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**DEMENTIA AND GUARDIANSHIP:  
CHALLENGES IN SOCIAL WORK PRACTICE IN A  
HEALTH CARE SETTING**

Margaret Mills

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

Faculty of Education and Social Work  
University of Sydney  
2015






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## **Abstract**

This thesis critically examines social work practice in complex and disputed situations where an alternative legal decision-maker is perceived as necessary for a person with dementia. Australia has unique adult guardianship legislation and social workers are actively engaged in the process in a variety of ways, such as weighing the benefits against the possible harm and lodging applications. Yet within the profession this is an area where there is very little research. The purpose of this study is therefore to enable social workers to better understand the dynamics involved in adult guardianship proceedings for a person with dementia and provide knowledge that can be used for more effective practice. The theoretical approach is to use perspectives from social constructionism, with the links which can be made to modernism and postmodernism being taken into account. Five research case studies were investigated drawing from the caseload of social workers in an aged care service at a large metropolitan hospital in Australia. A thematic network analysis of the findings showed that the research case studies are constantly evolving, where different players participate by bringing their own perspectives, and in this process alliances are formed which reflect underlying dynamics of power. There are many diverse and contested issues, such as varied understandings of dementia and capacity and differing constructions of the notions of risk, protection and responsibility. Some understandings are more highly valued than others and contextual influences impact upon decision-making, where the individual participant is embedded in a professional or private context. The implications for social work practice are that in a contemporary health and welfare context social work is well placed to make an important contribution through its traditional roles of negotiation, interpretation and mediation between those who have discursive rights and those who do not.

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## **Glossary**

### **ACAT – Aged care assessment team**

ACATs comprise of a range of health professionals who can provide an assessment of the requirements of older Australians in their own homes and work with an older person and their family to locate and refer to the most suitable aged care services available to them. ACATs also assess and approve older people for Australian Government subsidised aged care packages and entry into residential care facilities. The Australian Government engages state and territory governments specifically to operate and manage ACATs.

### **CACP – Community aged care package**

Individually planned and coordinated packages of care tailored to help older Australians with low level care needs in their home. ACATs assess whether the person is eligible for a CACP. They are subsidised by the Australian Government and typically provide 3 to 5 hours of direct assistance per week primarily for home help and personal care. These packages are delivered by charitable and other not-for-profit community-based providers (84%) and private organisations, state and local governments (Australian Government, April 2012). Under new legislation introduced in 2013 these are referred to as home care packages levels 1 and 2.

### **COPs – Community options program**

A case management service which helps older Australians and younger people with a disability remain living in the community. Jointly funded by the Australian Government and the NSW State Government under the Home and Community Care (HACC) Program. Typically this program provides coordination of a range of services and can broker private agencies to provide direct assistance in the form of home help, personal care and transport.

### **EACH – Extended aged care at home (EACH) packages**

Individually planned and coordinated packages of care tailored to help older Australians with more complex high level care needs in their home, including nursing care. ACATs assess whether the person is eligible for an EACH package. They are subsidised by the Australian Government and typically provide 8 to 15 hours of direct assistance per week. Equipment and aids such as incontinence pads are also provided. These packages are delivered by charitable and other not-for-profit community-based providers (84%) and private organisations, state

and local governments (Australian Government, April 2012). Under the new legislation introduced in 2013 these are referred to as home care packages level 3 and 4.

### **HACC – Home and community care program**

HACC is a joint Australian, state and territory government initiative that provides a range of basic maintenance and support services to help people maintain their independence at home and in the community. Typically these services include home help, personal care, respite and transport.

### **High level care**

High level care provides accommodation for older Australians who need personal care and related everyday living support (meals, laundry, cleaning services) and also covers additional services such as nursing care, equipment to assist with mobility, and therapy services. EACHs also provide high level care packages of care to older Australians living in the community. ACATs assess for eligibility for both residential and packaged care.

### **Low level care**

Low level residential care provides accommodation, for older Australians who need personal care and related everyday living support (meals, laundry, cleaning services). CACPs also provide low level packages of care to older Australians living in the community. ACATs assess for eligibility for both residential and packaged care.

### **Residential aged care**

Residential aged care is accommodation provided to older Australians. ACATs assess whether the person requires low or high level care in a residential aged care facility.

### **Research case study**

Unit of analysis of this study. Boundary includes the person with dementia and participants who had influence in their life when negotiations took place surrounding the need for a legal guardian. These participants include a social worker, family and service providers.

### **Socio-legal encounter**

A term used by Vittoria (1992) to refer to events bounded in time and space which take place in the context of guardianship law within a particular judicial milieu. Involves the process of transferring decision-making power from a person to another. In this thesis the term is



synonymous with research case study. The encounter of a guardianship hearing, its preparation and boundaries.

**Service provider**

A charitable or other not-for-profit community-based organisation, or a private for profit community-based organisation, that provide services to older Australians through community aged care packages, extended aged care at home care packages and home and community care programs.

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## Introduction

Within the wider cultural context of contemporary Australia older age attracts considerable attention. Often there is a duality of positive and negative messages. When linked to early retirement and financial security, growing old is portrayed as opening up chances to pursue lifestyles filled with opportunities for consumption, leisure activities and new experiences. Alternatively, older age is associated with deteriorating health and it is often quoted in the media that, as a consequence of people living longer, there is an "epidemic" of dementia. The term dementia is used in varied ways but it is primarily understood in Australian culture as an illness with a range of associated behaviours requiring particular medical and social responses. It is mostly depicted as having a trajectory of irrevocable decline where the person can become a financial and emotional burden to others. This raises crucial questions about what it means to be a person with dementia in the Australian context, especially if that person's decision-making ability is challenged. This thesis critically examines these social situations and the engagement of social workers in the adult guardianship process within an Australian legal context.

For diverse reasons some people with changing abilities attributed to dementia are identified as needing an alternative legal decision-maker, through the process of adult guardianship, as they are perceived as being unable to make their own decisions. As a person may lose basic decision-making rights, this process can be one of the most restrictive and powerful types of legal intervention that may be imposed. It is important, therefore, to explore this process and what it means to the person concerned as well as to the significant people involved in the process. It may enhance the life of the person concerned by ensuring their needs are met and dignity maintained. However, it may also do harm if used inappropriately or create a situation which is detrimental to the wellbeing of an older person (Carney & Tait, 1991).

Social workers as professionals are actively engaged in the adult guardianship process in a variety of ways, such as weighing the benefits against the possible harm for individual clients, lodging applications and providing recommendations regarding applications. Social work is a profession that is traditionally and uniquely positioned between the private and the public spheres, where what takes place in personal experience and private relationships concerns the rest of society (Howe, 1994; Parton, 1994) and adult guardianship clearly

occupies such a space. Yet within the social work profession the process of guardianship for people with dementia is an area where there is very little research. As M. Hughes argues in relation to a new wave of recommendations for more substantial restructuring of Australia's aged care system, despite an increasing number of social workers being employed in the aged care sector the voice of the social work profession has been "missing in action." (M. Hughes, 2011, p. 533).

In the Australian context there is a growing body of literature regarding decision-making with people with dementia in areas closely associated with guardianship, for example advance care directives and substitute financial decision-making through measures such as enduring powers of attorney (Squires & Barr, 2005; Tilse, J. Wilson, Setterlund, & Rosenman, 2005). However, the majority of the literature with a direct focus on issues surrounding adult guardianship comes from professions other than social work, such as law and medicine (Bennett & Hallen, 2005; Peisah, Brodaty, & Quadrio, 2006). Whilst studies undertaken by members of the social work profession overseas raise issues that may be seen as significant to the Australian context, for example the idea that decisions are based on values and beliefs about practice (Iris, 1988; Schiemer & Anetzberger, 1999), the background to these studies reflect very different legal frameworks of guardianship to the Australian context. To address this gap in the literature the purpose of this research is therefore to enable social workers to better understand the dynamics involved in adult guardianship proceedings for a person with dementia and provide knowledge that can be used for more effective practice.

Vittoria (1992) draws on the work of Goffman (1961) to propose that guardianship hearings are what Goffman (1991) refers to as "encounters" in that they are events bounded in time and space with a preparation period leading up to a legal gathering of the participants. These encounters are socio-legal in that they take place in the context of guardianship law within a particular judicial milieu. They are a temporary creation of a group, which is involved in the process of transferring decision-making power from one person to another. To put it another way, a focus on the socio-legal encounter of a guardianship hearing, its preparation and boundaries, may be viewed as the arena where the contested, complex and ambiguous issues that are unique to each individual situation are played out by the participants. These types of socio-legal encounters are the focus of the primary research question of this study which is:



*In a contemporary Australian health and welfare context what are the challenges in social work practice with older people, their families and other professionals in disputed, complex and uncertain situations where a legal alternative decision-maker is perceived as necessary?*

In order to address this research question this study seeks to explore and understand the perspectives of all the participants in socio-legal encounters. To achieve this, two areas of theoretical importance and research are bridged. Firstly, at the heart of socio-legal encounters is the person with dementia who is embedded in social structures such as family and health and welfare services, Accordingly the impact of health and social welfare structures, policies and services on participants in socio-legal encounters is viewed as crucial. The health and welfare sector is an area where there have been profound structural changes over the last thirty years and consequently theories and research relating to the impact of changing social policies and reforms are focused upon. The second area of focus concerns more directly the way labels of dementia are given and decision-making capacity is viewed and conceptualised. These understandings have also changed dramatically over the past thirty years. In turn both of these areas of theoretical importance and research have had a historical and contemporary influence on social work practice and this is explored in this thesis.

Therefore, there are two central arguments in this thesis. Firstly, it is argued that identity in older age is shaped by social contexts and for those with the label dementia what that means within these contexts is crucial. It follows that contemporary policies can shape the meaning of old age and can also influence the practice of social workers. Secondly, it is argued that dementia and capacity discourses have been constructed and changed over time and consequently dominant discourses can shape social work practice. From the social work practice perspective, how dementia and capacity are understood in complex social situations such as socio-legal encounters are crucial as these understandings can dominate the interactions of those involved.

The impetus for this thesis grew out of practice-based social work knowledge. The researcher is a social worker with extensive experience in social work practice with people with dementia and their families and is currently a practising social worker in this field. The research topic arose out of experience working with the conflicting dilemmas and issues that arise in social work practice where an alternative legal decision-maker is identified as being needed by a party involved in a particular social situation. These socio-legal encounters are individually unique and complex and can be extremely stressful and emotionally painful for

those involved. There are varied contexts, such as family conflict or no apparent family support for the person with dementia, and there can be disputes and conflicting opinions between the participants. There are commonly multiple health and social welfare agencies involved.

This thesis is concerned with investigating socio-legal encounters and is structured in eight chapters. Chapter One outlines the theoretical perspectives of this thesis and the framework used to present the literature review, as well as clarifying terminology. The approach of this study is to use perspectives from social constructionism, with the links which can be made from social constructionist perspectives to modernism and postmodernism being taken into account. Chapters Two and Three comprise the literature review. Chapter Two is entitled "The influence on social work practice of how shifting health and welfare discourses have shaped the experience of ageing." This chapter examines the literature that addresses the two interrelated components of how health and welfare systems have a dominant impact on how old age is constructed, and can shape identity and the experience of ageing, and so accordingly influence the practice of social workers engaged with older people. Chapter Three is entitled "The influence on social work practice of how shifting dementia and capacity discourses have shaped social action." This chapter moves to a narrower focus on dementia and capacity discourses and reviews the literature aimed at understanding the impact of how dementia and capacity discourses are constructed and have changed over time and how social work practice has responded to these changes.

Chapter Four presents the methodology of the study. Chapters Five, Six and Seven present an analysis of the findings of this thesis in an integrated way in the context of the literature review. Each of these three chapters is structured around an organising theme based on a thematic network analysis. The theme of Chapter Five reflects the impact of private and professional contextual influences on participants in the process of decision-making in socio-legal encounters where there are clear differences in how decisions are made and underlying inherent power dynamics. The focus of the analysis in Chapter Six is on how participants' knowledge bases, which support the process of decision-making, are diverse and constantly shift and change. This is highlighted through the impact of critical events and constructions of risk and capacity. In Chapter Seven, how ethical dilemmas involve balancing responsibilities and rights is explored. The theme pertains to how responsibility for action is

negotiated between the participants in socio-legal encounters and that the notion of protection may be viewed as multilayered. Chapter Eight comprises the Conclusion to the study.

# Chapter One

## **1.1 Theoretical perspectives: social constructionism and the links to modernism and postmodernism**

This chapter concerns the theoretical approach of this thesis and the consequent framework for the literature review. Use of terminology is clarified and particular positions taken regarding theoretical stances are identified. As highlighted in the Introduction, the theoretical approach chosen is to use perspectives from social constructionism to critically examine how dementia and capacity discourses, within the wider context of health and welfare, variously influence the context of social work practice with older people. The links which can be made from social constructionist perspectives to modernism and postmodernism are taken into account and provide the framework for the following two literature review chapters.

