has for too long ignored the empirical evidence related to the impact of racism on health outcomes (Bhopal 1998; Krieger 1993, 2003; Williams 1999; Williams, Neighbours and Jackson 2003). The combination of the structural nature of the medical discipline, and the discipline's bias for relying solely on biology for a diagnosis has resulted 'in the failure by clinicians to adequately investigate disease and treat people from certain ethnic groups' (Crampton et al 2003, p.596).

Peter Crampton and his colleagues reviewed a program that sought to reduce the impact of institutional racism on Indigenous groups in New Zealand. They reviewed a cultural safety initiative with the explicit stated program aim: 'to minimize any assault on the patient's cultural identity' which had been embedded in the University of Otago's medical curricula for four years; (2003, p. 595). The purpose of the cultural immersion program was to foster and analyse individual response to racism. The authors discuss the benefits of this program which immerses third year medical students in the culture and language of the Maori. According to Crampton et al (2003, p.596) the program 'is an effective means of learning about oneself and about another culture'. The aim of the program is twofold, first, to raise awareness and change behavior of a future medical practitioner, and second, to change the system from within by transforming the culture of medicine.

The model proposed by Jones shows that there is an inherent relationship between the three levels of racism. She claims that institutionalised racism is the most damaging because it is both embedded within and perpetuates the historical lie of racial superiority; because it bases its rewards and bestows privileges based on race, it promotes biological determinism and finally it encourages the misuse of power to oppress and marginalise (Jones 2000). According to Jones, 'once institutionalized racism is addressed, the other levels of racism may cure themselves over time' (2000, p.1214).

Interpersonal levels of racism

With the increased number of studies detailing self-reported experiences of racism there is now clear evidence linking racism with poor health outcomes (Krieger 1993, 2003; Williams 1999; Williams, Neighbours and Jackson 2003; Bhopal 1998; Jones 2000; Harris et al 2006; Snowden 2003; Paradies 2006a; Paradies, Harris and Anderson 2008). The link between racism and poor health outcomes, as well as

social and economic disadvantage, is what Essed termed 'everyday racism' (1991).

Jones (2000, p.1213) describes personally mediated racism as:

a lack of respect, (poor or no service, failure to communicate options), suspicion, (shopkeepers' vigilance; everyday avoidance, including street crossing, purse clutching, and standing when there are empty seats on public transport), devaluation (surprise at competence, stifling of aspirations) scapegoating ...and dehumanization (police brutality, sterilization abuse, hate crimes)'.

Internalised racism described by Jones is an 'acceptance by members of the stigmatized races of negative messages about their own abilities and intrinsic worth' (2000, p.1213). It is characterised by a lack of self-belief, acceptance of a limited future for themselves and their family, rejection of their culture and race, and a sense of hopelessness and powerlessness in their life (Jones 2000).

Personally mediated levels of racism: An analysis of participants' experiences of the multiplicative effects of stigma, discrimination and racism

The participants in the study experienced multiplicative effects of stigma, discrimination and racism. A useful framework for analysis of the everyday racism proposed by Feagin (1991) and Hein (2000) is that of avoidance, rejection, verbal harassment, physical harassment and physical threats. An Aboriginal family living with a serious mental illness will experience stigma and discrimination because of the mental illness. These effects will be amplified by the stigma and discrimination of racism which adds another layer of stress. This reality needs to be considered in any analysis of care-giving and mental illness for Indigenous people. Yin Paradies' provides a definition of racism:

Racism can be thought of as one of many types of oppression which, along with its dialectical opposite privilege, can be based on a range of social characteristics including gender (sexism), sexuality (heterosexism), physical and mental able-ness (ableism), age (ageism), class (classism), nationality, body size/shape, criminality, religion, and language/ accent among others (2006c, p. 144).

A specific finding in this study was that caregivers reported that much of their stress came from the multiple demands of existing within family and community relational systems which had experienced, and were experiencing, multiple race-related trauma in an ongoing manner. Participants described this context as giving a distinct shape to their experience of their family member having a mental illness. In turn, the impact of contextual, race-related trauma, affected their experience as caregivers

and they described this as making their experience distinct from non-Aboriginal people giving care to their family members.

Caregivers were generally confident in their capacity to care for their family member. They felt it was the conflicting demands placed on them by mainstream services because they were an Aboriginal community and family member which impacted on their care-giving capacity. Insensitive and sometimes calloused health service responses undermined their care-giving capacity. Responsive services and health professionals were central to their sense they could be successful in caring for their loved one. Having their requests misinterpreted or their service access blocked on the basis of prejudice and racial misconceptions was described by caregivers as a core and central theme of their care-giving experience.

When the participants spoke about their experiences of racism their body language would change and sometimes they would literally shake with fury as they recounted their experiences. While some participants lacked sophistication when they tried to articulate their responses, their experience of oppression was clearly relayed in the distress which emerged when talking about their experiences of personal racism. The emotional distress of participants must be included as part of the data validating their experience as Aboriginal caregivers.

In the second interview several of the participants recounted their experiences of racism in their interactions with society and with the mental health system. For example, when Andrea (a participant) who has a serious mental illness was asked what it was like to be Aboriginal and have a mental illness, she was particularly animated and forthcoming. When asked the specific question on her experiences of racism, she changed completely; she became fervent, angry and very passionate in her response.

I mean it's bad enough living with a mental illness but they look at you because you're Aboriginal anyway; you're getting the look and it's ten times worse if you've got a mental illness. I mean, people look at you like you're lower than low and you're not. It's not right! It's badder than being low but then you're lower than low. You can't win! I think it's really, really bad and I think really serious.

The view that Aboriginal people are 'bad' is an experience often shared among Aboriginal people. This was further amplified by the dual discrimination of mental illness. For Andrea : 'it's ten times worse if you're got a mental illness. I mean people look at you like you're lower than low'. The strong language used by Andrea to describe how she felt is an indication of the intensity of being under constant surveillance and being judged. In his study, *The Continuing Significance of Race*,

Feagin reported similar events from African American participants who described themselves 'as seen as shoplifters, as unclean, as disreputable poor' (1991, p.107).

Sarah (a participant) also described her experiences in equally graphic terms, 'I think people think that we, Aboriginal people with a serious mental illness, are all criminals to some degree'. The perception is that Aboriginal people with a mental illness commit crimes more than other people. Feagin reported a similar finding in his study; the constant stress for an African American of being viewed as a criminal, as one of the respondents in his study commented:

being black in America is that you have to spend so much time thinking about stuff that most white people just don't even have to think about. I worry when I get pull over by a cop...I worry when I walk into a store that someone's going think that I'm in there shoplifting (1991, p.114).

The above comments demonstrate what Feagin calls 'the pyramiding character of discrimination' (1991, p114). Even though the experiences of racism described by Feagin occurred in another time period and in another country, what both Andrea and Sarah describe in graphic terms is similar and constitute the common multiplicative effect of experiencing both the stigma and discrimination of living with mental illness being compounded by racism. It is what Essed (1991) referred to as 'everyday racism'.

Many of the participants in this study experienced what Jones refers to as personally mediated racism – that of a lack of respect. Andrea felt that being Aboriginal she was constantly under suspicion, having to deal with shopkeepers' vigilance and everyday avoidance, which made her feel bad, in her words 'getting the look and it's ten times worse if you've got a mental illness'. Andrea recounted her experiences of racism in 'everyday life' in society and with the multiplicative effects of stigma, discrimination and racism. She spoke about how people living with a serious mental illness continue to suffer alienation in the general community, of an experience of people being afraid of her and of being treated differently: 'They would treat me different, a lot different, and I would feel it...I kept thinking that they thought I was a threat to them'. Andrea's experience concurs with Jones' (2000) description of suspicion as part of the experiences of personally mediated racism. Suspicion includes increased vigilance by shopkeepers as well as everyday avoidance by members of the public. Andrea's experience of being treated differently was traumatic and she described it as inflicting hurt.

Joan, (a participant) whose son needed hospitalisation for his first episode of a mental illness, experienced the pyramiding effects of discrimination and racism.

Their treatment at the hospital by the psychiatrist was an example of what Jones described as personally mediated racism, which 'can be intentional as well as unintentional, and includes acts of commission as well as acts of omission' (2000 p.1213). Jones states personally mediated racism 'manifests as lack of respect (poor or no service, failure to communicate options)' (2000, p.1213).

The experience of Joan and her family at the hospital and with the psychiatrist was a display of personally mediated racism. Even though the psychiatrist's actions could be construed as unintentional, they constituted both an act of commission as well as of omission. Firstly, answering her phone, and then leaving the family telling them she would be gone for only ten minutes, was a mistake. The family were already quite stressed and anxious; the fact that the psychiatrist was absent for longer than ten minutes further exacerbated an already tense situation. Joan's son had arrived at the hospital in an agitated state and to have the assessment interrupted further agitated him. The psychiatrist showed a lack of respect to the family, and this was an omission of her duty of care. The impact of this action has to be added to, and considered within, the family's everyday experiences of being disrespected and ignored.

Her second act, one of commission, occurred when, despite the fact that she had caused some of the agitation, the psychiatrist organised for the psychiatric emergency team to go to the family home to bring Joan's son into the hospital. She did this without either informing or discussing with the family her decision. Again she displayed a lack of respect. The family were angry that the psychiatrist had not discussed her decision with them. The family blamed the psychiatrist for the events at the hospital and later for events that happened at their home. The little regard the psychiatrist had shown for the family demonstrates a clear example of personally mediated racism, as defined by Jones, of poor service and a failure to communicate options (2000). Again, the impact of this act is exacerbated by the family's ongoing and everyday experiences of unsolicited hostility from others on the basis of race.

The psychiatrist's other act of commission was to involve the police. The family were distressed that the hospital had not told them that the police would be accompanying the mental health nurses and were particularly distressed by police involvement (with all of the implications of criminality) arising from their attempt to seek health services for their son. They had no prior knowledge that the police would arrive which further added to the traumatising impact. Jones includes dehumanisation (including multiple experiences of unnecessary police intervention or of police brutality), as part of the personally mediated racism individuals can

experience (2000). Feagin includes physical threats and harassment by police officers as part of his five categories of discrimination against African Americans (1991). It is common knowledge that Aboriginal Australians have had and continue to have, a fractious and difficult relationship with the police force as a body. In Australia there have been some high profile cases of police brutality against Indigenous Australians (Hooper 2009), some of which are still unresolved. It can be stated unequivocally that relationships between Aboriginal people and police are often difficult and fraught. The psychiatrist had committed two acts of personally mediated racism in the decision to involve the police. Firstly, through commission by authorising the police to accompany the mental health nurses to bring Joan's son into hospital, and second, through omission by not informing the family that the police would be involved in going to their home to assist the nurses in bringing Joan's son into hospital. The family were traumatised by this experience which could have been avoided at the hospital if the psychiatrist had been respectful in her approach to the patient and his family.

Institutionalised levels of racism: An analysis of participants experiences of the multiplicative effects of stigma, discrimination and racism

There were number of examples of institutionalised racism as defined by Jones that were experienced by participants. One was the example of Jenny (a participant) who tried to access support for her son from the mainstream mental health system and was told by a male mental health nurse that the service could not, or would not, provide her with any support for her son, even though he was eligible, 'because the system viewed his situation as being too difficult'. Institutionalised racism is evident in this situation as 'institutionalized racism is often evident as inaction in the face of need' (Jones, 2000, p.1212). Power and access to society's privileges are often inherently assumed in cases of institutionalised racism. Institutionalised racism can be played out in relationships, where one person in need of services accesses another, who has the institutional power to help, but is rejected on the basis of race. As Paradies states 'The intertwined concept of privilege/oppression can be defined as: A societal system in which actors are divided along socially constructed dimensions with power unevenly' (2006c, p. 144).