Clearly social constructionism is subject to many interpretations and as Burr outlines it can be seen as a theoretical orientation which, to some extent, underpins newer alternative approaches that have emerged in psychology, the social sciences and humanities, such as "critical psychology", "deconstruction", and "discourse analysis" (Burr, 2004, p. 1). Therefore any one description of social constructionism is inadequate as it is a very broad term that encompasses many different meanings. Burr maintains that it draws on influences from a number of disciplines including philosophy, sociology and linguistics and cannot be traced back to a single source (Burr, 2004, p. 268). Its philosophical roots have been influenced by the works of Marx, Kant and Nietzsche (Burr, 2004), Durkheim (Houston, 2001) and Wittgenstein (Thornton, 2006; Witkin, 1999). Social constructionist perspectives can be seen to be particularly relevant to the field of ageing and dementia as emphasis is placed on the processes through which people define themselves and their identities. As Parton and O'Byrne argue constructing social realities is seen as an ongoing aspect of people's everyday lives and relationships (Parton & O'Byrne, 2000b, p. 1).

Although there are many interpretations, for the purposes of this thesis social constructionism refers to a broad theory of knowledge that had its origins in the publication of Berger and Luckmann's book *The Social Construction of Reality* (1967), which drew on the view that as people we construct our own and each other's identities through our everyday encounters

with each other in social interaction (Burr, 2004, p.13). It is possible to identify a number of recurrent features shared among different writers that are said to have a family resemblance (Burr, 2004, p. 2). Accordingly, there are four key assumptions outlined by Gergen (1985, 1999). Firstly, social constructionism dictates that a critical stance is assumed toward taken-for-granted knowledge or understanding of the world, including our own understanding. It challenges the view that conventional knowledge is based upon objective, unbiased observation of the world and proposes that individuals must be careful of making assumptions about how the world appears to be. As an example, Gergen argues that emotions are not "out there" to be studied but acquire meaning from context of usage. For example, how anger is expressed may be dependent upon whom the person is angry with and a judgement about how angry to be (Burr, 2003 p.128). Secondly, she argues that the way in which an individual commonly understands the world is historically and culturally specific. This means that all ways of understanding, including knowledge acquisition, are historically and culturally relative and these can change over time and place. An individual cannot assume that their ways of understanding are necessarily the same as others. This is relevant to the main arguments put forward in this thesis that relate to how identity in older age is shaped by social contexts and what the concepts of dementia and capacity mean within these contexts. Thirdly, knowledge is sustained by social processes. Gergen argues that an individual's common ways of understanding are not derived from the nature of the world as it really is but that people construct understandings between themselves by the use of language. Fourthly, knowledge and social action go together in that the negotiated understandings between people can take a wide variety of different forms but each different construction also brings with it a different kind of action from human beings. For example, if dementia is constructed as a disease to be treated, the action is to provide medical intervention. Gergen argues that some constructions of the world sustain some patterns of social action and exclude others and are bound up with power relations. Also, language is a form of social action as when people talk the world is constructed (Burr, 2004, pp. 2-8).

Gergen, as a social psychologist, has used the term "social constructionism" to refer to his own and others' related perspectives since the 1970s. These four assumptions have been put forward by writers across the disciplines of social work and psychology as presenting perspectives of social constructionism (Burr, 2004; Houston, 2001; Parton, 2003; Parton & O'Byrne, 2000b; Witkin, 1999). In these four assumptions Gergen challenges what he describes as the modernist presumptions of psychology. At the core of modernism is a belief

in a knowable world that constitutes its subject matter based on the notion that observable behaviour is the focal concern. In addition to this he suggests that modernism presumes there are universal properties, principles or laws that may be discovered about the subject matter. Gergen critically interrogates the idea that empirical methods, such as the controlled experiment, can provide absolute truths about the nature of the subject matter. For Gergen, modernist views see research as progressive in that false beliefs can be abandoned in the move toward the establishment of reliable, value-neutral truths about the object world (Gergen, 1999, pp. 18-20).

Gergen argues the postmodern turn means that the subject matter is "vanishing" and fundamental questions are raised about the way language operates, where discourses about the world revolve around social processes which then become crystallized in terms of rules and options. Ideas arising from modernism about universal properties shift to contextual reflection where the roots of the preferred discourse are questioned in regard to what patterns of culture are sustained and what is discouraged. Using controlled experiments as a method of research is therefore marginalised and the modernist grand narrative of progress is abandoned. Factual knowledge then is saturated by perspectives and truth can be a matter of which perspective is prioritised (Gergen, 1999, pp. 20-25).

Further links between postmodernism and social constructionism are made by Gergen, who draws on the works of Foucault with regard to interpretations of knowledge and power. As perspectives are developed and integrated into society, social arrangements are altered and discourse about issues such as sexuality and madness can operate as a focus for social change (Foucault, 1979;1980 cited in Gergen, 1999, p. 23). This is also applicable to dementia and the concept of capacity. As with many other social constructionists, Burr also makes links to modernism and postmodernism in regard to discourses and subjectivity. She defines a discourse as a "set of meanings, metaphors, representations, images, stories, statements and so on that in some way together produce a particular version of events." (Burr, 2004, p. 64) Subjectivity "is a term used by social constructionists to refer to the state of personhood or selfhood." (Burr, 2004, p. 204) For Burr, the production of identity and subjectivity are through discourse (Burr, 2004, p. 105). She draws on the work of Harre, who argues that the form of subjectivity people live and experience depends upon the particular stories or narratives available to us in our culture and embedded in language. Therefore, people of all cultures organise their personal experience into a meaningful system which can be called the

"self" (Harre, 1985;1998 cited in Burr, 2004, p. 139). The notion of subjectivity challenges the modernist idea that identities are fixed and personalities are self-contained, whereas subjectivity allows for identity to be constructed out of the discourses culturally available to individuals and created through language and meaning (Burr, 2004).

### **1.1.1 The realism vs. relativism debate in social constructionism**

These links between social constructionism, modernism and postmodernism are also pivotal in understanding the debate within social constructionism about relativism. There is a continuum of acceptance of relativist ideas and people vary in the distance that they are prepared to travel along this continuum (Burr, 1998, p. 15). Spanning the continuum are relativity and pluralism at one end and, at the other, an emphasis on the influence of certainty and fixing beliefs in specific contexts. Burr (2003) outlines how, although the tenets of social constructionism appear to lead to a relativist position, some have resisted this. Those that have resisted argue that an external world exists independently of individual subjectivities. This view accepts that whilst knowledge regarding this world is constructed, direct experience is mediated by the relatively enduring structures of a society into which a person is born and lives their lives; where there are values and beliefs that impose constraints on what it is possible to do and say (Burr, 2004, p. 95). However, for those sympathetic to the opposite end of the relativism continuum, everything is viewed as a social construction where different constructions of the world can be judged only in relation to each other and not by some standard or universal truth. Here the growth of the scientific tradition of positivism that accompanies western rationality is viewed as a highly elaborated set of conventions brought about by one particular culture.

Along this continuum the positions taken are varied and there can be much overlap. Burr argues that "in the differences of opinion as to the existence of some (in principle knowable) reality behind social phenomena it is not necessarily the case that those who adopt a more explicitly relativist position retain no concept of reality." (Burr, 1998, p. 18) She proposes that those adopting a relativist position towards the end of the continuum do not deny the existence of a material reality but question that it can be directly known and would find problematic the idea that reality is reflected in language (Burr, 2004, p. 102). For example, Collier's (1998) stance is that there is a real world which pre-dates experience of it and the language used to describe it, whereas for Brown, Pujol and Curt (Brown, Pujol, & Curt,

1998) what is real is what is manifested - such as experience and consciousness - but that structure is contingent on language. It may be argued that, for those who take up positions at the fixed beliefs end of the continuum the danger is that the values and beliefs held regarding "reality" are so close to the status quo that by default this can lead to a position that does not challenge taken-for-granted knowledge. Alternatively, at the other end of the continuum, it may be argued that the danger is one of nihilism or paralysis. If all perspectives are given equal weight, how is it possible to argue the legitimacy of a position if there is no presence of "truth" or "reality". Burr argues that both views are based on values and many participants in the debate agree on the necessity of making moral and political choices (Burr, 1998).

Hruby (2001) links this debate with three waves of social constructionism where what he describes as the postmodern turn in social psychology can be seen to particularly influence the second wave. He relates the first wave as arising from Berger and Luckmann's *The Social Construction of Reality* (1967), where language allows building of subjective social meanings, but argues that significant authors, such as Berger and Luckmann (1967), Kuhn (1962) and Wittgenstein (1990), did not actually support an implicit relativism perspective. The second wave he describes as a shift to postmodern social constructionism and its striking characteristic is its "unlikely combination of uncompromising social critique with unbounded epistemological relativism." (Hruby, 2001, p. 55) For Hruby, the third wave of social constructionism is one that leads to a reappraisal of what he calls indiscriminate relativism. Although he relates the second wave to the work of Gergen, he does not claim Gergen travels to the end of the relativism continuum but that this second wave emphasises the paradigm shifts of the 1970s where the prevailing academic milieu was linked to the conceptual liberation implied by relativism.

Pendulum swings in relation to perspectives on relativity are also identified by Gergen (1985) in the historical context of social constructionism. However, the pendulum swings, for Gergen, range from objective truth to the end of the relativity continuum. Gergen strives to transcend the debate. He argues this can be done by an alternative scientific metatheory based on constructionist assumptions. According to his thesis, challenging the western conception of objective knowledge by an alternative metatheory "would remove knowledge from the data-driven and/or the cognitively necessitated domains and place it in the hands of people in relationship" (Gergen, 1985, p. 272). For Gergen, scientific activity is governed by normative rules so investigative methods do not have to be abandoned, but individuals can view these



rules as historically and culturally situated and so subject to critique and change (Gergen, 1985, p. 273).

The position taken in this thesis regarding relativity is one that travels down the continuum and reaches agreement with those who argue that language generates the reality we know. It is through culturally available discourse that meaning and identity is constructed by individuals. However, the tension is, in Gergen's terms, that this does not deny that there is the existence of a material reality beyond discourse. So as Burr argues "we can talk of things being at one and the same time socially constructed and real." (Burr, 1998, p. 22) Put another way, this does not deny the materiality of events, but that our way of understanding reality is through discourse, which underpins perceptions of reality. This stance is one that reflects the strength of relativism in that challenges can be made to the taken-for-granted knowledge in contemporary Australian society regarding the concepts of dementia and capacity. It also allows for acceptance of plurality of knowledge and the possibility of creating social change through discourse. The dilemma is, as Merttens (1998) expresses, if an explicit relativist perspective aids in challenging the status quo, what version of events are chosen and how are some accounts privileged over others?

Merttens, making particular reference to education, argues that as individuals are located in their own value system judgements can only be made and defended from within this system. So the best outcome is to adopt practices which appear to create possibilities for increasing quality of life and ensuring that marginalised voices are heard. This can produce practices that are more likely to provide alternative constructions for individuals (Merttens, 1998). This value position is relevant to decision-making in complex social situations that social workers find themselves in. Social workers in a health and welfare contexts are embedded in the discursive structures available to them, such as within the context of an institution like a hospital. Recognition of plurality of knowledge and the different constructions of meaning made by people within the complex social situations in which social workers operate means that different perspectives can be included in the discussions and negotiations. Also, this recognition can provide a platform for social work to mediate and advocate individual perspectives.

Looking at dementia, the position taken within this thesis is one that agrees with a relativist perspective of social constructionism as outlined above. Since the beginning of the twentieth century the term "dementia" has been used in discourse in western countries to construct

different meanings which reflect a range of understandings of the term. Historically and culturally different terminology reflects many different socially constructed meanings embedded in the use of language. Since Greek and Roman times philosophical and literary sources have referred to what have been seen as the natural consequence of ageing, such as memory loss, confusion and loss of other physical functions (Berchtold & Cotman, 1998; Forstl, 2005; Karenberg & Forstl, 2006; Lacey, 1999). Plato and Aristotle describe "forgetfulness" and "stupidity" in older people and Cicero maintained that an active intellectual life could postpone what he saw as mental decline associated with older men of lesser character (Karenberg & Forstl, 2006). Both Chaucer and Shakespeare commented on the inevitability of "dotage" and what they saw as age-related disabilities. In the seventeenth century, Layman argues, a large number of older women, who today could be perceived as having a dementia, experienced horrendous deaths as a result of social action arising from superstitious beliefs. They were identified by others as witches (Lyman, 1989, p. 598). Since the twentieth century, in discourses that reflect dominant views, dementia is generally used as an umbrella term to refer to a variety of medical classifications of illness. However, there is no medical consensus on what factors cause what can be seen as a plethora of conditions or how each illness should be classified. This in itself reflects different constructions of what comprises a specific illness (Krishnan, 2007; Lautenschlager & Martins, 2005). The most well-known classification is called Alzheimer's Disease.

In contemporary society there are many widely different, varied and disputed meanings attached to the word 'dementia' and this makes using the term very problematic. However, dementia is used here to describe an older person who perceives themselves, or is perceived by others, as having decision-making difficulties due to changing abilities. What is important from a social constructionist viewpoint is that the narrowness and evaluative impact of a medical diagnosis is not accepted and it is how people are treated that is more important. How these changing abilities are viewed in social interaction involves the interpretation of experience within our particular cultural context of assumptions, norms and values as well as the economic structure of the society (Burr 2003, p. 40). As a result, change can be viewed as a deficit or framed more constructively. Accordingly, and in common with the literature reviewed, the person or group of people who are the focus of this study will be referred to as the person with dementia or people with dementia.