To add to the insult the worker offered Jenny a trailer in a remote location and recommended that she abandon her son. The experience between the worker and Jenny could also have been partially on the basis of classism for Aboriginal women are statistically more likely to be lower socio-economic status (Australian Bureau of

Statistics and Australian Institute of Health, 2008), and therefore more likely to experience multiple discriminations. Jenny is a sole parent and because of her lower socioeconomic status, she is in a more powerless social position in relation to the worker. Jones notes 'it is because of institutionalized racism that there is an association between socioeconomic status and race' (2000, p.1212).

The attitude expressed by the worker included attributes of stigma, discrimination and racism. Two issues of concern are, first, because of their privileged employment and systemic position the worker felt that they had the right to determine how Jenny should be a parent. Second, because Jenny was female, the male worker may have assumed the position of power privileged to him because of his gender. He adopted the familiar role of the dominant male, a position legitimised in western society, in directing her personal choices rather than providing systemic support for the mental health issue faced by her son. Most western societies have structures that support institutionalised racism (Jones 2000) and patriarchy because of the power and privilege ascribed to White people. What is disturbing is the lack of accountability within western institutions that allows such behaviour to occur. This worker was employed in a powerful position and in a powerful institution. As a White male he used positional power in telling a black woman that she should leave her children. For Jenny her experience with the male mental health worker and the system was a microcosm of the multiplicative effects of stigma, discrimination and racism.

Jenny's son is Aboriginal and has a mental illness, she approached a mental health service for assistance, and her plea for formal help was rejected. Jenny was advised to leave her son and drive away from her responsibility. Was there an assumption that because the caregiver was a sole parent, Indigenous and on a limited income that the health worker judged that the support he was providing was appropriate even if not related to his professional role? Would someone who was a White, employed male be offered this type of advice if they asked for assistance for a family member with mental illness?

The support offered to her as a caregiver was with the following advice: 'you're in the too hard basket for most places... you are going to be given the run around and I think this was the reason why he said you may as well pack your things and go.' Jenny experienced this advice as racist, directed to her as an Aboriginal caregiver. Jenny believed she was given this advice because she and her son were Aboriginal and because of the serious nature of his mental illness – a dual discrimination. If in defining someone as 'too difficult' the system acknowledges it cannot respond

effectively to serious mental illness, then how equipped is the system to respond to the dual discrimination of Aboriginality and mental illness?

Sarah's (a participant) negative experience with a mental health practitioner highlights the practice of silencing:

The thing that she said to me was so upsetting that I just couldn't believe that she was a psychologist or psychiatrist...[t]he way she spoke to me was like she really put me down. Like she said to me if I was a good girl then I...I can remember the sort of words she used. She said, 'If you be a good girl then you might get your kids back'.

Sarah's explanation of what she felt it was like to be Indigenous and to have a serious mental illness highlights the invisibility of privilege and discrimination,

I think people think that we, Aboriginal people with a serious mental illness, are all criminals to some degree. The perception is that Aboriginal people with a mental illness commit crimes more than other people'.

Indeed, the masking of the true beneficiaries of social systems is skilful, because disadvantage is often labelled as a failure to integrate into the system, thereby cleverly shifting the blame away from the system and onto the person. As Fine (1997, p. 60) states, the real social differences have been 'converted into an institutional story of gendered/racial success and failure'.

Systemic racism is a conscious process for it is reflected in the concept of 'privileged irresponsibility', whereby, because of race, people are denied their rights to care (Jones 1997). Even though it is difficult to quantify an incident as a form of systemic racism (Paradies, Harris and Anderson 2008), there were several examples where the participants believed they were disadvantaged because they were Indigenous. A good example is that of Jenny's experience of the mental health worker refusing to assist with the excuse that her situation was deemed to difficult—would she have been treated differently if she was non-Indigenous? Joan's son's experience with the psychiatrist in his initial assessment—would this have happened if the family was not Indigenous? And Sarah's experience with a psychologist telling her to be a good girl and she might get her kids back—is this a form of racism in which Sarah is treated like a child or infantilised? It is difficult to categorically state that these were forms of systemic racism, but one could ask: Would the same response been directed to them if they were not Indigenous?

The capacity to wield power is the difference between prejudice and racism. The prospect of being able to exert influence and control over the type and construction

of systems and their structures in society authorises the creation and continuation of a racial social order (Jones 1997).

Cheryl described her disbelief at the actions of the hospital where she was an inpatient, when 'they wanted to bring the welfare in, brother...to take my kids. My husband walked out of the meeting'. For Cheryl and her family, a shift in the power relationship between them and the hospital occurred with the arrival in their lives of a support worker. The presence of the support worker provided the space for a shift in consciousness, both in the system and in the family. The worker was able to gain the trust and respect of the family, and as a result was able to work more effectively with and for them. This is an important point in the work of raising critical consciousness as families dealing with a serious mental illness in one of their members need allies in working with the mental health system.

There has been limited research about the impact of racism and care-giving in Australia in the context of mental illness (Paradies, Harris and Anderson 2008). Care-giving for people living with a serious mental illness can be affected by a range of factors, including significant levels of perceived support from mental health professionals and from caregivers' own informal social networks.

The presence of a professional with knowledge of the system can be extremely valuable resource when working in cross-cultural settings. For example, as I have already mentioned earlier in Chapter Two, the example given by Fadiman (1997) of the Hmong family, with their sick daughter and with limited communication skills, who were extremely vulnerable in a health system that had no knowledge of Hmong culture and which was based on Eurocentric values and philosophies. The presence of a social worker who was an ally for the family and who was also a part of the dominant cultural group, was an invaluable resource. She provided excellent support, in particular, in translating the needs and desires of the family to healthcare professionals. Importantly, this social worker had a strong commitment to social justice and human rights that extended beyond the role of just being a support person, and as consequence she both argued and supported their issues passionately (Fadiman 1997; Hopper 2006). The bond that existed between the family and the social worker was powerful. Upon hearing of the sudden and unexpected death of the trusted worker, Foua, the Hmong mother, was grief stricken:

When I heard Jenny was dead, my heart broke, I cried because Jenny had told me she wasn't going to get married and she would never have children of her own, so she would help me raise my children. But she died, so she

couldn't do that, and I felt that I had lost my American daughter (Fadiman 1997, p. 252).

Professionals are often advised not to get too involved with families; indeed, they are often advised to maintain 'professional distance'. However, there is a fine line that workers negotiate when working with the vulnerable, the disenfranchised and the poor. There are different expectations of paid support work, as opposed to unpaid or voluntary work because

[an] unpaid, uncoerced *gesture* is the culturally sanctioned vehicle for communicating genuine acceptance, the crude simulacra 'delivered' under the auspices of 'community support teams' (or even by skilled outreach workers) are bound to feel forced and artificial (Hopper 2006, p. 220).

Hopper makes a critical point here because service providers are caught in a bind – if they present as too empathic and non-judgmental they can be accused of not being professional. There is also the expectation among many professionals that those receiving professional care and support should be grateful. In addition, those receiving care and support are expected to do so without complaint and with gratitude, which, according to Farmer (cited by Hopper 2006, p. 220), is a form of 'conditioned silence'.

Personally mediated levels of racism: Eugenics and cultural racism

The potential for cultural racism is always present within cross-cultural interactions. The combination of privilege, power and ethnocentrism in a society influenced by Eurocentric principles usually results in practices and values that serve the interests of the dominant group. Unless there are mitigating practices to reduce the influence of the combination of privilege, power and ethnocentrism, then Indigenous people will continue to be subjected to policies and practices that are racist (Altman and Hinkson 2007).

Cheryl recounted her experience with hospital staff using graphic language: 'They don't look at us as a figure [but] as monkeys that's how they [the staff] look at us'. Her description of Indigenous people as being seen as less than human is an accurate description, not only of her own experience but of the historical notions of White supremacy. Cornel West, an Afro-American scholar, and a Professor at Princeton University, talks about the eugenic notions of hybridisation and racial inferiority: 'When he [Linnaeus in the 1750's] first acknowledged that hybridization of species occurs, he chose black people and apes as the probable candidates, while restricting such unions to black women and male apes' (1999, p.78).

The theory of White supremacy was the ultimate prize for his successor Georges Louis Leclerc de Buffon in his book *Natural History of Man* (1778). According to West (1999) White was the true and normal colour for humans, and black was an anomaly. For Aboriginal people in Western Australia it is common knowledge that in the early 1900's Aboriginal people were identified under the Department responsible for Fauna and Fisheries – a clear demarcation that they were seen as primitive and less than human. Indigenous Australians still hold within their collective consciousness the negative stereotype of their culture and of them being seen as *less than human* which is unfortunately still believed in pockets of White Australia.

Taken in this context Cheryl's tale of 'being seen as a monkey' is not only a personal experience of being treated as sub-human but also an accurate reflection of Indigenous peoples' historical and intellectual experience of racism. Racism remains a taboo topic in Australia, rarely acknowledged or discussed. Policy can address institutional racism but may be less effective in addressing individual and cultural racism when operating in a mainstream context, where workers are required to multitask and work across a variety of domains and policy imperatives. The experiences of care-giving, when viewed through the lens of race, are different. Racism was discussed throughout the data analysis and literature as it was consistent theme that emerged from all of the participant narratives. The experiences of Indigenous caregivers are different from non-Indigenous caregivers because of their ethnicity.

9.5 Standing tall: The morality of care-giving

The ideology of care-giving

The ideology of neo-liberalism that centres around individualism and universalism offers no real solutions but benefits the privileged and powerful and encourages indifference and inattention to the needs of the most vulnerable in society (Tronto 1993). (Refer to Chapter 4 for a fuller discussion). In the neo-liberal worldview, to be needy is to be weak, and in the new world order of neo-liberalism, weakness is a sin and a wasteful indulgent exercise (Giroux 2008). A more insidious element of neo-liberalism is that power and privilege can be used to support the ideology of inequality (Tronto 1993).

The rise of neo-liberalism in Australia in recent years has had a major influence of the delivery of health services (Turner 1997, 2005). In particular the concept of universalism in the delivery of mental health services has become more the norm with the introduction of a market based approach; an approach that implies 'one size

fits all'. Universalism is ironically linked to individualism as both are associated with the ideology of neo-liberalism. The neo-liberal view of promoting individualism as a means for liberation should not be confused with the concept of individualism in the provision of services, as the neo-liberal approach to individualism predominantly benefits the privileged and powerful (Giroux 2008; Grande 2008). Individualism as concept proposed by neo-liberalism asserts that it releases the individual, 'from the traditional constraints and provides the basis for the development of new forms of sociality, in which autonomy, linked to the rights to be an individual, is achieved and recognized through social relations' (Fine 2005, p. 254).

Individualism in the context of provision of care-giving is, I believe, a more preferred and appropriate option, than the universal approach of 'one size fits all', as it accommodates the issue of diversity and the recognition of the unique needs that exists because of culture, ethnicity and class. For example, in providing a service for care-giving constructed around personal needs fits with the philosophy of the community collective as it applies to Indigenous people, the poor and the marginalised. The universalistic approach to service provision is problematic, particularly for Indigenous people, because it does not recognise the diversity of need in regards to service provision because of cultural issues.

Unfortunately, health services have adopted the universalistic approach to service provision, which has been problematic for Indigenous people. The unintended implications for Indigenous people of the universal approach offered by mainstream health services has been the low participation of Indigenous people accessing mainstream services because of their cultural inappropriateness. Cheryl stated that because of her negative experience in hospital, she was distressed by not being able to speak with an Indigenous worker when she was a patient. This experience motivated her to successfully advocate with other Indigenous people in her community for the positions of Aboriginal Health workers to be employed at their local hospital, '[t]hrough our local Aboriginal women's group, there were 15 women, there were grannies, some men, mums and cousins we argued for and now have black faces at the hospital. We now have two Aboriginal workers working at the hospital'.

The principles of individual patient centred care models provide an excellent example of what is called a 'wraparound model of care' that is being practiced by some of the not-for-profit agencies working in the mental health sector in Perth. Unfortunately, 'wraparound model of care' is not being practiced in the public mental

health system in the way intended: as a meaningful partnership between practitioners, patients and their families. The Aboriginal Community support Service was crucial in providing families with education and support so they could participate and make informed decisions on their mental health care. Since its demise there has been no specific service for Indigenous families living with a serious mental illness. The future for mental health services for Indigenous people and their families in Western Australia is still undecided. It is hopeful that with the recent formation of an Aboriginal mental health policy unit within the Health Department the situation may improve the services for the mental health needs of Indigenous people.

Given that care-giving is so critical in people's lives and it is curious that it has been so marginalised, both politically and culturally. Tronto (1995) believes that a major contributing factor could be that the most powerful in our societies have undervalued, and continue to undervalue, the importance of care-giving and its contribution to the stability of society. Many of the participants experienced firsthand the insensitivity by mental health workers to their issues of care-giving, as Jenny noted on her efforts to get support for her and her son:

I am desperate for some support because he won't leave the house. I am having trouble with him leaving the house, I need someone to come to my home and do an assessment but the hospital will not visit you in your home. You have to go to them...his major problem is leaving the house, getting out of the door. Because all these places say that you need to go to them it makes it impossible'.

Care-giving has only recently been acknowledged and given priority by social researchers and the policy makers (Henderson 2005). Care-giving is critical to human life, and as humans we will all need care at some stage of our life. Yet even though care-giving has had some acknowledgement to its importance to the stability of society, there is more to be done in regards to public policy of care-giving and Indigenous people living with a serious mental illness.

Risk and care-giving

Risk and care have their own unique set of issues; governments are increasingly concerned with the economic viability of care, irrespective of the knowledge of the benefits to society of care and care-givers. The importance of care-giving in society becomes more real when it becomes a personal experience, for care-giving is an activity that requires attention, dedication and commitment. As Sevenhuijsen (1998, p. 22) states that on a practical day to day basis, 'caring is a form of acting, and that the ethics of care – by the very nature of values and virtues such as attentiveness and responsiveness – is rooted in a mixture of caring about and taking care of'.

Participant Gina spoke of the importance of being present with the task of care-giving; '[d]on't leave them, well you can leave them but just be watchful. To be alert to certain things that might be happening in their life'.

There are always concerns with control and power, and in the context of care-giving it is a difficult and vexed issue. Care-giving as a day-to-day activity can encourage dependency, as care-recipient can relinquish their power of decision-making over to care-givers. There is unfortunately, always the risk of abuse and exploitation, so care-giving needs ongoing review, and society needs to be more proactive in ensuring that there is no mistreatment. The challenge for policy-makers and political leaders is to listen to the community and to respond to their needs on the issues of care-giving. Importantly, being prepared to recognise and acknowledge that care-giving is a culturally determined experience and that it requires partnership with communities for a better understanding of their issues.

The ethics of care-giving as a social practice

The debate for care-giving continues, particularly the concept of an ethics of care. An ethics of care is about the activity of care in the public sphere which, as Sevenhuijsen (1998, p. 15) states:

demonstrates the necessity of locating the ethics of care within notions of citizenship, if it is acquire a significant political meaning without being slotted into a concept of identity politics or a one-dimensional idea of interest promotion, or indeed a nostalgic return to harmony and consensus.

It is without question that care is an integral part of a person's life, it therefore necessary to include the principles of an ethics of care in any development of a theory on care. Importantly, any theory on care should not be exclusively linked to gender, but, as Tronto (1993, p. 125) states, '[i]f care is tied to the "naturalness" of women's caring, then it is either instinctive, or deeply social or cultural behaviour, and therefore not part of the realm of moral choice'. For this reason an ethics of care needs to be enshrined within a moral and political framework, for care-giving is influenced and shaped by the structures of power in society.

More importantly, care-giving should not be used to marginalise or disadvantage either those providing care or those receiving care, by treating them as 'other' or as 'different' or even 'deviant'. This is challenging for a society that does not link the concept of an ethics of care with moral qualities. The concept of an ethics of care is complex but it is necessary because moral qualities are important in the activity of care-giving.

Four critical elements essential to the activity of care-giving

There are four crucial elements, according to Tronto (1993), essential to the activity of care-giving – attentiveness, responsibility, competence and responsiveness. Attentiveness requires the ability to be caring and considerate of the needs of others because if one is not considerate to those who are being cared for then it is not possible to provide quality care-giving. As Tronto (1993, p. 127) describes it, '[a]ttentiveness, simply recognizing the needs of those around us, is a difficult task, and indeed, a moral achievement'. To be attentive the care-giver needs to put on hold their own aspirations and plans so that they can be present for others (Tronto 1993). Gina understood the importance of attentiveness as care-givers, as she noted of her role:

I need to be very watchful of noticing every move so as to keep an eye on her. To see, you know, what she was doing all the time was important. Of caring for somebody that you know is your child with a mental illness, as opposed to mental illness in the community because in the community you can go home from it'.

Responsibility is the second element of an ethics of care, in the Tronto model, and it is an essential component to the concept of an ethic of care. Importantly, responsibility should not be confused with obligation, as '[r]esponsibility is a term that is embedded in a set of implicit cultural practices, rather than in a set of formal rules or series of promises' (Tronto 1993, p. 131-32). Ultimately, responsibility to care is situational and almost always personal. Responsibilities range from being a parent in raising children to being a community member and looking after elders and in some societies of looking after the most vulnerable in our communities. Indeed, responsibility in the context of care-giving is embedded and influenced by culture, gender, class and family. The participants understood the importance of responsibility as care-givers, as Ellen noted, 'I suppose we have to have a lot of understanding and lots of love because you got to really care about what you're doing'.

The third element in the ethics of care is competence. There is often the misguided view that people are born with the attributes of competency, and that somehow it is a instinctive characteristic. This is a false assumption. Competence must be viewed in the entire context of care-giving, but first it must be assumed that attentiveness and responsibility are present. However, because of limited capacity in families due to stress and constraints of resources, this is not always possible. Mental health providers, as it has been already shown in this study, have often compromised their duty of care to the participants. For this reason the element of competence needs to

be included as an essential element in the activity of care-giving, for not to do so allows for the diminution of care-giving as an important activity in the stability of family and community.

There is unfortunately, too often a rush by those in more privileged or powerful positions to 'blame the victim'. For example, care-givers in this study reported how friends and community members were often critical to them for not being 'good responsible' parents because of the behaviour, due to their illness, of their family members. It was easier to blame the parents than to recognise the difficulties they confronted on a daily basis, due to living with someone with a serious mental illness. Linking responsibility to competence is complex but necessary for it provides another level of accountability to those charged with, 'taking care of' others. Tronto (1993, p. 134) states, '[e]specially in large bureaucracies, this type of "taking care of," with no real concern about outcome or end result, seems pervasive'. Too often, there is an escape clause for inaction or indeed, for the lack of accountability by service providers. Unfortunately, the reality is that there is often a more disengaged approach to health provision, as Fine (2005b, p. 259) states, significant down-sizing by service providers has another more insidious element, it 'mask(s) cost-cutting and serve(s) to shift blame for failure onto the client'. The advice given by a mental health nurse to participant Jenny to flee her situation without telling her anyone is tangible evidence of this disengagement.

The fourth element in an ethics of care is responsiveness to care-giving by the care-receiver. Being responsive to care by the care-receiver is an important issue in the ethics of care model as it entails not just being responsive to the standards set by society, or governments, or other interests, but principally refers to responsiveness to care by the recipient of care, a very important distinction. Participant Andrea who has a serious mental illness understood the importance of the efforts of care-givers, as she noted of her grandmother's support for her:

It was really scary for everyone. It was like they all stood down from it...and it took for Nana to stand up and say, 'No now is time that we stand together so who's going to stand with me'. It took a while but they all stood up in the end.

The value of a framework for care-giving is essential to ensure equality and to mitigate the abuse of power and oppression to those who are most vulnerable, the care-givers and care-recipients. Greater efforts are needed to ensure that care-givers and care-recipients are empowered to withstand the forces that would oppress and marginalise. An ethical framework to care-giving that offers a new social vision of care-giving has merit and as an initiative it should be pursued further.

The ethics of care-giving that comprise attentiveness, responsibility, competence and responsiveness presents a solid foundation for a framework in the development of an Indigenous model of care-giving, which will be explored further in the next chapter.

9.6 Summary

This chapter provided a discussion of an analysis from both the findings and the literature in regards to care-giving in the context of the five themes identified in the previous two findings chapters. In this chapter there was a broader discussion on the five themes of *Challenges of living with a serious mental illness*, *Knowing the care-giver role*, *Staying the distance*, *Voices of resistance* and *Confronting racism*. Each of the themes is linked, and importantly in this chapter the aim was to deepen an understanding of the complexity of care-giving from an Indigenous context. This chapter explored the issue of racism and its implications on the activity of care-giving in the context of Indigenous people living with a serious mental illness. The issues of care-giving confronting Indigenous people are complex and unique, for includes racism which is often excluded in any debate on care-giving. The aim of the chapter was to link the key issues of social injustice and racism as it affects care-giving for Indigenous people living with a serious mental health illness.

The next chapter *Reframing the work of care-giving: An Indigenous model of care-giving* broadens the discussion of Tronto's four essential elements to care-giving to include an Indigenous context to care-giving. I will discuss the concept of an Indigenous research framework from a personal experiential perspective. There are three intended audiences for the outcomes of this study – the participants - community members, policy makers and public health researchers. Often research and health interventions 'miss' the role that care and relationships play in sustaining health. Therefore, for care-giving to be valued as a practice within society, it will require a seismic shift by policy makers to recognise the contributions that care-giving provides to stability within the community, for both Indigenous and non-Indigenous community members.

Chapter Ten: *Reframing the work of care-giving – Conclusions*

10.0 Introduction

Using the model of care-giving as outlined by Joan Tronto in the previous chapter, in this chapter I develop an Indigenous model of care-giving. I recommend an Indigenous ethics of care framework that underpins the proposed Indigenous care-giving model. The chapter has been organised in two parts; the first explores an unexpected outcome of the study, the concept of an Indigenous research framework, as understood from a personal experiential perspective. The second part broadens Tronto's four essential elements to care-giving to develop a new paradigm of an Indigenous model of care-giving. The chapter also focuses on the dissemination of the findings of this research study and provides the framework for the distribution of the findings of the study in the context of representation and audience. Further discussion points from the study are directed at each of the three key stakeholder groups – participants and community members, policy makers and public health researchers.

The chapter is divided into three sections:

Challenging unreflective research practices: An Indigenous research framework explores the challenges of doing a qualitative study and, in particular, the issue of respecting the voice of the participants and the responsibilities of being an Indigenous researcher in this process.

Connecting the dots on care-giving: An Indigenous model of care-giving provides an overview of the concept of an Indigenous ethics of care framework and Indigenous model of care-giving. The current literature on care-giving is premised on Eurocentric values and principles and does not include an Indigenous perspective. In this section I offer what I believe is the foundation for an Indigenous model of care-giving.

Epilogue: So where to from here? recommends potential ways forward from the vantage point of this research.

10.1 Challenging unreflective research practices: An Indigenous research framework

The challenge of doing qualitative research

While at all times challenging, the process of performing qualitative research can at times be contradictory and confusing. Carney (cited in Weis and Fine 2000, p. 106) states:

Many of us who are interested in questioning/overturning dominant cultural ideologies have had the experience of collecting data from participants whom we know are victimized by these discourses of domination...We expect and search for languages of resistance...we find languages of what looks like reproduction.

For Indigenous researchers this should not come as a surprise because the hegemonic process to de-legitimise Indigenous Australian culture has been constant, and has successfully portrayed Indigenous culture as primitive, violent, and uninformed (Dodson 2007).

In this study I have used the method of critical ethnography. According to Weis and Fine (2000), the principles underpinning the methodological approach of critical ethnography are contained in the following questions:

1. Were the narratives or 'voices' of the participants linked to their historic, social and structural lived experiences?
2. Were multiple methods used so as to allow for different modes of analysis?
3. Were the findings that were commonplace and uninteresting included?
4. Did participants have input into how the thesis was shaped? Did they challenge, debate or disagree with the findings? If there were disagreements how were these resolved?
5. Were there limits or conditions placed on the statements of the participants?
6. Was there reflection on how the data could be used in the public domain, particularly the possibility of exploitation or oppression?
7. Was there the use of the passive voice, as a means to hide the researcher's voice behind the participant's stories?