While there are many possible different theoretical approaches and perspectives that could be taken to the topic of dementia, and any subsequent perceived incapacity and need for a legal alternative decision-maker, the approach taken here is one that allows for an analysis of the shifting discourses in social contexts in contemporary Australia. The approach assists in understanding how specific discourses surrounding these concepts arise, and how some discourses become privileged over others. The claim by Gergen that "forms of negotiated understanding are of critical significance in social life" (Gergen, 1985, p. 268) is particularly relevant to complex social situations and understanding how the participants make decisions. In contemporary Australian society there are different and competing discourses surrounding dementia and capacity and it is to understand these different discourses, where there is a mixture and overlap of ideas, that makes the theoretical approach particularly relevant. Utilising social constructionist perspectives to challenge modernist concepts and ideas enables a form of analysis that can explore the underlying tensions and aids in the analysis as it allows assimilation of diverse material regarding the shifting discourses.

## **1.2 Framework for the Literature Review**

It was established in the Introduction that the framework for the literature review was developed using key concepts from social constructionism with connections being made to both modernism and postmodernism. Clearly, the perspectives from social constructionism drawn upon in this thesis do not form a unitary theory but a wide framework for understanding that sits in the broad sweep of postmodernism. The term postmodernism in itself covers a broad variety of developments and means different things to different people, but for the purposes of this thesis it is the links with social constructionism that are of particular significance. To clarify the use of the terminology in the context of this study, "modernism" refers to the key ideas and values characterised by the Enlightenment (Fawcett, 2009a, p. 120). Drawing upon the explanation of Fawcett and Featherstone (1998) the term "postmodernism" is distinguished from "postmodernity" and refers to a range of theoretical perspectives which can be related in various ways to discussions about postmodernity or the postmodern condition (Fawcett & Featherstone, 1998, p. 68). Postmodernism is viewed here as a movement that challenges the core notions of the Enlightenment, such as reason and a belief in progress. However, although the word "post" means "after" this does not mean the demise of Enlightenment ideas. Crotty (1998) outlines that postmodernism can be viewed as

a reaction to modernism with continuity between the two strongly maintained. Alternatively, it may be viewed as definite rupture that calls into question all that modernism asserts (Crotty, 1998).

The view taken here is consistent with the first view in that there is continuity and a mixture of beliefs; the boundaries between modernism and postmodernism are not a dichotomy but blurred. For example, views based on reason and rationality existed prior to becoming core notions of Enlightenment understandings. Similarly, these same notions are present in contemporary settings and from a postmodernist perspective can be challenged. The view adopted on postmodernism here is consistent with one that Fawcett takes from a critical postmodern perspective. Fawcett argues that modernism and postmodernism orientations are not opposite sides of a coin but can be drawn on to produce a form of analysis that makes links and explores tensions (Fawcett, 2000 cited in Fawcett, 2009a, p. 124). Fawcett argues that critical postmodernism can address the arguments that relativity can create paralysis in taking action as there can be an inability to choose one version of events over another since if all views are given equal weight a decision can never be made. By posing questions in relation to the operation of knowledge and power, Fawcett argues, social workers can draw attention to what information is being privileged and what information is being downgraded in particular contexts (Fawcett, 2009a, p. 124). Critical postmodernism therefore emphasizes the significance of negotiation and although "all views may not be given equal weight all views are attended to and outcomes are negotiated in specific contexts or situations." (Fawcett, 2009a, p. 125)

Whilst there are interlocking ideas and much overlap, the key concepts put forward by several authors (Burr, 2004; Crotty, 1998; Fawcett, 2009a; Gergen, 1985, 1999; Howe, 1994; Powell, 2006) that mark the differing discourses between modernism and postmodernism can be grouped into three significant areas for the purposes of analysis in this study. These three significant areas are used to present the material in the literature review in Chapters Two and Three. Firstly, there has been a shift in discourse from the modernist use of grand narratives and ideas of progress to postmodernist ideas of pluralism and difference. As outlined in the preceding section of this chapter, Gergen argues that in modernist presumptions there is a belief in universal properties, principles or laws that may be discovered about these properties (Gergen 1985,1999). A modernist belief in progress means that the world can be made better by controlling the natural and social world and then improving it (Howe, 1994, p. 516).

However, postmodernism challenges that objective knowledge can be disconnected from historical, social and cultural contexts and that the world can be understood in terms of grand narratives. Rather, there is co-existence of a multiplicity and variety of situation-dependent ways of life which Burr refers to as pluralism (Burr, 2004, p. 12). At a macro level of society this shifting discourse may be seen as underpinning structural change in health and welfare services.

Secondly, there has been a shift in discourse from modernist ideas of reason and certainty to postmodernist discourses of uncertainty and complexity. Modernist ideas are based around an understanding that reason provides more freedom to individuals and therefore more certainty (K. Healy, 2005, p. 194). So there is a search for the objective truth to understand the nature of reality through reason and rationality (Burr, 2004, p. 10). For Gergen, the taken-for-granted world of reason and emotion in psychology means that if reason dominates, then emotion is anti-rational and its discourses are not favoured. In postmodernist discourses there is a shift from reason and certainty to uncertainty and complexity. Reason and certainty are not perceived as the liberating tools envisaged but can be viewed as political instruments to privilege the views of some groups, for example professionals over service users (Fawcett, 2009a, p. 121). Truth can be seen to be located in different contexts. Language and discourse influence how the world is to be seen and relate directly to power as opposed to authority ground in rational thought.

Thirdly, there has been a shift in discourse from modernist notions centred around fixed identities where personalities are self contained, unitary and unchanging (Burr, 2004). Postmodern concepts raise the idea of subjectivity where personalities are not fixed but created through language and meanings are fluid and change (Lyotard, 1984; cited in K. Healy, 2005, p. 196). So identity is constructed out of the discourses culturally available to individuals.

### **1.3 Summary**

This chapter has presented the theoretical approach of this thesis. Use of terminology has been clarified. The position taken in this thesis regarding relativity has been delineated as one that agrees with a particular relativist perspective of social constructionism in agreement with those who argue that language generates the reality known by individuals and that it is

through culturally available discourse that meaning and identity is constructed. Also, regarding dementia, the position taken has been made clear as one that agrees with a relativist perspective of social constructionism. The framework for analysis of the literature review was presented and this review follows in Chapters Two and Three.

## Chapter Two

The Introduction to this thesis presented the overall background, purpose and research question and provided an outline as to the content of each chapter. Chapter One introduced and explored in some depth the theoretical approach taken and the consequent framework for the literature review. Terminology was clarified as were particular positions taken in this thesis, such as those regarding relativity and dementia. This chapter contains an Introduction to the Literature Review before turning to the main purpose of the chapter, which is to review the literature in relation to the first area of theoretical importance and research, that is the impact of changing health and social welfare policies, structures and services on those who are growing old

### 2.1 Introduction to the Literature Review

In the Introduction to this thesis it was noted that in contemporary Australian society older age in the wider cultural context can attract a duality of attention, sending both positive and negative messages. It was observed that one reason for the negative focus of attention may be that the dominant understanding of growing old portrays ageing as a medical problem focusing on diseases, their causes, management and treatment. Correspondingly, whilst the topic of ageing attracts a great deal of medical and social research, little attention has been paid to studies that address how health and welfare contexts directly affect health professionals and older people and their families with whom they engage in practice. However, as was also raised in the Introduction, over the past thirty years a succession of health and social welfare policy reforms have been implemented that have had an unprecedented impact on the way old age is constructed and services are delivered (Biggs & Powell, 2001; Webb, 2006). There is a growing recognition that one of the major difficulties in understanding ageing is that it has not been influenced by social theory (Powell, 2006; Powell & Longino, 2001). Powell argues that theoretical innovations in gerontology have lagged behind other sociological narratives and identifies that "part of the problem about lack of social theory in the study of ageing relates to the field of gerontology itself. Gerontology as a scientific discipline has been dominated with a preoccupation with biomedical sciences and its constituent elements of decline models" (Powell, 2006, pp. 3-4).

Underpinning these health and welfare policy reforms are parallel discourses that reflect changes in the ways that labels of dementia are given and decision-making capacity is viewed and conceptualised. Since the scientific foundation of modern medicine in the eighteenth century (Knight, 1998) in western countries the conventional understanding of dementia has been medicalised and it has been understood as a disease with associated decline due to neurodegenerative changes. This understanding is increasingly being challenged as it has become more accepted that how we think about, and communicate with, people who are seen to have a dementia and their social, historical and cultural context can all be of more significance (Downs, Clare, & Mackenzie, 2006; J. C. Hughes, Louw, & Sabat, 2006; Kitwood, 1997; Nolan, Ryan, Enderby, & Reid, 2002).

In Australia, if an older person is perceived to have diminished capacity and the ability to manage their affairs is disputed, when all informal arrangements break down adult guardianship is the legal mechanism designed to appoint an alternative decision-maker (Carney & Tait, 1998). Australia has unique legislation in the area of adult guardianship but the literature reflects that little attention has been given to social work practice within this socio-legal context (Logan, 1991). Each instance can be complex and multi-layered and there are distinctive relationships between the older person, their relatives or significant people and professionals involved. Also, the health and welfare systems in which these social situations are embedded are complex and largely uncoordinated (Australian Government, April 2012). Most significantly, as raised in the Introduction to this thesis, the stakes are high as a successful application for guardianship takes away the right of an individual to make their own decisions in certain areas. This strikes at the heart of the core social work values of self-determination and social justice (Australian Association of Social Workers, 2010). It is also central to the primary research question of this thesis concerning the challenges faced by social workers within these socio-legal encounters.

The perception that a legal decision-maker is necessary is pivotal to this study as it raises two fundamental issues. Firstly, why it is necessary to understand how decisions are being made in these complex social situations and, secondly, why it is necessary to understand the notion that there ought to be somebody with responsibility to decide who has the ability to make these decisions and who does not. These questions relate to how claims are made that a person lacks the ability to make their own decisions and what criteria are taken into account in making these claims. What is seen as appropriate can relate to what values underpin health



and welfare systems as well as to understandings of dementia and capacity. These issues are explored in this literature review.

The two literature review chapters address two of the central arguments raised in the Introduction to this thesis. This current chapter will critically examine literature from the institutional perspective of how health and social welfare systems have had a dominant impact on how old age is constructed and influence on social work as a profession. This is in order to argue that contemporary policies described as neoliberal, or new public management (Connell, Fawcett, & Meagher, 2009a), shape the meaning of old age and dominate the practice of social workers in contemporary Australian society. Chapter Three will focus on literature that aims at understanding the impact of how dementia and capacity discourses have been constructed and have changed over time, and how social work practice has responded to these changes. The argument presented is that from the social work practice perspective how dementia and incapacity are understood in complex social situations are crucial as these understandings can dominate the interactions between those involved.

## **2.2 The influence on social work practice of how shifting health and welfare discourses have shaped the experience of ageing**

K. Healy (2005) argues that at the macro and micro levels of society, the context within which social work is practised is shaped by the dominant discourses from both an institutional and professional knowledge and values base. In order to argue that contemporary policies shape the meaning and construction of old age, and influence the practice of social workers engaged with older people, the theme of this chapter is an exploration of the literature relating to these two interrelated components. The literature reviewed in this chapter draws on the perspectives of a number of authors who argue that ageing is a socially constructed event which is influenced by a number of elements such as the political economy, where structural pressures and constraints, including the role of the state, influence the experience of ageing (Biggs & Powell, 2001; C. L. Estes & Phillipson, 2002; Phillipson, 1994; Powell, 2006; Powell & Biggs, 2000; Powell & Longino, 2001; Titterton, 2005; Tulle-Winton, 1999; Walker, 2000; Webb, 2006).

These authors challenge the representation of ageing through the modernist gaze as a medical problem focused on the diseases of those growing old (Powell, 2006). Equating ageing with illness is seen as shaping the attitude of the person themselves and those of others towards them in a negative construction of ageing (C.L. Estes & Phillipson, 2002). Challenging this taken-for-granted knowledge allows for an understanding of the impact of the health and welfare reforms that have taken place over the last three decades and how social work practice has subsequently been influenced. The authors who provide critiques of these reforms argue that they are influenced by ideologies that reflect privatisation, self-responsibility and consumerism within the health and welfare system and the dominance of the discourse of risk (Powell & Biggs, 2000; Powell, 2006; Webb, 2006). Also they coincide with an increase in the consideration of power vested in professional opinion and introduced techniques such as case management (Biggs & Powell, 2001).

In this chapter the shift in discourse from grand narratives and progress to pluralism and difference provides a focus for the literature that presents an overview of structural developments in health and welfare services since the Industrial Revolution. The shift in discourse, from reason and certainty to uncertainty and complexity, is particularly relevant to two fundamental concerns in contemporary social work practice. Firstly, there is the modernist conceptualisation of risk which increasingly affects those who are ageing, particularly those with the label of dementia, and professionals working within health and welfare contexts (Green & Sawyer, 2010). The second concern is developments made in social workers' understanding and approach to ethical issues, which may be viewed as one of the most significant developments in the last thirty years and pertinent to decision-making (Banks, 2006). Attention is therefore paid predominantly to these two concerns in the analysis of the literature surrounding this shift in discourse. Thirdly, the shift in understandings from fixed identities to subjectivity is particularly relevant to understandings of the "self" by those growing old. Although obviously not a homogenous socio-economic group, what is significant to older people is the changing discourse surrounding the relationship of those who are ageing to employment which has emerged in conjunction with modernist notions.

## **2.2.1 Grand narratives and progress to pluralism and difference**

### **2.2.1.1 The modernist message: ageing is a time of physiological change and dependence**

As explored in Chapter One, ideas from modernism mean that the world can be understood in terms of grand narratives that have universal applications. Powell (2006) argues that the modernist set of beliefs that emerged to shape a view of ageing is based on western rationality and the growth of the scientific traditions of positivism. For Powell, the modernist message of grand narratives, or "big stories", is that the experience of growing old is constructed by an all-embracing dimension, where the characteristics of older people are reduced to biological factors and a search for the reason human beings change over time in terms of physical and physiological changes (Powell, 2006). This construction of ageing may be linked to financial and physical dependence brought about by industrialization (Lacey, 1999). The Industrial Revolution itself is generally regarded as being associated with the key ideas of the Enlightenment, including the modernist messages of grand narratives and progress. The underlying belief in progress means that once an empirical search finds the reasons for this frailty, and physical and mental diseases, cures can be found. However, in the meantime there is little to be done. This section explores these modernist messages by providing an overview of their impact on structural developments in public policy arising from the Industrial Revolution. This is to argue that the main modernist message regarding the experience of ageing is that it is a time of physiological change and dependence. This message is particularly relevant to those given the label of what is contemporarily referred to as dementia.

It is important to note that the literature reviewed in this thesis aims to provide an understanding of the developments and current construction of ageing in western cultures and in particular in Australia. To understand how the modernist message of grand narratives and progress underpinning these structural changes influenced a unique and significant shift in how identity is constructed in older age, a brief exploration of the impact of perceptions of ageing in other societal contexts is helpful.

It appears that there are many examples, historically and in different cultures, of a positive construction of identity with ageing. In many indigenous communities, such as indigenous Australians before white settlement, there were complex social systems and welfare based upon cooperation, sharing, personal and family obligations (Baldry & Green, 2002). Others

argue that historically traditional Chinese society provided a high status to older people as they were valued for their accumulated knowledge and position within the extended family. In India, before industrialization, older people had responsible leadership and decision-making roles due to their perceived wisdom and knowledge (Powell, 2006, p. 21). There is a view that respect for older people, particularly through patriarchy, was present in Ancient Greece (Powell, 2006, p. 21). However, Gilleard (2007) outlines that although in both Roman and Greek societies little collective provision was made for older, sick or disabled people, the Byzantium Empire established lasting legacies in that a mix of institutions providing accommodation and charity created a prototype of the "welfare state". Gilleard argues that older age acquired a distinct moral authority in this society, which was not evident in Greek or Roman times, and the construction of older age as one of authority and respect as evidenced by the necessity of most figures of authority being seniors, such as abbots or senators. However, women had to be aged 60 years before they could be appointed deaconesses (Gilleard, 2007). Field (2011), also argues that in Britain a mixed welfare state precedes what can be referred to as modern provision. He states that mediaeval institutions, which could be seen as hospitals today, were church-run and such communities looked after frailer and older people. Parishes, which were the first basic administrative units in Britain, had a responsibility to their poor and before the new Poor Law Act of 1834 "beggars" were sent back to their parish of origin for help.

Applying social constructionist perspectives, the resulting social actions arising from the Industrial Revolution can be seen to have brought about social change on an unprecedented basis. As the Industrial Revolution progressed migration to urban areas led to problems on a social scale not experienced before. In Britain, the Poor Law Act of 1834 initiated a change in service delivery through the creation of "poorhouses", which can be seen to represent a form of residential institution. Phillipson (1994) notes that "outdoor relief" was seen as too expensive and in place of this the poorhouses had an emphasis on keeping conditions squalid so that people would be encouraged to find employment and avoid dependency. Further he argues these poorhouses represent a denial of citizenship as a means of controlling the poor and unemployed. For older people, who became dependent on this form of support, it was not until the close of the eighteenth century that the regime was softened with reforms that gave older people the freedom from having to wear a uniform and to go out for walks (Longmate, 1974, cited in Phillipson, 1994, p. 105). Field argues that the Poor Law of 1834 can be seen as being introduced to apply the principle of "less eligibility" where help was only offered if a

person came into the "house", as the poor law institution was known (Field, 2011, p. 2). This was a shift in dominant ideas when, due to the influence of the Christian Church charity was seen to be a sign of one's piety and direct relief in the form of giving was to alleviate need, not to change the root causes of poverty.

The concept of offering help through a "house" or institution to those who are eligible, because they are not able to work to contribute to the vision of progress, may be viewed as a significant structural change in service delivery that was inherited from Britain with the early white settlement of Australia. With early white settlement in Australia, British influences were largely replicated. Although there were similarities in developments of social welfare provision, such as identifying the deserving and undeserving poor, there were also contrasts in that Australia had no history of poorhouses (Carney, 2006). However, the social action of building institutions was enshrined in the subsequent laws of the colony. As Howe points out, if what were seen as the social and biological deficiencies of people put a limit on what could be achieved, this either dimmed the modernist vision or reconstructions were needed (Howe, 1994, p. 517). Fine (1999) describes how the New South Wales Government's response to welfare support was to provide grants to a third party and therefore channel funds to non-government organisations. In 1818 the Benevolent Society was established and in 1821 the government funded the building and operation of a destitute asylum on behalf of this Society. Other public and charitable destitute asylums followed. Fine (1999) says that initially in the colony older people needing support due to physiological change became inmates of facilities for the destitute, similar to other members of the population. These were older people who became dependent because they were either unable to provide for themselves or did not have families to support them. As in Britain, a second, more benevolent approach to older people emerged, driven by public enquiries regarding the condition of older people in the asylums.

In the New South Wales (NSW) context the number of asylums grew and one asylum in particular became the state centre for older people in 1893. Thus the main welfare provision for older people who were financially dependent was institutional care. This included people who, in contemporary terms, would be viewed as having dementia. In the early twentieth century Australia pioneered collective legislation through the establishment of pensions (Chenoweth, 2008). Paradoxically, whilst laying the basis for the growth of a culture of rights and entitlements, the establishment of an aged pension also reinforces the modernist message that identity in older age is experienced as a time of physiological change where an inability

to participate in the workforce results in financial dependence. Fine (1999) outlines that there was an expansion of other welfare provisions, outside of institutional walls. In 1900 district nursing services were established and in 1944 the NSW Housekeepers Emergency Service was introduced. After World War II there was a greater expansion of social service provisions which impacted on the experience of growing old.

Chenoweth (2008) notes how Australia developed a number of post-war initiatives which formed the basis of a welfare state based on Keynesian economics. Associated with the theory of John Maynard Keynes there was a strong emphasis on governments taking active and interventionist roles in the economy. This paralleled developments in other parts of the world and Macintyre describes how the welfare state came to be seen as a built-in economic and political stabilizer. Macintyre argues that the relationship between the individual and state was one where the state had a responsibility and where the individual did not have to be identified as lacking in some way to receive a service (Macintyre, 1999, pp. 113-114). He also argues that after World War II the notion of welfare "rights" was asserted unambiguously in Australia as recognition that for those who could not work welfare could not be left to organisations set up for charitable purposes (Macintyre, 1999, p.111). As Powell states, from this view point growing old was a collective experience with some notions of shared responsibility (Powell, 2006, pp. 130-131). However, as Biggs and Powell argue, it was still difficult to fit older people into the narratives of production and work and to reconcile growing old into the rhetoric of progress and investment in the future (Biggs & Powell, 2001).

Walker (2000) identifies distinct phases in the post-war European evolution of social policy. In the first phase pension systems were consolidated, social expenditure rose rapidly and the main goal of public policy was to provide for income security in old age and ensure the transition of older workers from employment to retirement. Walker also argues that low pension payment rates, in relation to income from work, were seen as justified as the economic needs of older people were perceived as being less (Walker, 2000). In the second phase, in the decade starting from the mid 1970s, Walker argues that the social meaning of ageing was reconstructed again and hence the social action changed. Due to the massive fall in economic activity and collapse of employment there was a growth of pension measures to encourage early retirement. The growth in early retirement reconstructed old age from a simple age-related status with a single lower entry point into a broader category. This

unchecked growth of early retirement, Walker argues, may be seen to have reinforced the devaluation of older people and laid the basis for the mounting concern about the economic consequences of the population ageing and projections of dependence ratios. While clearly there is a differential impact upon an older person, depending on their socio-economic position, overall Walker's arguments are significant in that they reflect what is now a contemporary dominant discourse.

Alongside these changes Phillipson (1994) outlines the shift in provision of welfare services post World War II. In Britain, this involved a new focus on providing non-residential care, as opposed to non-hospital care, with a key element being the development of a range of services to support people's needs at home. Australia followed suit in 1969 with home support services and paramedical services being introduced, and Meals On Wheels services in 1970 (Carney, 2006; Saunders, 1994). The positive aspect of this shift, Phillipson argues, is that the provision of these services symbolised the move from institutional care to the maintenance of older people in their own homes. However, on the negative side, this move also heralded the view that keeping people at home can be a cheap alternative to institutional care and transfers responsibility back to family obligations (Phillipson, 1994).

Post World War II, longer term institutional care for older people, which was a responsibility of the Australian Federal Government, became a national concern. While the individual states maintained responsibility for hospitals, as these were increasingly acute care facilities with advanced technology, alternative longer stay provision was needed for older people. Fine shows how private facilities expanded rapidly as Federal Government funding was extended by a relatively unregulated nursing home subsidy to develop residential homes for elderly people. The argument used by the Federal Government was that privately run nursing homes were a cheaper alternative to long-term acute hospital accommodation (Fine, 1999). This argument is a very familiar one to Australians today. Fine further describes how, in 1953, the National Health Act defined nursing homes for the first time and, in 1954, grants on a pound-for-pound basis towards capital costs were introduced. There was high participation by the private sector and between 1962 and 1968 nursing home bed numbers grew at a rate which was out of proportion to the increase in the aged population (Fine, 1999, pp. 14-15).

To address this growth in nursing home care, the Age Care Reform Strategy of 1983-1996 introduced the development of Aged Care Assessments Teams to complement new residential care benchmarks and authorise admission to residential nursing home care. In

1983 the Home and Community Care Program was also introduced under this reform, to provide a range of in-home services. Until 2013, and the introduction of further substantial aged care reforms, these two elements were the core features of services in Australia, along with the established funding arrangements for residential care for older people. The Age Care Reform Strategy of 1983-1996 laid the foundations for the succession of health and social welfare policy reforms that, it is argued in this thesis, have had an unprecedented impact on the way old age is constructed and services are delivered.

### **2.2.1.2 Postmodernist questioning: ageing is a diverse contextual experience**

Whilst it was argued above that the main modernist message regarding the experience of ageing is that it is a time of physiological change and dependence, it is argued here that postmodernist notions of pluralism and difference question that growing old is dictated by one embracing aspect of biological and physiological change. Rather, older people are situated in many different contexts where there can be ambiguity and plurality of knowledge. As observed in Chapter One, from a postmodern stance grand narratives and progress can be seen not to bring about freedom and liberty for people, but can lead to oppression and exclusion, for example in the institutionalisation of older people, particularly those with dementia. While there is disagreement about when this shift in discourse to pluralism and difference began, or if it began at all, what has been identified as important to this thesis is the time starting from the early 1980s when, after a period of more liberal policies in the 1970s, Australia followed global economics and was profoundly influenced by globalization and the rise of neoliberalism or the new public management (Chenoweth, 2008; Connell, et al., 2009a). Dominant discourses, which can be subjected to postmodern questioning, have arisen associated with the marketisation and privatisation of services where older people are portrayed as consumers with choice. In the literature there is some agreement that this time of great structural change marks another substantial shift in the construction of identity and experience of ageing. This shift is associated with a growing awareness of the phenomenon of population ageing and its perceived potential economic consequences (Chenoweth, 2008; C. L. Estes & Phillipson, 2002; Fine, 1999; Phillipson & Biggs, 1998; Powell, 2006; Saunders, 1998).

Federal ageing policy in Australia, prior to these substantial shifts, related mainly to age pensions, subsidies for nursing homes and two major programs. The Home and Community



Care Program and Aged Care Assessment Program, introduced in the 1980s, were viewed by governments as insufficient to meet the demands of the growing aged population and ability of those in the workforce to support them (M. Hughes, 2011; Saunders, 1998). The literature shows that many authors view this demographic crisis, and associated intergenerational equity issues, as a feature of globalisation (Biggs, Phillipson, Money, & Leach, 2006; C. L. Estes & Phillipson, 2002; Foner, 2000). In the Australian context Saunders argues many statistical projections have tended to be accepted as "facts" regarding budgetary implications of the projected trends in the population age structure. He states that although these calculations can be a useful first step, the debate has been taken over by people who see demographic change as an opportunity to claw back the culture of entitlement of the welfare state days, as it does not take into account "healthy ageing" and contributions to society which cannot be measured, such as the care of grandchildren or volunteerism (Saunders, 1998, p. 21).