There are obvious challenges for Indigenous and non-Indigenous researchers when conducting research with Indigenous people. What is universally agreed upon is that there is a need for a set of guidelines that outline the requirements for doing research with Indigenous Australians. In Australia the National Health and Medical

Research Council (2003) developed a set of guidelines for researchers to comply with when they are conducting research with Indigenous people.

This research study was influenced and guided by a series of ethical approaches, from Australia and overseas. I drew on the National Health Medical Research Council's *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* (2003) as the foundation document. I also relied on the perspectives of Indigenous Australian academics on Indigenous research approaches. These academics included Ian Anderson, Sandra Eades, Cindy Shannon, Lester-Irrabinna Rigney, Dennis Foley, Martin Nakata and Aileen Morton-Robison. My research was also informed by New Zealand Maori and Canadian First Nation ethical approaches as defined by Maori academics Russell Bishop and Linda Tuhiwai Smith, and Canadian First Nations academics Cora Weber-Pillwax, Marie Battiste, Michael Marker, Charles Menzies, Michelle Pidgeon and Donna Cox. This is an exciting period as Indigenous researchers in Australia, New Zealand and Canada are developing ethical guidelines for doing research with Indigenous people that will protect Indigenous knowledge and heritage.

As an Indigenous researcher, I have been aware of the importance of not reproducing and reinforcing the dominant discourse that emphasises privilege and power. Researchers are located at a nexus of power in Western society (Tuhiwai Smith 2003) and when research is conducted with Indigenous people it should not result in re-colonisation (Bishop 2005). These are critical issues for all researchers, but even more so for Indigenous researchers who have 'insider' connections which provide additional challenges in avoiding dominance (Tuhiwai Smith 2003).

In conducting this study, I was mindful of the importance of the need to protect Indigenous culture and to respect Indigenous worldviews, at the family level, at the community level and, where relevant, in relation to other Indigenous groups. Within the framework of Indigenous knowledge and epistemology there is an understanding of the importance of relationships which are held within oral traditions of history and culture (Cook-Lynn 2008). Indigenous knowledge and its epistemology are unique, and this knowledge needs to be protected from challenges to its legitimacy (Battiste 2008).

My position in the context of my research is that of an activist (Grande 2008). Fine, as cited in Madison (2005, p. 6), defines the activist researcher as one who, 'takes a clear position in intervening on hegemonic practices and serves as an advocate in exposing the material effects of marginalized locations while offering alternatives'.

Researchers who adopt the activist position understand firstly, that Eurocentric research practices are linked to the continuation of social inequality; secondly, that there is no such thing as research neutrality, everything is political; and thirdly, that there needs to be more political activism on the part of researchers (Menzies 2001). Indigenous researchers have a lived experience and understanding of the corrosive effects of colonisation, but they must also be cognisant of their privileged roles as researchers and of the need to adopt the role of political activists in dismantling the structures of oppression (Cook-Lynn 2008; Grande 2008). Now, more than ever, this needs to occur as Indigenous people, like other marginalised groups, are struggling in the face of the political indifference of governments to their plight.

The political, social and cultural implications for care-giving are always present for Indigenous Australians. For them, the impact of colonisation and racism remains a core issue. Racism, a consequence and cause of colonisation, is rarely discussed or debated openly in Australia; indeed, discussion is often actively discouraged (Behrendt 2007). Australia's history is imbued with policies based on race, with 'Whiteness' being the colour of privilege (Lake and Reynolds 2008). In Australia, as in other colonised nations, White Australians have used 'Whiteness' to shape their own domestic reality and to privilege those who are 'White'. Those who are racially not 'White' are classified as 'Other', and inferior, as the noted Afro-American philosopher W.E.B. DuBois stated early last century, 'Whiteness is the ownership of the earth forever and ever, Amen' (cited in Lake and Reynolds 2008, p. 2).

In 21st century Australia, racism is still very much alive and present, with some evidence that the incidence of racism is increasing (Paradies and Williams 2008). Unfortunately, because racism can be a politically controversial issue, the focus on de-legitimising and discrediting Indigenous voices of dissent to racist practices has resulted in their voices being labelled 'Other' in popular rhetoric, and as a consequence often considered to have no value (Behrendt 2007).

Framing the work

Mental illness in the Australian Indigenous community is an issue of grave concern as I experienced first-hand in working the mental health area. This combined with having observed how racism, marginalisation and poverty have had serious negative impact on Australian Indigenous people living with a serious mental illness. Understanding this reality was a critical in the framing of this research I was therefore very mindful of the importance of using reflexivity throughout the course of the study. The 'voices' of the participants were linked, where relevant, to the

historical, social and structural positions within which they live their lives. For Indigenous Australians, their post-colonisation history has been appalling, the combined effects of colonisation and racism has resulted in overtly and inherently racist policies targeted at Indigenous people (Reynolds 2000). The voices of the participants in this research were infused with the stories of how they had been portrayed as 'Other' in negative terms, and how dominant 'White' racist policies of colonialism are disguised within the political spin of 'inclusiveness'. One participant, Noel, stated of his experience with the health system:

That you're a lazy black bastard, that's all they've got to say about you. You're a lazy black bastard and you're 'mad'. But why are we 'mad', you know? You know people have to realise that just because you're Aboriginal it doesn't mean that you're bad. Because you've got a sickness it doesn't mean that you're 'mad'. You're the same as any other person on the street but we do have problems, and we have to face our problems.

Syed Hussein Alatas's work entitled *The myth of the lazy native* (1977) analyses the application of the notion of 'the lazy native' in Southeast Asian countries colonised by Europeans where the concept of the lazy native was applied to Indigenous people by European colonisers. In her book *Mission Girls* (2001), Christine Choo refers to Alatas' work which exposes the economic implications of European colonisation on Indigenous people. The reality was that European colonisers abused Indigenous labour to increase their profits to satisfy their own insatiable greed, and labourers were labelled 'lazy' if they were not engaged in what the Europeans defined as productive labour. Indeed, in Australia, Indigenous people were treated more like slaves because of the indentured labour system. There is no such thing as the 'lazy native' but rather a corrupt and greedy system that privileges race and power.

The participants in my study were able to recognise that social injustices were a daily part of their lives. Their voices spoke, if not directly then in allegories, of the oppression and exclusion that were a part of their lives because of their race, their Aboriginality. They could see that in a country of immense wealth Indigenous people were still living in conditions similar to those living in very poor countries. It is considered by some that in a number of Indigenous communities in Australia people live in 'Fourth World' conditions, that is, conditions similar to the 'Third World' but within a 'First World' country. Participants in my study were aware of the gap in health caused by poverty and poor living conditions, with Indigenous people more at risk in every disease category (Council of Australian Governments 2003). This is

highlighted in Barbara's explanation of her daughter's situation and her mental illness

...either when she came out of jail or through other difficult periods including homelessness or just her whole life, as it has been quite chaotic. It's either been in jail, homeless or in a mental hospital or in some institution somewhere.

Participants were aware that the alternatives to mental health services were always a limited measure because these alternative organisations themselves had long experienced empty promises of more resources being provided that would enable more appropriate services for Indigenous people.

On race

The thematic thread for this study is racism because, on the issue of Aboriginality, racism was definitely the 'elephant in the room' for the participants. The word 'racism' was not often used to describe the experiences of the participants, but was implicit in their discussions and was accepted as part of their reality. Racism was a constant presence floating in and through the stories of the participants, sometimes alluded to generally, but never denied. In this study, participants sometimes used allegories, with voices contextualised by racialised language. When they shared stories of family, of interactions with their community, of interactions with police and with mental health system, these stories were all presented within the context of and through the lens of 'race'. Race infused the narratives of participants' interviews and the art they created as part of the research process because for Indigenous Australians, racism's historical effects through colonisation have shaped structures and relationships in Australia.

To understand the connection of mental illness to race it is essential to recognise what it means to be Indigenous in Australian society. Put simply, life can be very difficult. As Weis and Fine (2000, p. 40) state: 'Race is a social construction. But "race" in a racist society bears profound consequence for daily life, identity, social movements, and the ways in which most groups *other*'. Indeed, it can be said that Race is more than a social construction, in some societies it has become a 'genetic' marker for privilege. In Australia, 'Whiteness' is the colour for privilege, and Indigenous people are aware of this reality. That privilege is associated with race is widely known and accepted, but is not spoken about in a perverse form of 'political correctness' that is an effective method in silencing the voices of dissent (Menzies 2001).

Many of the participants spoke of their own feelings of being disenfranchised because of their Aboriginality. They spoke of feeling displaced in this country and not feeling included as citizens because they are treated with indifference and insensitivity, not only by those in the wider community but also by those working as mental health service providers. The participants shared stories of how people are afraid of them, how people avoid them and are distrustful of them, and how they are looked at with disgust. All these personal and intimate accounts reveal the depth of alienation some Indigenous people feel in this society,

Whose stories? Whose voices?

The importance of ensuring proper representation of the voices of the participants was something of which I was constantly aware throughout the research. This meant being cognisant of, and therefore careful not to misrepresent, the participant voices. A key consideration in regards to misrepresentation was the possible implications for participants if I emphasised the injustices committed by oppressive systems, without due regard for the wider consequences that could come from publication of individuals' stories. I was aware that narratives provided by participants, were both intimate and deeply personal and needed to be treated respectfully. The participants had placed their trust in me, the researcher, and had expressed confidence that their stories would be respected and held with integrity.

There is always the temptation for researchers who value social justice and who see themselves as 'activists' to present their findings in a way that will shock and, they hope, as a result improve the situation for participants. However, there are also wider implications of this approach (Bishop 2005). With regard to representation there is sometimes the temptation to only disclose the most interesting parts of stories, to code the data in an effort to uncover the exotic, the bizarre and even the violent. This process could be described as voyeuristic in that when reviewing the data there is always the risk that the researcher only tries to discover the 'gems' that will be topical and of interest. However, the exotic does not portray the full effect of mental illness and racism on people's daily lives. Weis and Fine (2000, p. 64) found that in their research, 'most of [their] transcriptions detail interactions with friends, kin, neighbours, children and television. These portraits, though rarely stunning, constitute much of life in poverty and should not be relegated to the edited-out files'. There needs to be a place for the common and uninteresting data, the ordinary, to be included and to not do so would be disingenuous. In my study there was the opportunity for the ordinary to be included as part of the participants' stories as it

provided for a more complete representation of their lives and a much fuller and richer account than just the moments that involve tragedy.

On responsibility

Researchers have a responsibility to be transparent with their processes, and in particular, in how the discourse is to be presented to the key stakeholders, the participants, policy makers and public health researchers. For example, researchers have a responsibility to be clear about their research intentions. For example, Fine (cited in Weis and Fine 2000), refers to working 'at the hyphen', the space where researchers lack reflexivity. It is in this space that researchers choose to remain invisible in their research process by hiding behind the language of research such as 'methodologies' and 'epistemologies'. An approach to research of working 'at the hyphen' which allows the researcher to stay invisible and distanced in the research process is particularly demeaning and disrespectful when working with Indigenous people and the disenfranchised (Weis and Fine 2000). It reinforces the researcher's position of power.

The methodology of a critical ethnographer challenges the concept of working 'at the hyphen'. Critical researchers are mindful to stay connected and engaged, thereby being reflexive throughout the research process. Reflexivity entails being subjective and present, by not creating distance between the participants and researcher. The academic discipline of health unfortunately encourages researchers to be 'objective', with the idea of not getting too close to the participants, with the rationale that, according to the academics, it could result in 'researcher *bias*'. Interestingly, the so-called 'objective' approach to research is ineffective when doing research with Indigenous people, for Indigenous research methodology is relational (Foley 2003). A more progressive view is to abandon the illusion of objectivity in research, or what Madison (2005, p. 8) describes as the, 'value-neutral fieldwork methodology that favours the analytic evaluation of the natural science model'. Socially just research requires researchers to abandon objectivity, and embrace subjectivity because 'we are not simply subjects, but we are subjects in dialogue with the Other' (Madison 2005, p. 9). There is now a growing number of Indigenous researchers who are challenging the authenticity and legitimacy of Eurocentric research practices that promote the so-called value-neutral model of objectivity. They are calling into question the relevance of this approach, particularly in an Indigenous context (Battiste 2008; Foley 2003; Rigney 2001).