M. Hughes and Heycox highlight that in Australia over the last 30 years the shifts in aged care policy mean that there has been a gradual dismantling of what, in comparison to other countries such as Britain, could be viewed as a fairly modest welfare state, with its language of rights and moderate universal provisions, to the language of individualism and the self-responsibility of neoliberalism (M. Hughes & Heycox, 2010, p. 52). Neoliberalism has extended capitalist principles and values of the free market so that social policy and welfare needs are increasingly met by the not-for-profit and private-for-profit sector competing and selling services to consumers (Connell, et al., 2009a). Macintyre argues that the language of inclusion and participation is now used to legitimate the transfer of responsibility from the community to the individual (Macintyre, 1999, p. 114). Self-responsibility has meant an expectation that, alongside the older person, partners and families will be providing most of the rebalanced care, which may be seen as a cost saving measure and a way of reinforcing values that emphasise the family and women's care-giving roles (M. Hughes & Heycox, 2010; Macintyre, 1999; Powell, 2006). As Phillipson (1994) argues, difficulties can arise because family relationships do not always operate on a basis of a ready-made set of moral rules set out for older people.

Australia's historical inheritance of direct provision of services by charitable, religious and community-based non-profit providers means there has been a longstanding relationship between governments providing direct funding to the sector while influencing, but not

necessarily controlling, the type and quality of services (O'Connor T. & Sacco, 1993). However, as M. Hughes and Heycox outline, in contemporary policies governments still exercise considerable control through the funding arrangements, which includes terms of service contracts, to service providers and agencies compete with each other in tendering processes (M. Hughes & Heycox, 2010, p. 7). For T. O'Connor and Sacco there is an irony that has developed in the last thirty years in that while governments are shifting more responsibility onto the not-for-profit welfare sector for market-based outcomes in the delivery of services, they are taking increased control of identifying priorities, setting standards and linking efficiency controls to the prospects of continued funding. This, they argue, creates a clash of different and incompatible values between a market values approach by government and a social responsibility values approach by the not-for-profit welfare sector, which has traditionally been seen as the more innovative sector in delivering welfare services in Australia (O'Connor T. & Sacco, 1993, pp. 6,7).

Some reorientation towards services in the home came about with the Age Care Reform Strategy of 1983-1996 (Fine, 1999). In this there was an underlying notion that older people are individuals with different needs. In 1992 community aged care packages (CACPs), for those who require assistance comparable to a low level, or hostel level, of care were introduced. The implementation of *The Aged Care Act 1997* saw the expansion of CACPs and extended care at home packages (EACHs) for those identified as having higher needs equivalent to nursing home care. The *Home and Community Care Act 1985* governed the provision of other basic direct support services to older people such as meals on wheels, domestic home help, and in-home respite. These two principal Acts of Parliament ensured national regulation of services for older people and consequently direction and allocation of funding. Until 2013, and the introduction of the Australian Federal Government's Living Longer Living Better aged care reforms, while some major public agencies remained, such as The Home Care Service of NSW, and ACATs situated in the health system, private-for-profit and not-for-profit large and small organisations have competed for funding for both packaged care and the provision of basic services under the *Home and Community Care Act 1985*. However the future of The Home Care Service of NSW is uncertain under new aged care reforms being implemented by the Australian Federal Government in 2013, and ACATs may in the future be privatised and are being renamed as "Assessment Teams." There has been an exponential growth in the number of providers of services and the nature of these services resulting in a system where there is diversity but not uniformity (Australian Government:

Productivity Commission, 2011). For example, a program that offers a respite live-in carer is available in some metropolitan areas of Sydney but not others.

In 2013 the Australian Federal Government introduced reforms described as "an integrated reform package, which will fundamentally change the structure and dynamics of Australia's aged care system." (Australian Government, April 2012, p. 1). The associated report of the Productivity Commission acknowledged many weaknesses in the aged care system current at the time, such as a lack of continuity of services, variable quality of care and financial inequities (Australian Government: Productivity Commission, 2011, p. XXIII). However, it appears that the report builds upon the structural changes and developments arising from the initiatives in the 1980s. As M. Hughes (2011) notes, the recommended reforms continue to advance the neoliberal restructuring of Australia's health and welfare systems. However, these newest structural reforms do provide safety nets and acknowledge the needs of diverse groups. Nevertheless, the language used in the report of the Productivity Commission reflects neoliberal values, based on privatisation and marketisation, in that older people are viewed as consumers with choices and taking responsibility for themselves.

### **2.2.1.3 Influence on social work**

It is argued in this thesis that the shifting discourses outlined above, which influence the construction of identity in older age, have in turn had a profound influence on social work practice. As Powell claims, as a result of modernist thought, dominant discourses of dependency formed the foundations of social work practice developments in relation to older people (Powell, 2006, p. 100). Conversely, the contemporary context of social work practice has shifted to one of duplication and fragmentation of services where identity in older age is shaped by consumerism and notions of individuality and self-responsibility.

The Poor Law Act of 1834 is identified by Philp as the space into which social work first emerged. This space was between the two discourses of wealth and poverty, and subsequently between the powerful and the weak (Philp, 1979, pp. 93-94). What is significant for Philp regarding the Poor Law Act of 1834 is that along with the Industrial Revolution and associated structural change, the end of feudalism created a mobile class of poor people who were seen as a more direct threat to the social order. Philp argues that in the discourse of charity, as part of this first form of social work, a kind of mediation or double representation

was effected. The social worker represented the humanity of the privileged to the poor and the essential "goodness" and social nature of the poor to the privileged (Philp, 1979, pp. 93-94). However, embedded in this mediation is a means of social control as the discourse of charity is, as Philp expresses, one of a giver and a receiver. This origin of social work, Philp argues, is important as how social work is different from other professions is rooted in this history and its own knowledge base.

Tracing the origin of social work practice back to the nineteenth century demonstrates the unique position of social work as traditionally positioned between those who have discursive rights and those who do not (Biggs & Powell, 2001). Philp (1979) argues that knowledge takes place within a framework which is not a set of conscious propositions but has structure that takes its form from a specific set of social relations. Similarly, Howe argues that it was within the nineteenth century's growing ideas about the relationship of the individual to society that social work formed in the space between the two discourses of wealth and poverty. "Social" being seen as the space that arises between the private and the public where the state influences the world of private relations (Howe, 1994, p. 517). These points regarding the origin of social work are central to this thesis, as it may be considered that the role of social work in socio-legal encounters in contemporary Australia is to take up a position between those who have discursive rights and those who do not.

Biggs and Powell take these arguments further in that while identifying social work as developing as a hybrid in the space between the public and private sphere, as a halfway point between individual families and the state, they argue that the growth of social work in the twentieth century became increasingly dependent upon its inter-relationships with the welfare state and the rise of new forms of regulations dependent upon professional power (Biggs & Powell, 2001, p. 9). These authors also point out that it is at this point that social work also took on the contradictory characteristics of benevolence and social control of people, described by Biggs and Powell (2001) as juggling the double perspective of external coercion and personal cure and by Howe (1994) as care, control and cure. These double perspectives are pertinent to the primary research question of this thesis concerning the challenges in social work practice in socio-legal encounters where the right of an individual to make their own choices is at stake.

In relation to social work ethics, Reamer (1998), who draws attention to the influences of historically specific dominant discourses, refers to concern about the morality of the client as

an early social work ethical issue, as well as ethical obligations to promote social justice and reform the causes of poverty (Reamer, 1998, pp. 488-489). Developing understandings by social workers in relation to ethical issues are particularly relevant to this thesis and a fundamental social work concern enlarged upon later in this Chapter.

There is historical and contemporary debate about how social work developed in Australia, often centred around what L. Hughes (2008) calls the professional/amateur dichotomy (Gleeson, 2008; L. Hughes, 2008; McMahon, 2003). The social work literature reflects that there have been significant challenges to the traditional historical interpretation of social work development in Australia which has centred on the professional status of social work and its origins in either the 1920s British model of lady almoners or the first social work university graduates. The idea behind these interpretations is that social work came ready-made to Australia rather than evolving within an older context (Swain, 2008). However, the first two social workers to complete post graduate studies in the USA in the 1920s, Parker and Moffitt, are viewed as establishing a strong professional base in Australia which differed from that of almoners in that their education in USA had a holistic and social justice approach (Gleeson, 2008, p. 213).

The challenges to the traditional interpretations of the development of social work practice in Australia are rooted in the notion that in exploring early history and provision of social services, social work knowledge is gained and can be further developed in the Australian context. L. Hughes (2008) argues that research on the work of groups of Catholic Sisters in the late nineteenth and early twentieth centuries found that these religious organisations were operating from specific bodies of knowledge in that their aims, methods, and forms of organisation in performing social welfare work had much in common with professional social work which developed later. However, to fully establish social work as a "profession" it was viewed that social work needed to distance itself from these origins in Christian charity. Rather than prototype social work, these Catholic Sisters and their counterparts were viewed as operating as religiously motivated non-professionals functioning on the basis of their emotions. They therefore needed to be replaced by "those using a body of knowledge and a systematic scientific approach" (Graham, Coholic & Coates, 2006; Witz, 1992 cited in L. Hughes, 2008, p. 227). This highlights the point made by Gergen (1985; 1999), raised in Chapter One, that the taken-for-granted world of reason means that if reason dominates then emotion is constructed as anti-rational and its discourses disfavoured.

Similarly, McMahon (2003) argues that by reframing the antecedents of Australian social work, a more activist and social justice foundation is established for the beginnings of Australian social work. McMahon challenges the narrow focus on social work as imported from Britain and the USA because this means that Australian nineteenth century social activists are overlooked historically as social work prototypes and so knowledge, which could be regarded as innovative, regarding the provision of social services in Australia over the last 200 years, is lost. McMahon refers to the social welfare work of charities in this era, such as the Brotherhood of St. Laurence founded by an Anglican priest, and the Catholic Sisters from different Orders who in the nineteenth century established schools, hospitals and refuges. He also argues that Caroline Chisholm, an activist who assisted immigrant women in NSW had the ability, like those in the religious charities, to link personal troubles with land reform which involved politics, production and social restructure.

The NSW Board of Social Study and Training (BSST), formed in 1928, is credited by Gleeson (2008) as Australia's first professional training body for people viewed historically as professional social workers. He notes that this body disconnected from the notion that its future workers dispensed charity. Rather, it was "medical social work" (Gleeson, 2008, p. 212). What is important to note is that the numbers of social workers in Australia was reported to be extremely low in comparison to contemporary times. From a professional social work practice perspective, Lawrence (1976) argues that there were very few social workers in Australia in charitable organisations and acute care hospitals prior to World War II, and a significant expansion did not occur till the 1970s when the short-lived Whitlam Government created a climate for substantial growth in social welfare services. The social workers prior to the 1970s who were likely to provide services to people with dementia were those attached to psychiatric hospitals and Lewis (1988) reports that only six social workers were employed in psychiatric services in Australia in 1951. However, in current times more than 1300 social workers graduate every year from twenty five university schools of social work (Mendes, 2008).

It appears that fundamental changes in social work practice can be identified post World War II. Philp (1979) sees this shift as arising from the allocation of new discursive rights, which developed from values underpinning the "welfare" state. He suggests the division is no longer between the deserving and the undeserving but one between the respectable and legitimate demands of labour and the deviance of the rest. Here it is notable that the "rest" includes

many older people, particular those with dementia. For Philp, social work shifted to occupy the space between the respectable and the deviant, those with access to political speaking rights and those excluded. The task of social work was to represent a picture that was not immediately visible to others, and negotiate on behalf of those identified as mad, bad and stigmatised (Philp, 1979, pp. 96-97). Alongside these shifts in dominant discourse Reamer (1998), notes significant shifts in discourses surrounding ethics in social work practice. Previous preoccupation with the clients' morality progressed to a focus on the morality, values and ethics of the social work profession and in the 1960s and 1970s ethical issues underpinning social justice, reform and civil rights came to the fore. Also, social workers were asked to examine and clarify their own personal values (Reamer, 1998, p. 490).

Social work as a profession developed in the post World War II years overseas and in Australia due to the increase in public spending associated with the "welfare state." (Biggs & Powell, 2001; Ife, 1997) However, McDonald, Harris and Wintersteen argue that, overall, social work did not assert itself as a key profession in welfare in Australia compared with Britain, where there was a strong emphasis on the decentralization of social work teams and the delegation of decision-making to them at the local level (McDonald, Harris, & Wintersteen, 2003, p. 199). Nonetheless, a strong professional base was established by social workers in Australia where, to be employed as a social worker, eligibility for membership of the Australian Association of Social Workers is a necessary requirement. Ife describes how social work education was influenced by British writers who were strong advocates of the welfare state as a mechanism to meet the needs of the people as a matter of a right and just society (Ife, 1997, pp. 5-6). The heritage for the profession in the 1980s was that its services were largely provided through the structures of the welfare state in the public and private not-for-profit sector.

As is pivotal to this thesis, over the past thirty years health and social welfare policy reforms have greatly influenced the way old age is constructed and the delivery of services. Within the concepts of grand narratives and progress that gave rise to identities in older age associated with social dependency Biggs and Powell raise the point that with the marketisation of welfare a stable point has itself has been eroded along with the traditional role of social worker as provider and counsellor (Biggs & Powell, 2001, p. 12). Powell argues that health and welfare systems have influenced and changed the role of social work from a service-orientated approach to one of assessment and case management. He further argues

that interpersonal elements of professional power have reduced social relationships to an emphasis on the "management" of older people. Here there is a fundamental shift from social work practitioner to a case manager or managerial identity (Powell, 2001, p. 125). However, there is little research into how this managerial identity in the Australian context plays out in an environment that has different institutional arrangements in terms of the marketisation and privatisation of services for older people.

For Webb (2006), much of Australian social work has followed global changes in that it is now practised in an organisational context dependent on complex and often contradictory rules, regulations, procedures and policies to be followed, not the least of these being associated with occupational health and safety issues. Wallace and Pease argue the question of whether social work has accommodated or resisted neoliberalism is important. While identifying that neoliberalism has impacted on the structural and organisational context of social work practice they draw attention to the lack of empirical research studies globally, and in particular the Australian context, on the effects on social workers. What research has been carried out generally centres on the concerns of the demise of the welfare state and consequences for social work, and the impact on social workers' roles and values (Wallace & Pease, 2011, p. 135). At the micro level the impact of neoliberalism on Australian social workers is under-researched. K. Healy and Meagher (2004) draw attention to increasing budgetary constraints and to the devaluation of caring work. McDonald and Chenoweth (2009) found that the managerialist framework of institutional change within the statutory agency Centrelink, which provides income security benefits, destabilised social work in that it promotes values and rationalities at odds with the profession. Similarly, Chenoweth found Centrelink has become a highly technologised service using call centres to provide services, computer and web-based information (Chenoweth, 2008, p. 57).

This brings to the fore the profound impact of technology, not experienced since the Industrial Revolution, and the consequences for social work practice. Biggs and Powell (2001) see "case/care management" as technologies of social work practice. The revolution in the use of the computer is now indispensable in the surveillance of social workers in their day-to-day activities to monitor outcomes and performance. Similarly for monitoring and surveillance of social work clients, such as older people, technology has reached new heights. These technologies add considerably to complexities in practice, as does the rise to prominence of the concept of risk, which is addressed in the next section.



This section has presented an overview of the shifting structural developments in health and welfare systems arising from the Industrial Revolution by an analysis of the modernist message that ageing is a time of physiological change and dependence and postmodernist questioning where ageing is viewed as a more diverse contextual experience. What is significant to the central arguments of this thesis is that these developments highlight the impact of changing health and social welfare systems upon the individuals at whom these varying policies, and resulting services, are aimed and the consequent influence on social work practice. The next section concerns the shifting discourses from reason and certainty to uncertainty and complexity where, as noted in the Introduction to the literature reviewed in this chapter, there is a predominant focus on the central aspect of the conceptualisation of risk for older people and developments in social workers understanding and approach to ethical issues.

### **2.2.3 Reason and certainty to uncertainty and complexity**

#### **2.2.3.1 The modernist message: to be confident in expectations and future predictions**

It was raised in the Introduction to the review of the literature in this chapter, that pivotal to this shifting discourse is the modernist conceptualisation of risk which increasingly appears to affect those who are ageing and the professionals with whom they engage. The notion of risk is significant to this thesis as it is pertinent to the primary research question regarding challenges faced by social workers in complex socio-legal encounters, as the growing emphasis on risk and the development of risk-taking approaches has been identified as one of the major changes in health and social welfare services (Titterton, 2005, p. 13).

It is argued here that for older people the modernist concepts of reason and certainty are bound up with what Webb (2006) describes as expectations about being secure and confident in the safe prospect of some future event. The literature reviewed previously, where the modernist message is directed by grand narratives and progress, reflect some of the notions of reason and certainty that are relevant to the modernist message of confidence and prediction in the future and will not be repeated here. What is significant in this section is the pivotal aspect of the conceptualisation of risk for older people, particularly those with dementia, which has been outlined as a major facet of modernity (Green, 2007; Powell & Wahidin, 2005; Webb, 2006). The link of risk to certainty is that risk can be seen to be a modernist

notion that has come to assume accelerating and expanding prominence (Powell & Wahidin, 2005). Risk may be regarded as arising from the modernist message of security and certainty in that the larger certainty of modernism has been broken down into smaller contextual certainties. Within these contexts identified risks can be measured, controlled and managed whether at an individual, institutional or on a national level.

Powell and Wahidin (2005) outline that prior to the Enlightenment the concept of risk excluded the idea of human fault and responsibility. Rather, it was a natural event. However, by the eighteenth century the concept of risk started to become rationalised under the new scientific discourses and by the late nineteenth century the notion of risk was extended to include human responsibility. Something could be done to control and prevent misfortune and minimise risk through the action of humans (Powell & Wahidin, 2005, p. 75). Both Beck (1986) and Webb (2006) highlight that the modernist concept of risk became associated with the concepts of improvement and progress, and applied to the workplace and the operation of technology where some decision-making is involved by people. Webb (2006) argues that risk has ultimately become more abstract and de-personalised and so not immediately observable (Webb, 2006, pp. 34-35). Responsibility for risk also has become associated with rules of assignment through political market, and legal institutions (Beck, 1986).

If modernist notions of reason and certainty resulted in constructions of ageing as a time of dependency, the ambiguity is that these concepts also resulted in providing a firm ground on which many older people could predict the future (Biggs & Powell, 2001). Webb highlights how the welfare state can be viewed as being designed for protection against risk of illness, disablement and older age (Webb, 2006, p. 53). However, with the expansion of the concept of risk, and the dominant modernist message that risk can be managed, controlled and minimised, risk becomes associated with expert knowledge (Webb, 2006). Risk can therefore be identified by experts with expert knowledge, although experts can contradict each other (Powell, 2006; Webb, 2006).

While there are many theories focusing on the concept of risk and risk assessment (Green, 2007; Titterton, 2005; Waugh, 2006; Webb, 2006), risk in the context of older people is generally viewed as negative and welfare professionals are perceived as having a professional responsibility to provide appropriate safeguards. Webb (2006) describes risk management as focusing on categories of people, whereas risk assessments are concerned with individual risk. He defines assessment of risk as a process that assesses the likelihood of harm occurring

in the future and tries to predict its eventuality (Webb, 2006, p. 71). In line with the negative view of risk for older people, Titterton argues there is the dominance of a safety first approach amongst welfare professionals, whereas risk-taking can have beneficial as well as harmful outcomes for everyone, including older people. Risk-taking can be linked to the issue of rights and who has the right to take a risk and who defines this risk (Titterton, 2005).

The rise of risk is associated by many with the rise in the culture of blame and a declining confidence and trust in professionals who are located in organisations, both public and private, that can appear to promise much but fail to deliver (Green, 2007; Green & Sawyer, 2010; Powell, 2006; Powell & Wahidin, 2005; Titterton, 2005; van de Zandt, 2000; Webb, 2006). Green (2007) identifies that there is an increasing pressure on government, organisations and professions to eliminate accidents and adverse incidents and to demonstrate control over a range of risks. This means that organisations and professionals not only address primary risks to their clients and workers but also need to protect themselves from a second layer of risks, such as negligence, bureaucratic failure, complaints, and professional error. As Green says, sometimes it is difficult to ascertain just who is being protected, the client or the agency (Green, 2007, p. 406).

In a scoping review that investigates how groups of people perceive and understand everyday risks, Mitchell and Glendinning (2008) report that there seems to be very little research on the risks of damage to the psychological health of older people and their families as opposed to their physical wellbeing. One study showed that often an older person felt it was worth taking the risk if the psychological benefits outweighed any potential negative consequences, so older people sometimes engaged covertly in risky actions. For example the physical risks of falling when moving around outside the home may be weighed against the psychological benefits of social interaction. As the psychological benefit carries more weight, although professionals advise against it, outside activity may be engaged in covertly (G. Wilson, 1994, Clark et al 1996 cited in Mitchell & Glendinning, 2008). The research examined by Mitchell and Glendinning explored how older people viewed and assessed the risks they faced in everyday activities and found there was often a complex and lengthy process involved, including issues of personal choice and wanting to keep a degree of independence and control (Mitchell & Glendinning, 2008, p. 304). Another study highlighted that family and people close to an older person had subjective notions of risk which were tied up with relationships (Clarke and Heyman 1998, Clarke 2000 cited in Mitchell & Glendinning, 2008).

### **2.2.3.2 Postmodernist questioning: the rise of risk is allied with individualism and the marketisation of services**

Postmodernist questioning of reason and certainty and a shift in discourse to uncertainty and complexity may be linked to the structural changes which accompanied the rise of neoliberal "welfare". For Webb the shift is identified as one from where the state deals with contingencies rather than providing universal solutions by centralised planning. Whereas the welfare state was designed for protection against risk of illness, disablement and older age, there is a push to residual safety-net social welfare (Webb, 2006, pp. 53-55). It is argued here that postmodernist questioning shows that risk, which has become complex and multidimensional, can be allied with notions of individualism and the marketisation of services.

Complexity and uncertainty may be seen to be reflected in a shift from modest, accessible community home based services to expanded and more complex services which are hard to access. For an older person to know what services they can draw upon can present problems in contemporary Australian society (Australian Government: Productivity Commission, 2011). An inquiry commissioned by the Australian Federal Government to systematically examine the social, clinical and institutional aspects of aged care in Australia, found that the system was difficult to navigate, there were delays in assessments and discontinuous and variable care quality (Australian Government, April 2012, pp. XX-XXIV). There is an enormous amount of information available from different sources, such as agencies, help lines and websites, but the difficulty is for the individual older person to find what is suitable for them and make a link to a specific service. Once the appropriate service is located there are, more likely than not, waiting times. The exception to waiting times are care packages available to older people in public hospitals so they may be discharged. However, this moves the waiting time to 6 to 12 weeks later as these packages are time-limited. Generally, there is no continuity in the services offered, for example an older person cannot necessarily transition from a CACP to an EACH package with the same service provider (Australian Government: Productivity Commission, 2011). Several providers can offer the same service in one area so a "consumer" can make multiple telephone calls and be declined on each approach for a service and referred on to other providers, who in turn cannot assist. Complex

pricing, subsidy and private co-contribution systems that are inconsistent and inequitable have also resulted (Australian Government: Productivity Commission, 2011).

The Productivity Commission Report (2011) also identifies that there are gaps in provision of services where there is uncertainty about the availability of services on a short-term basis. For example health can fluctuate and if an older person leaves a particular service because they are experiencing a period of better health and independence they may not be able to re-engage with that service if their circumstances change. Another substantial gap is the provision of short-term assistance for older people who cannot identify a person as a "carer." While there are resources allocated to providing services to an older person living in the community whose identified carer is temporarily absent, there is no such allocation to those who cannot identify a carer. This is of significance as many agencies who provide EACH packages have associated policies that mean a package will not be allocated to a person who does not have a person identified as a carer.

Green and Sawyer argue that the expansion of community and home services for older people, including many targeted at people with dementia, is an approach that has led to new tensions which are articulated as risks. These tensions arise from perceptions that a greater number of people who have changing abilities need to be "managed" by community services and this entails multiple aspects of risk, such as the unregulated nature of the home as a work environment and community expectations about the role of service providers (Green & Sawyer, 2010). Consequently, service providers have developed ways to regulate and manage these perceived increased risks. In an empirical Australian study, Green and Sawyer found that frontline and management professionals providing formal care to older people in the community were influenced in their practice by different, complex and contradictory experiences of risk. This was evident particularly in terms of responsibility for risk, in defining who carries what risk and what are the liabilities. Risk responsibilities distributed across agencies became particularly difficult for their participants when several services visit the same home. Significantly, one conclusion of their study is that there is a systematic absence of shared understandings of "acceptable" risks in the community care of older people (Green & Sawyer, 2010).

For Powell western societies have moved from trust to risk because trust is incompatible with risk. Trust is based on expectations about future events based on the grounds of incomplete knowledge about the probability of an event occurring and incomplete control about the

occurrence of the event (Powell, 2006, p. 120). However, constructions of risk for older people can be based on the probability of a future event happening, for example a fall, and a focus on ways to "manage" this risk. Webb describes "risky" decisions as those where risk claims are not just propositions but become a narrative in attempts to develop an argument for or against a particular decision where welfare professionals can respond to a situation and take up a particular perspective. Sometimes these decisions can seal the fate of those being assessed regarding services and the allocation of resources and this has ethical implications (Webb, 2006).

In parallel with older age becoming increasingly associated with a dominant discourse of risk, other discourses have arisen in the past thirty years associated with new forms of social regulation and what can be linked to the consolidation of professional power. Biggs and Powell (2006) see the decline in trust in professionals' expertise being a result of an increased reliance on complex systems of managerialism and the technology of case management. Case management, they argue, is a mechanism which has deconstructed a centrally run state welfare system into marketised care. The management and delivery of services is increasingly indirect as the function of the case manager in Britain, usually a social worker, is to coordinate packages of care and to monitor the standard of services provided by others, such as private and not-for-profit agencies (Biggs & Powell, 2001).