An Indigenous research practice has its own epistemology based on values that enhance community and not on the Eurocentric approaches of objectivity and neutrality (Battiste 2008; Foley 2003). Indigenous research is focused on the critical analysis of the inequitable power relationships in Indigenous communities which have been impacted upon by colonisation. In Australia, this includes the renunciation of the hegemonic discourses that propagate myths that Indigenous people are hopeless, lazy and useless (Dodson 2007). Indigenous researchers raise awareness through conscientisation of our communities through research (Anderson 1996) in order to emancipate people from what Freire (1979, p. 31) calls, 'the "fear of freedom" which afflicts the oppressed, a fear which may equally well lead them to desire the role of oppressor or bind them to the role of oppressed'.

On reflexivity and voice: Transfer of knowledge

The transfer of information and knowledge to the key stakeholders who included participants/community members, policy makers and public health researchers was a significant element of the research process. The reports to stakeholders would focus on three key areas: firstly, the importance of Care in the stability of Indigenous community life; secondly, the impact of a neo-liberal philosophy on the delivery of health services, and thirdly the impact of 'social pathology' in the representation of Indigenous people.

An important outcome of this study for participants and policy makers is the assertion of the role of care-giving plays in providing stability in Indigenous families and communities. The influence of care-giving as both a practice and an ideology within an Indigenous community is considerable for the following three reasons. First, within the family context care-giving plays an important role in the stability and optimal functioning of the family unit, from looking after children and the elderly. Second, within the community context, the principles of care-giving are evident, as families and groups provide support to those requiring support and care, as is evident for example during 'Sorry business' or other important cultural events (Nangala, Nangala and McCoy 2008). Third, in the wider Australian context, the model of care-giving as represented in Indigenous culture is instructive for the connections of relationships and care are important in not only providing stability in Indigenous communities, but could also be applied to the wider non-Indigenous community. As Ellen noted of the importance of relationships and care in providing stability for her family:

I've said that if we work together we can we can conquer. We can do anything. If we all stand strong that's what I keep telling them and all the family. You can get over anything.

Neo-liberalism has had a major influence on the standards of the delivery of health care, and the effects have been particularly severe for Indigenous people. Western based health practices are themselves intricately linked to dominant ideologies (Turner 2005). Neo-liberal views have filtered through all aspects in the delivery of health services; noticeably with the introduction of tendering processes by the community sector for the delivery of health programs (Germov 2005a). The view held by neo-liberal governments is that the provision of health services should be market driven rather than as a service for the public need, based on the diversity of need, not necessarily determined by issues of ethnicity, class or gender (Fine 2004).

It is therefore imperative that policy makers and decision-makers review the notion of personal responsibility by the individual as an inadequate model for care. Henderson (2005, p. 244) reminds us that services that were previously viewed as social rights have been redefined as personal needs to be met by private rather than public means. Service providers and policy makers need to be reminded that the current neo-liberal philosophy has had an impact on the delivery of health services that has seriously increased the disadvantage for Indigenous Australians.

Neo-liberalism extols individualism and autonomy, and the neo-liberal view of welfare initiatives is also harsh and judgmental, with a generalised ideology that 'people abuse social welfare systems' (Hopper 2006). Unfortunately, there has been a historical shift away from the welfare state in the past two decades with the economic rationalists arguing that welfare programs are too costly and create dependence. Usually such assertions are made as grand sweeping statements without statistical or academic backing. Privatisation, outsourcing and contracting health services out into the market place are now considered good practice. Agencies providing social services now work on profit margins. It appears, thanks to neo-liberalism, that peoples' despair is now 'profitable'. The market is seen as the final arbitrator for the lives of citizens.

An issue for non-Indigenous researchers doing research with Indigenous people is the responsibility of respecting cultural representation. Researchers have an obligation to reflect on the following two questions: First, given the sensitivity of issues, what information should be included from a study? And second, of the information gathered, what should be disseminated as public knowledge? Maori researcher, Bishop, refers to the impact of this practice used by White researchers

as a form of 'social pathology' that is common when doing research with Maori people. This pathologising of Maori culture, Bishop claims, has the twin effects of firstly, implying that Maori culture is dysfunctional and not able to cope with the demands of modernity, and secondly, that Maori culture is inferior to the culture of the coloniser (Bishop 2005). Even if the researchers have 'good intentions' but by disseminating research results they misrepresent and humiliate individuals and communities, this also has the effect of de-legitimising cultural epistemologies and ontologies.

To Marker (2004, p. 105) research is 'a slippery term' in this cross-cultural context. An Indigenous approach to research is premised on a relational approach. An Indigenous relational methodology is not always easily identifiable, and as such is often disparaged and criticised as lacking rigour (Weber-Pillwax 2001). The impact of 'social pathologising' of Indigenous Australians by public health researchers is an important issue. Research with Indigenous people is not only difficult but can often be contentious, due in part to their long held suspicion and distrust of Eurocentric research. Eurocentric research is intricately linked to past colonising practices so there is always the issue of how to engage in research without re-oppressing Indigenous people (Tuhiwai 2003). The Australian National Health and Medical Research have developed a set of guidelines for doing health research with Indigenous Australians that have made health researchers more accountable when undertaking research in Indigenous communities (National Health and Medical Research Council 2003).

Researchers are an influential group who can and do play a major role in the lives of the participants. There is therefore a need for them to engage with the community in a way that, firstly incorporates partnership and collaboration, and secondly they should strive for more transparency in their practices. Thirdly, they should become aware that the practice of using 'social pathology' to highlight the social injustices towards Indigenous people needs to be reviewed, particularly if the consequences are misleading or it reinforces the notion of 'Other'. And finally, they should engage in the role of activist by assisting in the dismantling of structures that continue to oppress Indigenous Australians.

10.2 Connecting the dots: An Indigenous model of care-giving

An Indigenous framework of care should accurately reflect the lived experiences of Indigenous people as care-givers and care-recipients and ensure that their lived

experiences are framed in the context of the historical, social, cultural and political realities. The historical context in Australia includes the impacts of dispossession and forced removal of Indigenous Australians from their land and the state-sanctioned programs of separation of Indigenous children from their families. These policies have resulted in individual and collective grief and trauma that is still experienced across generations (Westerman 2004; Zubrick et al 2005). Collectively, the ongoing trauma of grief and loss in some of the participants' stories highlights graphically how the past is very present in the lives of Indigenous people, many of whom are living with mental health issues because of the forced separation from their families (Human Rights and Equal Opportunity Commission 1997; Zubrick et al 2005). In this section I discuss from an Indigenous perspective an ethics of care and the features of an Indigenous model for care.

Feminist theorists have been the most prolific and among the most persuasive and coherent in their arguments about care-giving, particularly around the debate on the politics of care. Care and care-giving are discussed in the health literature but, unlike the discipline of sociology, the health debate on care-giving is limited for a number of reasons. The health literature is so influenced by the bio-medical model that its focus is primarily on the physical rather than the emotional and spiritual needs of an individual. By refusing to move outside of the health paradigm researchers and policy makers continue to ignore the sociological, psychological and political determinants that are essential for the debate on care-giving.

The structural issues of care-giving are always present, particularly the limitations of the current understanding of the complexities of care-giving in an Indigenous setting. It is therefore critical to move beyond the current bio-medical understanding of care-giving, to an appreciation of how care-giving functions in Indigenous communities (Germov 2005a). Unfortunately, the bio-medical model of health care is punitive as its focus is on compliance, thereby stigmatising and enforcing social control over those who are non-compliant (Sharyn 2005). Therefore the term 'disenfranchised' is particularly relevant in understanding the tenuous relationships between health providers and some community members. According to Pyett (2002, p. 333) 'disenfranchised' implies 'deprivation, less than full citizenship of a society, unequal rights, and a lack of access to power and privilege'.

An Indigenous model of care-giving obviously has a cultural dimension. This was clearly present in the narratives provided by the participants, where culture was a core issue for them. Reference to what it means to be Indigenous was interspersed

throughout the narratives of the participants. Cheryl talked about how her culture was a place of refuge in moments of crisis:

Our culture, we love to bring our culture in especially when our minds start racing and our hearts starts racing. We will go and get our wool and make our headbands and our armbands and our belts. We are concentrating on our colour, we're concentrating on our culture and we know that at the end of the day the things that we make will be handed out, to share as part of our cultural experiences.

An Indigenous model of care framework, with reciprocity as a central component, should include the broader social and cultural determinants of health. There is a clear argument that the community controlled sector should be more involved in mental health care. Unfortunately, the Western Australian government does not share these ideals. As I stated in Chapter One, under the heading *Service context for participants*, the only two community controlled mental health services in Western Australia have been de-funded. There also needs to be a greater effort to target research towards building an evidence based support role for the Aboriginal community controlled sector in the delivery of mental health services.

Responsibility and voice: An Indigenous ethics of care

An Indigenous ethics of care is essential for the framing of an Indigenous model of care-giving. Tronto's ethics of care-giving, which includes *attentiveness*, *responsibility*, *relationships* and *reciprocity*, has relevance for Indigenous Australians for it fits with the attributes of respect and reciprocity that are core features in Indigenous relationships. An Indigenous ethics of care-giving needs to be comprehensive for like race, care-giving is a social construction. The four characteristics of an Indigenous ethics of care-giving that emerge from this research are *attentiveness*, *reciprocity*, *relationships* and *responsibility*.

Attentiveness

The first element of the ethics of care is *attentiveness*. Tronto defines the activity of awareness thus: 'One needs, in a sense, to suspend one's own goal, ambitions, plans of life, and concerns, in order to recognize and to be attentive to others' (Tronto 1993, p. 28). As the participant Gina described of her attentiveness to her daughter's situation:

I need to be very watchful of noticing every move so as to keep an eye on her. To see, you know, what she was doing all the time was important. Trying to, not being in control I think you could easily try and control the situation by watching and saying don't go there, don't do this, don't do that. Not controlling that person but allowing them to do whatever they have to do but just be watchful. And I wanted to say something about the difference in

this kind of care; of caring for somebody that you know is your child with a mental illness, as opposed to mental illness in the community because in the community you can go home from it. You leave it behind at work and you know, you learn to do those things, but with your child it's different as it's there with you all the time. It doesn't matter where you are you could out doing recreation or something like that just out and about but you still wondering what if. I think every one out there should know that caring for someone means keeping an eye on it.

Care-givers of people living with a serious mental illness are constantly alert to the changes in the person receiving care. In this study the care-givers disclosed how it was essential to be vigilant and attentive to the needs of the person receiving care, primarily because of the unpredictable nature of mental illness. People living with a serious mental illness are particularly vulnerable to harm and the care-givers were mindful of this situation.

Responsibility

The second aspect of an ethics of care is *responsibility* which, Tronto (1993, pp. 131-32) states, 'is a term that is embedded in a set of implicit cultural practices, rather than in a set of formal rules or series of promises'. Indigenous people are aware of cultural responsibilities, for the qualities of cultural responsibility are critical for the health, well being and continuity of their community. Andrea, one of the participants, understood the implicit meaning of responsibility for it was her grandmother who became her primary care-giver during the critical period of her illness. Her grandmother accepted this responsibility and was unwavering in her support for her grand-daughter. Andrea stated:

It was really scary for everyone. It was like they all stood down from it and it was more like Nana just stood up and its like, 'Well we're either going to be here to help, or otherwise we're just going to stand back and bicker amongst each other and nothings going to get done'. They were scared because they didn't know what was going on. And it took for Nana to stand up and say, 'No now is time that we stand together so who's going to stand with me'. It took a while but they all stood up in the end.