In contrast, in the Australian context K. Healy (2009) draws attention to the strategy which has involved the diversification of the social welfare workforce with an increasing proportion of non-professionally qualified workers and the rise of generic positions in management roles. In practice this means that in Australia there is no integrated system and with the increased reliance on the private sector to provide coordinated packages of care, this sector can employ coordinators of packaged care with whatever qualifications they see as appropriate. Often this employee is one who costs less. One positive aspect of the Australian Government's Living Longer Living Better 2013 reforms is that under its provisions coordinators of packaged care are required to have appropriate tertiary qualifications.

For Powell and Wahidin those who directly define and assess risk are the case managers in neoliberal health and welfare provision. They argue that growing old itself has become a managed process where there is a movement away from the helping relationship to case management. Case management means that, as an administrative power, case managers are also risk assessors and enforcers of the mixed welfare economy (Powell & Wahidin, 2005, p.

80). Similarly, risk assessment and management for Green presents particular challenges to social work practice in that the promotion of the priority of risk over client need can compromise social workers operating in protective domains as decisions can be based on probabilities of something that may occur in the future, not what is happening in the present (Green, 2007). This reflects a significant shift in how old age is constructed and the resulting influence on social work practice.

### **2.2.3.3 Influence on social work**

In response to modernist notions of reason and certainty social work with older people can be seen to have tended to take a positivist medical model to underpin practice, where growing old was an individualised experience of adaption to the inevitable physical and mental decline (Powell, 2006). However, contrasting voices have emerged, such as Rodwell (1990), who compares both a positivist and "naturalist" perspective to argue that attention to people and their contexts separates social work from other helping professions in health care and this notion was overlooked in practice. Rodwell argues against a positivist informed medical model to underpin social work practice based on individual treatment and a set of what she describes as scientific assumptions. As opposed to this, Rodwell argues that approaching knowledge from a "naturalist" perspective, which reflects multiple and constructed realities within specific contexts, and a belief in the relativistic nature of the world, is more advantageous to social work research (Rodwell, 1990, p. 28).

Post-World War II shifts in social policy created corresponding responses in much social work practice. Biggs and Powell (2001) argue that the growth of social work was dependent on its interrelationship with the welfare state, which provided its primary rationale and legitimacy. Social work became characterised by the notion of the "helping relationship" (Powell & Wahidin, 2005). In Britain social workers became key operators in social service agencies and gatekeepers to services. McDonald, Harris and Wintersteen (2003) observe that Australia took a different path in that it developed a highly targeted and selective income security system accompanied by an unevenly mixed economy of welfare. This presented a correspondingly different role for social work which they see as less centre stage (McDonald, et al., 2003, pp. 197-198). However, social work in many settings mediated between the socially excluded and the state, and the traditional social work role of provider and counsellor was established (Biggs & Powell, 2001). Biggs and Powell argue that the chosen method of

social work was based on psychoanalysis where the negative stance to older age reinforced professional power and the marginal positioning of older people. Psychoanalysis was not used as a form of therapeutic help but as a language and way of thinking which grouped older people and also suited the economic discourse that old age constitutes a drain on resources (Biggs & Powell, 2001, p. 11).

However, social work was also taken in another direction by a focus on community development. Payne outlines how, in taking a community development focus, there was a recognition that some social workers were concerned with community factors such as the adequacy of home and community services. The role of services were viewed as a principal factor in either preventing admission to hospital or enabling discharge (Payne, 1997, p. 203). R.J. Estes (1997) sees community development as a social work practice that sought to unite previously unorganized people into effective groups that worked together on shared agendas. In this way community development emphasized self-help amongst members of disadvantaged communities (R. J. Estes, 1997, p. 2). R.J. Estes outlines the history of the community development movement as arising in the early twentieth century with the establishment of settlement houses and neighbourhood centres in Europe and the United States. These movements' priority was to work with groups of people seen as disadvantaged, including older people who were economically or socially disadvantaged. Payne describes how in Britain and the United States government projects to deal with inner-city problems were a continuation of this community development focus in the 1960s and 1970s (Payne, 1997, p. 203). However, Payne notes this form of community development seems to have been regarded as a third aspect of social work and not as dominant as casework or group work.

A significant development in the 1970s was that Australia followed Britain and the United States in teaching a set of integrated methods that endeavoured to merge theories and practice and find a generic common base for practice, such as the widely used work of Pincus and Minahan (1973). Pincus and Minahan based their book explicitly on systems theory ideas, which challenged the previous psychodynamic perspectives by accepting and analysing the existing social order. It proved influential when social work was expanding and taking up roles in state agencies (Payne, 1997). Crisis intervention and task-centred models of social work practice also flourished in this era and had some lasting power as they provided an emphasis on environmental issues and structure to social work practice (Payne, 1997).



Howe (1994) describes these integrated models of social work practice as brave steps that he argues were aimed at the improvement of the self and society and the maintenance of order, which was typically modernist in the assumption that there is a fixed truth around social work knowledge and practice. This provided some certainty in social work practice based on logical reason. However, again there were opposing viewpoints as social work has not developed in a homogeneous way. There were developments in radical perspectives on social work practice where issues are defined as social and structural rather than individual. Here social work seeks changes between the individual and the environment and there is a critical analysis of society (Fook, 1993). A further example is social work practice which focuses on social action and where direct action is encouraged to be taken, often at a local level to change government or other official policies and practice (Payne, 1997).

With the shift toward neoliberal policies in the 1980s, Webb argues, social work followed global changes in how it is practised in an organisational context, and that the profession has become increasingly dependent on complex and often contradictory rules, regulations, procedures and policies to be followed. Not the least of these being associated with risk assessment and management and occupational health and safety issues (Webb, 2006). The practice of case management becoming a dominant technology of social work accompanied these changes. Clearly not all social workers act within a case management context but for those employed in health and welfare systems case management has, in contemporary Australia, become the dominant mode of practice, particularly in the delivery of home and community services. Consequently, it may be argued that neoliberalism has shaped the way in which social work is conducted. Some argue that these new discourses have left social work as being subject to further complexity, tensions and ambiguities, its knowledge base being continually questioned. However, as authors such as Banks (2006), Parton (1994; 2003) and Webb (2006) maintain, if this analysis is bleak in its implications for social work practice it does provide a postmodernist basis from which to challenge, resist and identify skills that are necessary to work in social situations of great complexity, such as socio-legal encounters. It is these challenges that are fundamental to this thesis and the primary research question

Parton (2003) argues that in the complex and uncertain situations that social workers find themselves in practice today there is a range of skills which have traditionally been at the core of social work related to process, where the ability to negotiate and mediate creatively

are of particular relevance. Expertise, as demonstrated by experienced professionals, is characterised by an ability to work in complex situations where there are competing interests and to prioritise factors in ways which allow clear action (Parton, 2003, p. 9). For M. G. Wilson (2004) the conceptual skills social workers can bring includes knowledge and understanding of the historical context as well as an ability to carry out structural analysis of the institutional context that social work is embedded in.

As raised in the Introduction to the literature reviewed in this chapter, developments in social workers' understanding and approach to ethical issues may be viewed as one of the most significant developments in the profession in the last thirty years. Ethical issues can form crucial aspects of socio-legal encounters and are central to the primary research question of this thesis regarding the challenges encountered in social work practice. These developments are particularly relevant to decision-making in social work practice and may counteract the notion that there is little space for professional judgement and discretion in decision-making, and so provide a tool for social workers to use as a form a resistance to the dominant neoliberal discourse. Although social work may be defined as task and performance orientated in neoliberal terms, it is the complexity and ambiguities embedded in social situations that bring ethical decision-making to the fore. (Howe, 1994; Taylor & White, 2006).

A new Australian Association of Social Workers *Code of Ethics* (Australian Association of Social Workers, 2010) reflects both that ethics can no longer be easily codified and the rising importance of philosophy in social work ethical literature, which emerged in the 1980s. This *Code* demonstrates an understanding that it may not be possible to make a rational choice between two values and acknowledges that ethical decision-making occurs within the context of managing power relationships. It defines ethical dilemmas as those that "may arise when a social worker must make a choice between alternative courses of action, each of which is supported by moral considerations and each of which may result in an outcome that is, in some way, undesirable." (Australian Association of Social Workers, 2010, p. 14)

For social work, what began in the nineteenth century as a concern about moral issues moved on to concerns about values. In the late 1990s, in decision-making theory, the use of rational decision-making "trees" (Cuzzi, Holden, Grob, & Bazer, 1993) has evolved into attempts to resolve complex ethical issues which involve questions about rights, duties, responsibilities and obligations (Banks, 2006; McAuliffe, 2010). From a human rights perspective Ife argues

that codes of ethics cannot provide a clear answer; the real world of social work is more complicated and messy and it is the underlying morality of the social worker's actions that is the issue (Ife, 2008, p. 122). For Ife, while ethics and rights may be involved in the same issue, ethical decisions can be seen as attached to the worker, whereas rights can be seen as attached to the person with whom they are interacting (Ife, 2008). Ife identifies an important trap in the discourse of ethics in that it is about individuals making ethical choices in specific situations and in this sense fits readily into the neoliberal ideology, as the social worker is described in terms of the individual practitioner making individual choices. However, if, as Ife argues, it is balanced by a human rights discourse, this shifts the attention away from the worker to the person or group the worker is interacting with (Ife, 2008, p. 122). For Gray and Gibbons social workers now make decisions where there is active dialogue in an interactional process and there are no right answers, only choices, for which they are responsible and need to justify and live with (Gray & Gibbons, 2007, pp. 222-223). To do this, social workers need to be comfortable with complexity and ambiguity. Banks acknowledges that social work is a profession that has a control as well as care function but argues that if social workers understand the nature of ethical decision-making they will feel less unnecessary guilt and blame for the outcome of decisions and actions which they are involved in. This blame Banks links to the "crises" of the welfare state, where social workers can find themselves in situations of unjustified and possibly public blame and attacks from the media (Banks, 2006, pp. 24-25). The emphasis of these authors referred to above is that discretionary judgements are involved in ethical decision-making.

Ethical decisions are based on values that inform social work practice, such as respect for persons, social justice and professional integrity (Australian Association of Social Workers, 2010, p. 12). However, social workers often face dilemmas when they experience competing and contradictory values such as between self determination and duty of care. Mattison identifies two major groups of ethical theories that have relevance to social workers in helping understand the principles on which ethical decisions are based. These are the deontological and teleological approaches. The teleological decision-maker acts in relation to the consequences that may result, where the greater good is valued or desired. Actions can therefore be justified on the basis of the consequences they create. However, the deontological approach maintains that fixed moral rules should dictate and define the rightness or wrongness of actions. It is grounded in the belief that an action, in and of itself, can be determined to be right or wrong, good or bad, regardless of the consequences. So how

a social worker makes an ethical decision can differ if influenced by these different approaches (Mattison, 2000). Another approach, Beauuchamp and Childress's four principles of biomedical ethics, have been influential in social work practice in health settings. These principles are: autonomy, or the obligation to respect the decision-making capacities of individual people; non-maleficence, or the obligation to cause no harm; beneficence, or the obligation to provide benefits and balance these against risks; and justice or the obligation to be of fair (Banks, 2006, p. 41). However, as Banks argues, principles need to be interpreted into what meaning they have and when, and how they are applied (Banks, 2006, p. 42).

The Australian Association of Social Workers (2010) *Code of Ethics* is useful as it emphasises a need for critical reflection on ethical dilemmas and the reality that ethical values conflict. There are a number of ethical decision-making models and the *Code* outlines a number of principles to guide rigorous and reflective decision-making, including having as full and relevant information as possible, being open and accountable, identifying key social work values or ethical responsibilities that conflict, weighing risks and documenting the issues considered, and the decision-making process. Banks (2006) outlines how a social worker's responsibilities, duties and roles can conflict. For example, social workers have responsibilities that conflict, such as those to society, employers, the profession and the client. She argues that courage and commitment are needed by social workers when justifying their decisions in complex cases and that it may be necessary to strongly argue a particular position. She also draws attention to the skills needed in resolving these dilemmas in that a beginning practitioner may regard a particular issue as an ethical dilemma whereas an experienced practitioner may not. Confidence, lack of power and clarity about the role of a social worker, a narrow focus on needs or rights of one particular individual or complexity becoming overwhelming are also identified by Banks as anxieties experienced around ethical dilemmas by trainee or inexperienced social workers (Banks, 2006, p. 161).

This section has presented literature with a focus on the modernist notion of risk that variously impacts on those who are ageing and the practice of social workers, and other professionals, in a health and welfare context. It has been argued that postmodernist questioning shows that risk, which has become complex and multidimensional, can be allied with notions of individualism and the marketisation of services where how risk is defined, by whom it is defined and who takes responsibility for it are issues of concern in social work practice. It has been expanded upon that a shift in discourse from reason and certainty to

uncertainty and complexity can be linked to the structural changes which accompanied the rise of neoliberal ideologies over the past thirty years. The direct effect on service provision has been examined. Various historical and contemporary influences on social work practice have been explored with particular emphasis on the contribution that can be made to contemporary social work practice by advances made in ethical understandings. The next section concerns the shift in understandings from fixed identities to subjectivity for those who are growing old.