Responsibility in an Indigenous context is holistic and it is not an activity confined to meeting just the needs of the immediate family but as a philosophy it has implications for the wellbeing of the wider community. Andrea's grandmother recognised the urgency of her grand-daughter's situation and took immediate control, mobilising all members of the family, across three generations.

Relationships

The third part in an Indigenous ethics of care is *relationships*. The attribute of *relationships* when applied to the activity of care-giving must be viewed in the entire

context of care-giving. The importance of relationships is learned from early age and Indigenous children are educated in the skills of genealogy and of the importance of familial relationships. These relationships are imprinted and are a critical part of their world view. The different nature and types of relationships shape their understanding of their cultural map and, over time, provide the competence in the care-giving role. Importantly, responsibilities in the Indigenous context are more extensive for they go beyond the immediate family into the wider community. Upholding these relationships is acknowledged and expected as being critical to the stability and wellbeing of Indigenous society. For Indigenous people, the holding and accepting responsibilities of relationships extend beyond the limited notions of time and place. When there is a need to ensure the holding of relationships nothing is insurmountable. Barbara described her involvement with her daughter to whom, despite her own and her daughter's difficulties, continued to provide support.

My daughter has always lived in NSW and she didn't always have my support but she didn't really want it. She is very strong headed, strong willed and stubborn like me. That sort of personality type and she got mixed up with drugs at an early age and there was a drug culture and stuff. I go over about every year; last time I was there was two years ago. After I painted her house I brought her furniture cleaned up the backyard. I got CDEP I did everything. I did a whole lot of, you know, domestic stuff to help her and I had just had a knee reconstruction so I wasn't in a very good mood. But I did all that and I just thought, 'Oh well', this was sort of not a farewell but like a I'm not doing very much because I've got little kids now. Sort of like, I can't be worrying about the big kids because I've got the little kids and if I'm worrying too much about the big kids well, how am I going to go? There's only enough time in a day or money in the bank. It's just the energy and time and money to be able to sort of worry about it. I don't really have enough for everybody like I used to because I'm not working myself. So she doesn't want to have anything to do with anybody that's part of the mental illness

Reciprocity

The fourth characteristic in an Indigenous ethics of care-giving is *reciprocity*. Reciprocity in Indigenous society is a critical part of the stability of community. Reciprocity provides for the well being and vibrancy of a community that has a deep knowing and trust that there are those in the community who will be there to provide care and that they in turn can receive care. It involves mutual sharing and being present in difficult circumstances. Reciprocity has allowed Indigenous society not only to survive but to adapt to the oppressive forces of colonisation. Being selected in the role of care-giver can be complex; it can be seen as an honour. As Crosato and her colleagues found in their Canadian study of Indigenous woman as care-givers, 'Aboriginal women in this study expressed feeling "honoured" to assume care-giving roles, as opposed to feeling stress and burden, and they perceived

caring to be honourable because they had the opportunity to fulfil culturally prescribed roles' (2007, p. 8). Reciprocity has provided the framework that has shaped and enhanced spiritual meaning and provided the sense of purpose among Indigenous people. In many ways it has mitigated the worst of colonisation (Battiste 2008). Joan described her experience of reciprocity by being present and available for her son and his family during his mental health crisis:

His wife was feeling very frightened because **that was why I was there** [My emphasis] but I was feeling like, 'Goodness there's got to be some way to deal with this', but we did not know what to do or what was going on. It was really strange to us and we felt powerless. Let me put it this way, we felt powerless, we felt the need to go and find out where we can get some help. It was beyond us it was bigger than us you know.

The attributes of an Indigenous ethics of care are indeed critical for Indigenous care-giving. An Indigenous ethics of care provides a safety net for the activity of care-giving.

Representation and voice: An Indigenous model of care-giving

The issue of how race, gender and class, through the lens of history, social and political situations shaped the participants' reality is critically important, because being able to connect the dots from context to personal life is essential in the emancipatory process. I was conscious throughout the research process of not replicating poor research practices of the past, particularly Eurocentric research practices that have been used to colonise Indigenous people and in which the Indigenous voice has been ignored and silenced.

The importance of care-giving in providing stability in the Indigenous community is also a critical topic, and one that has been largely ignored by Western society. Indigenous people understand the importance of care in providing stability and as such have prioritised care-giving in their families and communities (Crosato, Ward-Griffin and Leipert 2007). This contrasts with Western systems where access to care-giving is shaped by privilege and power, and not necessarily held in such high regard by society as a whole. There needs to be a shift in the way care-giving is perceived, away from how it is currently understood as 'a dilemma of autonomy or dependency to a more sophisticated sense of human interdependence' (Tronto 1993, p. 101). In contrast, care-giving in an Indigenous context is seen as an integral part of a person's life (Nangala, Nangala and McCoy 2008). Tronto (1993, p. 103) acknowledges the reality that care is not restricted to the human sphere but includes the spiritual for care should not be limited to the 'dyadic or individualistic'. Too often care is presented in the simplistic form as 'a necessary relationship

between two individuals, most often a mother to child', thereby discounting the complexity of the care activity in other types of relationships. Care cannot be categorised in a simplistic manner or just as a single experience, rather it is a phenomenon that is a holistic activity and an integral part of the process of life, as it is 'both a practice and a disposition' (Tronto 1993, p. 104).

The practice of care-giving from an Indigenous perspective is better understood as an activity when applied in the everyday setting. For example, the Indigenous model of care-giving I have proposed includes *caring about*, *taking care of*, *providing care* and *receiving care*. *Caring about* is the recognition that there is a need to provide a person with care and it has both communal and individualistic qualities. From an Indigenous context *caring about* is applicable to the person and to the person in context of their family, their community and the wider environment. There is no separation between the person and their place of physical and spiritual connection, both within family and community and 'country'. *Caring about* includes the spirit. It is imperative to have a cultural understanding of the holistic approach to care-giving and mental illness as it applies to Indigenous people. For example, Vicery and Westerman (Vicery and Westerman 2004, p. 5) discovered that symptoms of mental health as defined in the DSM-IV criteria, when corroborated and validated by Indigenous people, were quite illuminating. Symptoms of mental illnesses which Indigenous patients described they experienced were comparable with the DSM-IV criteria but were given their own interpretations (from an Indigenous perspective) as *longing for*, *crying for*, or *being sick for country*.

The second component in the concept of an Indigenous model of care-giving is *taking care of* which involves the commitment and responsibility in responding to the person receiving care needs. The concept of *taking care of* is more than just recognising that there is a need, but involves the commitment to being active in responding and resolving those needs. The activity of *taking care of* is therefore a deeper process; firstly it is about acknowledging the need, and secondly, it is about making the commitment to assume responsibility for the activity of care-giving. Being responsible is central to the activity of *taking care of* for responsibility is present within family and community and from a cultural perspective responsibility is integral to the continual health and welfare of Indigenous society (McCoy 2008). The recognition and practice of culture are central to the health and well-being of Indigenous communities and inherent in these cultural practices is the action of responsibility of *taking care of*, family, community and country (Marker 2004; McCoy 2008). Ultimately, *taking care of* is centred on the notion of responsibility for care-

giving and it is always situational and almost always personal. For example, the health and welfare of Indigenous societies is central to being responsible, from being a parent in raising children, to being an active community member, to looking after elders. Indeed, the component of *taking care of* is contained within the context of responsibility in the activity of care-giving and *taking care of* and responsibility are embedded and influenced by culture, gender, family and community. As Ellen noted of her experience of being a care-giver of her grand-daughter living with a serious mental illness:

I suppose we have to have a lot of understanding and lots of love because you got to really care about what you're doing I think. I was very emotional but I had to put that aside cause I knew that, like, getting emotional wouldn't help. I mean you do have your moments that are emotional, but I draw strength when you see how much they're trying. It doesn't matter, like, every day of our life, every hour, I suppose it will be how you've got to believe that it doesn't matter whatever you do you've got to believe that you're going to come through, that it will be good.

The third component of care-giving is the actual task of *providing care* which involves the responsibility of acting on behalf of those in need of care. It requires the total commitment to the task of care-giving. Indigenous people are familiar with the notion of responsibility to the commitment to *providing care*. It is common for Indigenous families to include three or more generations within a household, and the acceptance of *providing care* across these generations is accepted as the norm, this occurs despite the difficulties due to the lack of resources (Zubrick et al 2005). Mental health providers and others, as already demonstrated in this research study, have little understanding of the complexities that exist within Indigenous families and their communities. For this reason there is a need for mental health providers to become informed of the complexities and unique issues confronting care-givers in Indigenous families living with a serious mental illness.

The final attribute in the Indigenous model of care is *receiving care*. *Receiving care* assumes that the person receiving care will be responsive to the care-giving that is being provided. This study explored the experiences of care-giving, both receiving and giving, the participants who received care acknowledged the difficulties involved in the care-giving activity, they expressed their concern at the lack of services and support for Indigenous care-givers, this I believe, requires urgent attention, for the person receiving care is very dependent upon the continued health and wellbeing of the care-giver. This is reflected in Andrea's comments of the lack of support for care-givers:

There should be more supports for people to be care-givers for people living with a serious mental illness. To help people who are helping those living with a serious mental illness makes sense. For if you are working as a nurse in a ward it can be difficult because being around people with a mental illness is hard, as I tend to go a bit 'loopy' at times. Some people don't even know how to take me...That can be really draining and that's where they [care-givers] need the support. People need to be aware and have an understanding for as I said people are frightened, because they don't know anything about it, and they can get very frightened when they are around people with a mental illness.

The experiences of the participants in this study have shown how care-giving is a highly valued activity, and that they would like service providers to recognise their unique contributions to the activity of care-giving. Therefore, it is imperative that service providers engage with the Indigenous community in a more respectful manner. It should firstly incorporate partnership and collaboration, and this will provide for transparency in their practices; and secondly, it means being aware that they accept responsibility to move beyond the concept of the impersonal and to engage on a more meaningful way. This acknowledgment includes the recognition that service providers are not separate from the community they are an integral part of the community and that we all need to share as we are part of the web of life that connects us all. Being part of the same web means that, as we do to each other will also happen to us, so let us remember this in our work.

10.3 Summary of Key Findings

There were three key findings from the study; the first is the responsibilities of public health researchers to be more reflexive in their research practice and to be more proactive in dismantling and challenging ideologies that oppress Indigenous Australians. The second is the lack of understanding of Indigenous care-giving needs by mental health providers, and thirdly the proposal for an Indigenous model of care-giving.

The legacy of colonisation continues to negatively impact on the health and wellbeing of Indigenous Australians. An enduring legacy of colonisation has been the authority of certain research practices that have continued the oppression of Indigenous Australians. These research practices tend to reinforce Eurocentric dogma and reject Indigenous ontology. For this reason this research study was conducted as a critical ethnography using multiple culturally appropriate methodologies. The research was conducted under the direction of a Study Reference Group who provided technical and cultural advice. It used critical theory to interrogate the processes of colonisation and racism and their relationship to

oppressive practices, particularly how certain groups have been privileged in society because of race and ethnicity.

This study highlighted the disconnection between mental health providers and Indigenous Australian families living with serious mental health issues. A major concern identified in the thesis was the extent of the lack of knowledge by mental health providers of an Indigenous approach to care-giving. Participants reported that having to continually challenge the mental health system was both exhausting and often futile. The narratives of the participants reflected this reality; care-givers were prepared to put their own life on hold in order to help those they cared for yet they did not feel that they were doing anything out of the ordinary. A consistent theme was a picture of a mental health system under stress where workers are more focused on outcomes than on ensuring a respectful process. This reflects a serious problem at the interface between the mental health system and Indigenous families who are living with a serious mental health illness.

The third key finding from the study was the identification of an Indigenous model of care-giving. An Indigenous model of care-giving is underpinned by the characteristics of an Indigenous ethics of care: *attentiveness*, *responsibility*, *relationships* and *reciprocity*. The importance of being attentive in a care-giving relationship is critical as was indicated by the participants for to not be attentive could have tragic consequences. The second characteristic of reciprocity as was outlined is important to the continued wellbeing of Indigenous society. The third characteristic, the importance of relationships, is essential to the optimal functioning of Indigenous society. Knowing family and community relationships are a key part of an Indigenous world view. To live in the Indigenous world one has to have an understanding of their place within their community. Responsibility is the final attribute and in the Indigenous context it has greater meaning for responsibilities extends beyond the immediate family as it reaches into the wider community. Responsibility in the Indigenous context is about the people and the culture; for it includes family, community and a commitment to ensuring the continuation of Indigenous ontology. The stability and well being of Indigenous society are dependent on the maintenance of relationships and are central to an Indigenous worldview and spirituality. An Indigenous ethics of care reflects the key principles of the Indigenous worldview.

The core attributes of an Indigenous model of care-giving are its relational and responsibility components. To ensure the continued health and well-being of

Indigenous people it is necessary that individuals accept responsibility for the activity of care-giving beyond the individual to the family and community. The four key elements of an Indigenous model of care-giving are: *caring about*, *taking care of*, *providing care* and *receiving care*.

- **Caring about** is the recognition that there is a need to provide a person with care and it has both communal and individualistic qualities. In an Indigenous context, caring about is applicable to both the person and to the person in context of their family, their community and the wider environment.
- **Taking care of** involves a commitment to assuming responsibility to a person's care-giving needs. Taking care of is more than just recognising that there is a need, but involves the commitment to be active in responding and resolving those needs.
- **Providing care** involves the responsibility of acting on behalf of those in need of care. It requires the total commitment to the task of care-giving.
- **Receiving care** is ensuring that person receiving care is both responsive and content with the care-giving provided. Receiving care acknowledges that care-giving is a two way process, and that the health and well-being of both care-receiver and care-giver are respected.

Overall the Indigenous model of care-giving is relational; it incorporates the person's physical, emotional and spiritual wellbeing; it is the living embodiment of an Indigenous worldview. It was this relational commitment by the participants that provided the seamless transition to the care-giver role when required. This study showed that there is a considerable gap in knowledge and understanding by mental health providers to the attributes of relationships and responsibility that underpin the concept of an Indigenous model of care-giving. When mental health providers lack understanding of these attributes it has serious implications for their interactions with Indigenous people. This study offers recommendations for future research and for improved standards for mental health care provision.

10.4 Where to from here?

While the focus of this study was to understand the activity of care-giving from an Indigenous perspective within the context of mental illness, it did identify further gaps in the area of mental health. In this section, I present the following recommendations for both policy makers and public health researchers as well a list of future research possibilities.

Recommendations to policy makers and public health researchers

- 1. Ensure public policy that affects the lives of Indigenous Australians reflects the issues of race, class and gender through the lens of history which has been influenced by racism and exclusion.**

This study identified, through the stories of the participants, that the current mental health system is completely uninformed of the lived reality for Indigenous people. Unfortunately, Western-based health systems continue to fail in recognising and acknowledging the contributions of an Indigenous people and their concept of reality. There is a need for policy makers to ensure that public policy addresses this situation by ensuring mental health staff are more informed of the lived reality for Indigenous Australians, primarily because of the past colonial history of racism and exclusion.

- 2. Ensure public policy recognises and supports the premise that the principles underpinning Indigenous care-giving are central to the health and wellbeing of Indigenous families and communities.**

Through the narratives of the participants this study illustrated powerfully the potential for the activity of care-giving in providing stability and wellbeing to Indigenous families and their community. There is a need for policy makers to recognise the role and contribution that Indigenous care-givers of families living with a serious mental illness play in providing stability to Indigenous communities. This recognition should be extended to ensuring there are adequate resources and support structures provided that enable care-givers to continue in the role.

3. Ensure public policy recognises and mitigates the likely destructive exclusionary elements of the neo-liberal market approach to health care for Indigenous Australians.

Neo-liberalism has had a major influence on the delivery of health care in Australia. Neo-liberalism extols the virtues of the free market approach and the need for the individual to provide for their own care regardless of their economic, social or political circumstances. Indigenous people are still among the most disenfranchised and disadvantaged population group in Australia, therefore the impact of the neo-liberalist health care approach is particularly harmful for Indigenous Australians because of their lack of resources and support structures provided by the state.

4. Encourage public health researchers to review the practice of 'social pathologising' that occurs through the negative representation of Indigenous Australians in reports and publications.

An issue of concern for Indigenous Australians is the common practice of public health researchers of applying the notion of 'social pathology' in relation to Indigenous life. Maori researcher Russell Bishop defines the concept of 'social pathology' as the portraying of Indigenous people as dysfunctional (2005, p. 111). Social pathology is extremely damaging and harmful as it misrepresents Indigenous culture. The practice has the twin effects of implying that Indigenous culture is dysfunctional and not able to cope with the demands of contemporary society, and that Indigenous culture is inferior to the White society. In Australia there has been a practice of portraying Indigenous Australians as violent, drug and alcohol addicted and misogynist, and this portrayal damages the self confidence and morale of Indigenous people and communities. Public health researchers have a responsibility to ensure that given the sensitivity of the issues confronting Indigenous people, they should be more mindful of the unintended consequences of the reported findings from any study in which they are involved. They should also ensure that Indigenous people have greater input into the content of any findings from a study before they are made available to the wider community.

5. Encourage public health researchers to adopt a more proactive position when conducting research with Indigenous Australians.

Public health research practices should give priority to analysing the structures of power and re-empowering those who are the most disenfranchised. The task of public health researchers is to enlighten, educate and empower the community on issues of health inequality and social injustice. This can be achieved through meaningful collaboration with Indigenous Australians so that their stories that have previously been 'restrained and out of reach' are heard (Madison 2005, p. 5). Political activism needs to have the involvement of both Indigenous and non-Indigenous public health researchers for it to be truly effective.

Future research possibilities

1. Investigate the experiences of care-giving for Indigenous people living with a serious mental illness in rural and remote settings.

There is a need for studies exploring the issues in care-giving for Indigenous people living with a serious mental illness in rural and remote regions of Western Australia. The impacts of the geographical distance between Indigenous families living in rural and remote areas and the providers of specialist health care services in the metropolitan area have not been assessed to date. A major limitation of this study was that it only included Indigenous people living in the Perth metropolitan area.

2. Investigate the experiences of Indigenous people living with a serious mental illness in a forensic setting.

There is a need for studies exploring the needs and issues relating to Indigenous people living with a serious mental illness in a forensic setting, in prison or under supervision by corrective services (White and Whiteford 2006). The rates of imprisonment for Indigenous people living in Western Australia are very disturbing. In 2004 the rates of imprisonment of Indigenous people were 15 times higher than those of the general population (Department of Indigenous Affairs 2005). Therefore, studies that investigate the issue of forensic mental health, particularly in relation to Indigenous people, are urgently needed.

3. Investigate the level understanding of mental health providers of the importance of the cultural practices inherent in care-giving for Indigenous people in the context of mental health.

There is an urgent need for research that explores with mental health providers their level of understanding of the cross-cultural issues that arise when working with Indigenous people. In particular, there is a need for a more in-depth understanding of the significant relationships and values that are central to an Indigenous worldview.

4. Investigate the incidence and impact of racism on the provision of mental health services in the context of care-giving for Indigenous people living with a serious mental illness.

This study identified that racism is both present and persistent among mental health providers with whom the participants interacted. Participants in this study were strident in their views of the levels racism directed at them by sections of the community, including mental health providers. More in-depth qualitative research studies are needed to further investigate the incidence of the three types of racism – individual, institutional and cultural – with both Indigenous people and service providers.

5. Investigate and measure the quality of mental health services to Indigenous people living with a serious mental illness in the Perth area.

This study identified that there are significant gaps in the effectiveness and cultural appropriateness of the provision of mental health services to Indigenous people living with a serious mental illness. Further research is required to identify the underlying causes of the gaps in service provision to Indigenous people living with a serious mental illness.

6. Investigate the feasibility of the development of a sustainable and culturally safe framework for evaluating the delivery of mental health services to Indigenous people living with a serious mental illness in the Perth area.

There is a need for a study that develops a sustainable and culturally safe framework for evaluating the delivery of mental health services to Indigenous people

living with a serious mental illness in an urban setting. Outcomes from a study of this type would add significantly to the theoretical and methodological body of knowledge on the delivery of health services to Indigenous people living in the urban areas of Western Australia, as well as the remainder of Australia and internationally.

7. Investigate the incidence of economic stress involved in care-giving for Indigenous people living with a serious mental illness.

This study revealed that some of the participants, particularly those who were recipients of Federal Government income security benefits, experienced severe economic stress in their daily living. There is a need for a study to explore the relationship between mental illness and economic stress for families living with a serious mental illness.

8. Investigate the benefits of Indigenous people having representation on hospital boards and the governance bodies of other health services.

The New Zealand experience has shown that when Indigenous people have representation on Hospital boards they can have an impact on the delivery of health services to their communities. A study is needed that explores the viability of having Indigenous people selected onto hospital boards.

9. Investigate the effectiveness and appropriateness of mental health services as understood by both Indigenous people and mental health providers.

There is a need for a further study that explores the perception of mental health services by both the Indigenous community and mental health providers. There are still questions that need answers in regards to the perceptions of the effectiveness and appropriateness of mental health services as they are currently delivered. This study did not explore the perceptions of mental health providers in their interactions with Indigenous people. It is important that there is a study that explores further the issues of mental health providers.

A final word

As an Indigenous researcher it has been an immense privilege to have been involved in this study. It has been an incredible learning and humbling experience being able to work in my community. Sadly, the lives of Indigenous Australians people living with serious mental illness continue to go unnoticed and neglected. Regardless, the participant's stories were full of humour, and their sense of justice and the strength of family and culture, continue to offer hope for a positive future. I hope that this study will highlight not only the injustices, but also the strength of care-giving in an Indigenous context. Finally, an Indigenous model of care may offer pathways for more constructive relationships between Indigenous and non-Indigenous Australians.

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Every reasonable effort has been made to acknowledge the owners of copyright material. I would be pleased to hear from any copyright owner who has been omitted or incorrectly acknowledged.

Appendices

Appendix 1: Study Reference Group Members

1. Mr Colin Garlett, CEO, Derbarl Yerrigan Health Service
2. Associate Professor Colleen Hayward, Director, Kulunga Research Network, Telethon Institute Child Health Research
3. Ms Heather D'Antoine, Senior Research Fellow, Telethon Institute Child Health Research
4. Ms Geri Hayden, Project Officer, Aboriginal Health Council of Western Australia
5. Mr Glenn Pearson, Senior Research Officer, Kulunga Research Network, Telethon Institute Child Health Research
6. Mr Michael Mitchell, Manager, Aboriginal Mental Health, Western Australian Health Department
7. Mr John Vandergiezen, Mental Health Worker, Western Australian Health Department
8. Dr Rosalyn Walker, Indigenous Project Lead, Collaboration for Applied Research and Evaluation, Telethon Institute for Child Health Research
9. Associate Professor Deborah Lehman, Principal Research Fellow Division of Population Sciences Telethon Institute for Child Health Research
10. Adjunct Associate Patricia Dudgeon, School of Indigenous Studies The University of Western Australia Co-Supervisor
11. Dr Katie Thomas, Supervisor, Senior Research Fellow Curtin Centre for Developmental Health, Telethon Institute Child Health Research

**Appendix 2a: Human Research Ethics Committee of Curtin
University of Technology, Letter of Approval, 27
April 2006**

memorandum



To	Mr Michael Wright, 25 Lorraine Place HAMILTON HILL WA 6163
From	Stephan Millett, Executive Officer, Human Research Ethics Committee
Subject	Protocol Extension Approval HR 171/2005
Date	27 April 2006
Copy	Dr Katie Thomas, Centre for International Health Graduate Studies Officer, Division of Health Sciences

Office of Research and Development

**Human Research Ethics
Committee**

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

The Human Research Ethics Committee acknowledges receipt of your Form B report, indicating modifications / changes, for the project "*Out of the Blue*" *The Explored Experiences of Care Giving for Aboriginal People with a Serious Mental Health Disorder Living in the Perth Metropolitan Area: A Grounded Theory Study.*" Your application has been **approved**.

The project was originally approved on **18-12-2005** for a period of three years. The approval remains for three years and at the end of each year an application for renewal – Form B is required. The due date for this form is **18-12-2006**.

Your approval number remains **HR 171/2005**, please quote this number in any further correspondence regarding this project.

Thank you.

So Dr Stephan Millett
Executive Officer
Human Research Ethics Committee

*Michael,
amended letter
original for your
records.
Linda*

Appendix 2b: Derbarl Yerrigan Health Service Inc. Letter of Support and Endorsement, 6 April 2006



DERBARL YERRIGAN HEALTH SERVICE INC.

156 Wittennoom Street
EAST PERTH, WA 6004

Phone (08) 9421 3888
Fax (08) 9421 3884

Mr Michael Wright
Curtin University
Centre for Aboriginal Studies
GPO Box U1987
PERTH WA 6845

Dear Michael

Support and Endorsement of Pending PhD Study: *"The Explored Experiences of Care-Giving for Aboriginal People with a Serious Mental Health Disorder Living in the Perth metropolitan Area: A Grounded Theory Study"*.

The Derbarl Yerrigan Health Service Inc (DYHS Inc.) is pleased to both support and be a key stakeholder in your proposed PhD Study: *"The Explored Experiences of Care-Giving for Aboriginal People with a Serious Mental Health Disorder Living in the Perth metropolitan Area: A Grounded Theory Study"*, through Curtin University.

DYHS Inc. appreciates that the aim of this study is to explore the specific issues for carers of Aboriginal people living with serious mental illness. Accordingly DYHS Inc. gives permission for identified staff to recruit clients who fit the criteria for inclusion into the study. The organisation also supports the notion of co-authorship on publications arising from the study and having the opportunity to access any relevant information arising from the project.

Yours sincerely

Colin Garlett
President
Derbarl Yerrigan Health Service Inc.

6 April 2006

**Appendix 2c: Aboriginal Health Council of Western Australia,
Letter of Endorsement, 1 May 2006**

Aboriginal Health Council of Western Australia

Unit 2a - 4 , Wellington Fair, 200 Wellington Street, Perth WA 6000
PO Box 8493 Stirling Street, East Perth WA 6849
Ph (08) 9202 1393 Fax (08) 9202 1383

1st May 2006

Mr Michael Wright
25 Lorraine Place
Hamilton Hill 6163

Dear Michael

RE: "Out of the Blue"

Thank you for meeting with AHCWA on the 26th April 2006 regarding your PhD research study titled "Out of the Blue". As a result of the meeting The Aboriginal Health Council of WA has agreed to endorse your research project for ethics approval from the WA Aboriginal Health and Information Ethics Committee.

The Aboriginal Health Council looks forward to updates on the findings over the next few year and we wish you all the best in your endeavours.

Yours sincerely



Ms Gloria Khan
Chairperson

**Appendix 2d: Western Australian Aboriginal Health and
Information Ethics Committee (WAAHIEC),
Letter of Approval, 13 June 2006**

**WESTERN AUSTRALIAN ABORIGINAL HEALTH INFORMATION AND ETHICS
COMMITTEE (WAAHIEC)**

WAAHIEC Secretariat
Office of Aboriginal Health
189 Royal Street EAST PERTH WA 6004
(08) 9222 4441



Michael Wright
25 Lorraine Place
HAMILTON HILL WA 6163

**Investigate the issues for Aboriginal people in the Perth area who are living with
a serious and persistent mental illness of their experiences of community living.
117-9/05**

Dear Mr Wright,

Thank you for addressing the issues that the West Australian Aboriginal Health
Information and Ethics Committee (WAAHIEC) had with your application for the
above project.

The committee have approved your application, and you may commence
research.

Please note that approval for studies is for three years and the research should
be commenced and completed within that period of time. Projects must be
resubmitted if an extension of time is required. Also, it is a requirement of
WAAHIEC that a monitoring report be completed every six months. A copy of
this report can be found on the Office of Aboriginal Health's website,
<http://www.aboriginal.health.wa.gov.au/>

If you require clarification or assistance please contact me on (08) 9222 4441.

Yours sincerely,

Lauren Atkinson
Secretariat
WAAHIEC

13th June 2006

Appendix 3a: Flyer inviting Expressions of Interest in participating in study

Division of Health Sciences
Centre for International Health



Expressions of interest are sought for participation in a study titled:

‘OUT OF THE BLUE’

Giving and receiving care: The experiences of caregiving for Aboriginal people with a serious mental health disorder.

Are you:

- aged 18 years or older
- **A person who has an experience of caregiving to an Aboriginal person who has a serious mental illness, or an Aboriginal person with a personal experience of mental illness**
- Living in the Perth metropolitan area

Would you like to:

- **share your opinions and views on an Aboriginal person’s experience of mental illness?**
- **share your unique knowledge and experience of being a carer?**
- **contribute to understanding the challenges of community living for carers?**
- **contribute to future changes for living in the community as a carer?**

If you are interested in hearing more, or volunteering to be part of this study you are invited to:

- Ring 9266 7468 and leave a message for Michael to call you back (*you only need to leave your first name and a phone number*).

Appendix 3b: Participant Informed Consent Form

Curtin University of Technology, Centre for International Health

INFORMED CONSENT FORM

The explored experiences of care giving for Aboriginal people with a serious mental health disorder living in the Perth metropolitan area: a grounded theory study.

I _____
Given Names Surname

have read the information form explaining the project that will explore the experiences of people caring for an Aboriginal person living with a serious mental health illness.

- I agree to participate in this study, understanding that I may withdraw my consent at any time without reason and without penalty.
- I am 18 years of age or older.
- I agree to be interviewed by Michael Wright and to have the interview tape recorded.
- I agree if necessary to be contacted again to clarify any issues that may have arisen from the first interview.
- I understand that any information I provide will be treated as strictly confidential and will not be released by the researcher.
- I understand that my personal details held on any tapes used in this study will be destroyed at the conclusion of this project.
- I understand that any information collected for this study may be published provided my name or other identifying information is not used.
- I understand that after the study is completed, I will be invited to a presentation on the findings from the study.

Signature of Participant

Date

Signature of Researcher

Date

Appendix 3c: Participant Information Sheet

Curtin University of Technology, Centre for International Health

INFORMATION SHEET

The explored experiences of care giving for Aboriginal people with a serious mental health disorder living in the Perth metropolitan area: a grounded theory study.

Dear Participant,

My name is Michael Wright and I am a Doctor of Philosophy Scholar at the Centre for International Health, Curtin University of Technology. I am seeking your participation in a study that will explore the experiences of people caring for an Aboriginal person living with a serious mental health illness.

The purpose of the study is to identify what helps or hinders your ability to live the way you want to in the community. I am interested in hearing from you about the sorts of things that affect your health, well being and quality of life, including services you use and support you need.

I would like to invite you to part of this study. Information provided by you about your experience of being a carer will be obtained through an interview which should take between 60 to 90 minutes. The interview will be tape recorded, transcribed and analysed. After the contents of the tape has been analysed it may require a further appointment with you to discuss and clarify issues that may have arose during the transcription of your first interview.

Your participation in this is voluntary. You can withdraw from the study or during the interview at anytime. Any tape recording to this point in the interview will be erased or given to you. If you agree to an interview and to sign a consent form, you will be consenting to do the following:

1. Be interviewed by myself at a mutually agreed place where you will be asked to provide information of your experiences of caring for an Aboriginal person who has a serious mental disorder.
2. Have the interview tape recorded with its contents analysed.
3. All personal details provided by you will remain confidential, with no personal identification provided in any of documentation arising from the study
4. If necessary be contacted again to clarify any issues that may have arisen from the first interview.

To respect your confidentiality you will not be identified in any way from any of the personal information provided by you in the interview. Your identity will be protected in all of the documentation arising from the study, including my PhD and other reports or articles that may be written on the study. During the interview you may wish not to answer a question and even stop the interview and ask for the tape recorder to be turned off, your request will be respected.

The information provided by you during the interview will be stored in a locked file for the duration of the study. At completion of the study information provided on the tapes will be erased. As a Curtin University requirement all transcribed interviews will be stored in a locked file for five years after the project is completed, after which time it will be destroyed. As the principal researcher I will be the only person who will know your name.

Upon completion of the transcription of the interview you are welcome to read the contents. I am planning to hold a Seminar Presentation at the end of my study where all participants will be invited to attend where I will present on the findings from the study.

If you have any questions or require additional information concerning this study, please do not hesitate to contact me on (08) 9266 2993 (work). If you prefer, you may contact my supervisor Dr Katie Thomas on (08) 9266 3115 or Ms Colleen Hayward at the Telethon Institute of Child Health Research on (08) 9489 7758 who is the Chairperson of the Aboriginal Reference Group supporting this project.

Thank your interest in this project and please feel free to contact me if you wish to discuss this further.

Regards

Michael Wright

Appendix 3d: Questionnaire & Interview Guide

Thesis Title:

The explored experiences of care giving for Aboriginal people with a serious mental health disorder living in the Perth metropolitan area: a grounded theory study.

Semi structured Interview Guide

I will use a semi-structured interview format for this study. To help participants prepare for the interview, I will meet with them 15 minutes prior to the interview to answer any of their questions and to explain the purpose of the study. The participants will be told that they will receive a summary report on the outcomes of the study, as well as being invited to a presentation on the study to a wider audience of all participants at the end of the project.

The interview will start by asking the following two semi-structured questions:

Question 1: Tell me about your experiences of being a carer for an Aboriginal person living with a mental illness?

Question 2: Tell me about some of the things that you feel are unique to you as a carer?

Further questions asked within an interview will be dependent upon the responses from questions one and two.

To ensure the objectives of the study are met the following list of prompts/themes will be introduced during an interview.

Themes

1. How they came to be a carer.
2. How long they have been in the carer role?
3. What changes would they like to make in this role?
4. What are the main issues that they feel impact on their ability to carry out the role?
5. What has been their experience in dealing with health care professionals?
6. Do they experience discrimination from within the community because of being Aboriginal?
7. How do they feel that being Aboriginal has helped them in their carer role?
8. How has their family supported their role as carer?
9. What do they enjoy the least about their carer role?
10. What do they enjoy most about their carer role?
11. What are their main worries regarding their carer role?

A Demographic Information Sheet will also be completed with the participant prior to taping being completed.

At the end of the interview the research scholar who is Aboriginal and an experienced social worker, will provide a debriefing for the participant and assess their level of discomfort. If participants have experienced distress following the interview discussion with them of how they usually respond to such discomfort and with them develop a brief response plan. The researcher has arranged for two counseling agencies, Yorgum Aboriginal Counseling Service and the Wasley Institute to be available to see any of the participants should they require further counseling support as a result of issues that may have arisen from the interview. All participants will be given information or a business card on how or who to contact at either agency.

Appendix 3e: Demographic Information Sheet

DEMOGRAPHIC INFORMATION SHEET

‘OUT OF THE BLUE’

Giving and receiving care: The experiences of caregiving for Aboriginal people with a serious mental health disorder.

Participant ID: _____ Postcode where now living: _____

Date of Birth: _____ Gender: _____

Ethnicity: _____

If not from Perth where are you from originally: _____

Relationship to person who is giving or receiving care: _____ husband,
wife, child, parent, nephew, uncle

What age were you when this all began?: _____

How long does it take travelling to access medical appointments?: _____

Primary means of transport: _____ car, bus, taxi, lifts, etc

Are you able to be contacted by phone? _____ Y/N

If yes what type?: _____ landline, mobile

Length of time for the interview: _____

Date of Interview: _____

Appendix 4: Newsletters to Participants