## **2.2.4 Fixed identity to subjectivity**

### **2.2.4.1 The modernist message: the self in older age is fixed in relationship to work**

As considered in Chapter One, modernist understandings of the "self" generally emphasise the unitary individual who remains the same in all situations (Burr, 2004; Fawcett, 2009a). Identities are "fixed," for example, "working class person" or "an old person." As Burr expresses there are a limited number of discourses which the individual can draw upon (Burr, 2004, p.107). It was observed in the Introduction to the literature reviewed in this chapter that whilst older people form a diverse group, with the common experience of growing old, ageing does impact differently, particularly in relation to socio-economic position. What is important here is that dominant discourses regarding the relationship to work of those who are growing old are pertinent to changing discourses surrounding identity in older age. The modernist message explored here extends and consolidates the literature reviewed in the previous two sections of this chapter. This section argues that the modernist message regarding identity in old age is that it is fixed in values underpinning the older person's relationship to work, whereas postmodernist questioning shows that identity in older age can be a contested area where there can be many tensions and ambiguities.

Phillipson and Biggs argue that the focus of modernist conceptions of identity on the person's relationship to work has profound implications for the value attributed to later life (Phillipson & Biggs, 1998, p. 13). As a result of the Industrial Revolution a new discourse came into being; that old age contributed to poverty as many older people were unable to participate in the workforce due to changing abilities. Victor (1987) highlights that as a result of the Industrial Revolution many older people became linked to the deserving poor, whereas previously they were not differentiated from the "pauper classes" or the rest of society in

general. However, what is critical is that old age as an entity changed forever as older people emerged as a social group with a specific problem; that of growing old (Victor, 1987). This was due to the massive restructuring of the economy, where modernist conceptions of identity began to centre on the relationship to work and an individual's life course began to reflect age-segregated cohorts (Phillipson & Biggs, 1998).

Alongside this, Field (2011) describes another development in the nineteenth century that characterised Britain's welfare. This was the development of voluntary provision, with mutual and friendly societies delivering a range of benefits alongside those provided by local authorities. Thus entitlement to services through friendly societies began to be perceived as a right for those who had contributed. Subscriptions were paid by individuals in employment and consequently this excluded those who were older and could not contribute through their work efforts due to changing abilities.

These developments, where identity in older age became linked to work participation, may be viewed as the basis of what is referred to in the literature as "ageism". Whilst those growing old include individuals with a diverse range of characteristics, such as socio-economic status, ethnicity, cultural heritage and gender, ageism is the 'ism' that will affect all people who grow old. It is defined as "a process of systematic stereotyping and discrimination against people because they are old...ageism allows the younger generation to see older people as different from themselves" (Butler 1987, as cited in M. Hughes & Heycox 2010 p.91). As such age is seen as a fixed identity where the older person has to negotiate issues relating to this specific individual trait. M. Hughes and Heycox (2010) argue the social construction of age is one where contemporary beliefs about older people, their devaluation and the discrimination arising from these beliefs, are widely reflected in media and the health care system. As opposed to racism or sexism, it is one of the most pervasive yet least-challenged forms of discrimination in a youth-obsessed consumer culture.

Australia pioneered collective legislation, catering for what were seen as the hardships of old age and invalidity. The value of being deserving due to age was enshrined in legislation by establishment of pensions by the Commonwealth Government in 1908, which provided a new way of extending support to people who could not work, such as older or disabled people (Carney, 2006). By 1948 the concept of welfare rights was being expressed unambiguously and Macintyre quotes from the annual report of the Director-General of the Department of Social Services that "today, the right of the individual to security against loss of income due

to illness, old-age or widowhood, as well as the right of the family man to benefit to offset his additional financial responsibilities, find almost universal acceptance." (Macintyre, 1999, p. 112)

Chenoweth outlines that from Federation in 1901 the Australian welfare system was constructed around the family and the premise of a provider, a male worker supporting a wife and two children, so efforts were focused at fixing and protecting wages (Chenoweth, 2008, p. 54), and also alleviating additional extended family responsibilities for those who could not work. So, as Phillipson and Biggs argue, the fixed point of discussion was that the meaning of old age was to be constructed out of retirement and a maturing welfare state and family providing a link between the two (Phillipson & Biggs, 1998, p. 14).

Biggs and Powell (2001) outline the ambivalence in discourse between the older person being a stoical and heroic survivor in the immediate post-war period where this image was dependent on an absence of demand on the rest of society. Alternatively, old age was hard to reconcile with the rhetoric of progress and investment in the future as it was harder to fit older people into the narratives of production and work. However, what marks the modernist message of fixed identity, Biggs and Powell argue, is that it provided a firm identity for older people where welfare was seen as a just reward of citizenship and a right to which an individual was entitled.

Despite the discourse of rights and entitlements growing out of the welfare state (Macintyre, 1999; Saunders, 1994) growing old also became identified as a social problem and there was a growth in institutionalisation and medicalisation of the social and health issues faced by those who are ageing. Older people became more visible to the rest of society due to the increase of welfare services and the concept of old age as a burden to those of other generations in the workforce emerged (Biggs & Powell, 2001). However, significantly, the modernist notion of identity as centring on the individual's relationship to work was enshrined in legislation through retirement conditions as old age became associated with retirement (Phillipson & Biggs, 1998; Walker, 2000).

#### **2.2.4.2 Postmodernist questioning: identity in older age is a contested area**

Postmodernism challenges the idea that identities are fixed. As explored in Chapter One, identities are viewed as being constructed through the use of language. From a critical postmodern perspective Fawcett and Karban (2005) outline that the "self"

is regarded as having many facets ... and this means that there is a temporary fixing of "self" in specific situations and, although the self is positioned by social practices and discourses, in any one situation or context, there is agency and the "self" can also position (Fawcett and Karban, 2005; cited in Fawcett, 2009a, p. 125).

From a postmodern perspective different forms of ageism can be disputed. Negative attitudes towards older people, such as they will eventually require residential care, they are inflexible or are asexual, may be exposed as myths and implicit negative attitudes can be seen as likely to lead to paternalistic behaviour (M. Hughes & Heycox, 2010).

Phillipson and Biggs (1998) argue that with the erosion of welfare-based institutions in postmodern society, identity in old age has become a contested area. Rather than comprising a struggle against too much structure, those growing old are now confronted with the prospect of too little (Phillipson & Biggs, 1998). Some of the dominant discourses available to older people to draw upon to construct their identity in a postmodern society are explored here. However, as Phillipson and Biggs express, asking questions about the status of the "self" in older age is difficult as there is an absence of a strong research base in this area (Phillipson & Biggs, 1998, p. 18).

Contradictory messages regarding ageing in contemporary Australia were raised in the Introduction to this thesis, in that for older people who have retired from the workforce a new contradiction appears to have emerged between those who have the opportunity to live an active lifestyle and those who are viewed as being a burden or a cost to society. M. Hughes and Heycox (2010) outline how, due to people living longer, healthier lives, transformations in how old age is constructed have resulted in discourses where older people are encouraged to achieve an active and positive old age and opportunities abound for social and financial participation in the community. In many respects the opening up of these opportunities have not been available to previous generations on the scale they are today and this is to be celebrated. However, those growing old can be perceived as a burden to society; the media



pays frequent attention to spiralling health and welfare costs and other costs involved in collective provision for those with dementia, such as residential facilities. There can be complex messages that reflect the devaluing of old age (M. Hughes & Heycox, 2010, p. 1). Although individuals age differently, these different discourses are also associated with the "healthy young aged" being arbitrarily those under 79, and the "older" aged, over 80, who are more susceptible to chronic diseases due to their longevity (Biggs, et al., 2006; Fine, 1999).

Some see these contradictory discourses as being centred on the potential integration or segregation of older people (Walker, 2000). The more flexible retirement age and introduction of private and compulsory retirement schemes mean many older people do not have to depend on public pensions (Macintyre, 1999). For Walker the path that leads to construction of ageing as an active and integrated time of life provides an opportunity to reconstruct the meaning of older age away from its association with passivity and dependency to one concerned with activity and interdependence. Several developments suggest that the meaning of old age can be revolutionised, such as older workers being encouraged to remain in the workforce longer, involving older users of services in key decisions about the provision of their services, and new political groupings composed of older people being formed (Walker, 2000, pp. 305-306). However, the focus of this thesis is on a group of older people who cannot, due to their individual circumstances at a particular point in time, participate in the revolution of healthy ageing and may be prone to separation or marginalisation. Their unique circumstances involve socio-legal encounters that are embedded in health and welfare contexts and where their rights to make certain decisions are being challenged. As such they are situated in contexts where social workers and other professionals have a role and function to mediate in relations between the particular older person and the state.

Many authors draw on the theoretical work of Michel Foucault and his concept of governmentality to understand the construction of old age as a core focus of social welfare (Biggs & Powell, 2001; Parton, 1994; Phillipson & Biggs, 1998; Powell, 2006; Powell & Biggs, 2000; Powell & Longino, 2001; Tulle-Winton, 1999; Webb, 2006). Associating knowledge and power with expert knowledge is a dominant modernist orientation that may be drawn upon to understand constructs of identity available to older people in contemporary societies dominated by neoliberal policies. Governmentality refers to the "ensemble formed by the institutions, procedures, analyses and reflections, the calculations and tactics, that

allow the exercise of this specific albeit complex form of power." (Foucault, 1979, p. 20) Central to this is Foucault's argument that identities are kept in place through integrated systems of power and knowledge and a routine operation of surveillance and assessment (Biggs & Powell, 2001, pp. 1-2). Powell and Biggs see Foucault's work as contributing to the analysis of old age in that his theories of punishment and discipline, as well as his analysis of medicine and madness, have relevance to perceptions of older people and how they are subject to disciplinary techniques such as the medical "gaze" (Powell & Biggs, 2000, p. 6). The "gaze" refers to discourses and languages that shape the understanding of ageing into questions that centre on and increase the power of health professional (Biggs & Powell, 2001). This draws attention to the way ageing has become a medical issue and the construction of ageing as a medical problem, where knowledge is processed by scientific inquiry. Those who are labelled "old" are therefore subjected to the power of professionals who operate through institutions and face-to-face contact. The discourse that is accepted as the "truth" is that of the professional and this is reinforced by the questions that professionals ask and the data collected. Biggs and Powell argue that this knowledge that is collected then progresses to a certain definition of a problem area where the most powerful voices heard are those of professionals, while other, often dissenting, voices of professionals with lesser status and older people become delegitimized (Biggs & Powell, 2001, p. 7).

The professional discourse described above may include the language of terms such as frailty, vulnerability, financial resources, and expected levels of needs and resources. Tulle-Winton (1999) draws attention to one of Foucault's key arguments; that resistance is constitutive of power. The older person is expected to accept the dominant professional discourse and resistance, or lack of agreement with those scrutinising them, leads to marginalisation of their opinions where they can be labelled as uncooperative or as lacking insight. Resistance is often applied by the older person in statements like "I don't feel old" (Tulle-Winton, 1999, p. 289). This highlights the number of distinguishing but paradoxical aspects of neoliberal governments that are observed by Powell to include an increasing dependence on professional expertise while older people are encouraged to be active participants in their own "managed care" through empowerment and being self-responsible (Powell, 2001, p. 128).

### **2.2.4.3 Influences on social work**

Many influential social theories of old age may be viewed as emerging from the modernist message that the self in older age is fixed. These theories have in turn influenced social work practice and highlight how different understandings of ageing persist and contribute to how identity is constructed. These social theories are too broad to examine in any depth here but, significantly, through the lens of hindsight, these theories tend to present older age as a time in which an individual needs to adapt, and reinforce the social exclusion of older people. Powell (2006) argues that a focus on individual pathology, assessment and need for adjustment by older people was established by functionalist sociological ideologies which dominated in the United States from the 1930s. Instead of growing into old age, the person declines and there is a negative focus on loss of abilities (Powell, 2006, pp. 46-47).

Historically this dominant approach has been challenged, developed and changed. Role theory, for example, assumes that people occupy positions in social interactions and each role has a set of expectations in the context of relationships (Payne, 1997, p. 160). It can therefore be practical in its analysis of human interactions although, as Payne (1997) argues, it is generally functionalist in character as there is still an emphasis on adjustment and loss. Powell observes that both disengagement theory and activity theory had foundations in functionalist sociological theory. Disengagement theory proposes that an older person prepares for later life by withdrawing from the pressures of interacting. Seemingly opposed to this, activity theory puts forward the notion that those successful in older age maintain their roles and participation in life. Conversely, in unsuccessful ageing these roles are lost (Powell, 2006; Victor, 1987). Dissatisfaction with the approaches of disengagement and activity theory led to developments in other ways of theorizing about ageing. Development theory proposes that understanding later life requires knowledge and an understanding the person's earlier history. However, although diversity in ageing and the development of new possibilities for older individuals are both acknowledged, there is still a focus on adaptation to old age and adjusting to loss of role and relationships (Powell, 2006; Victor, 1987). Going in another direction, labelling theory emerged. This presents the concept of the self as derived from interaction with others and the social environment, and so identity for older people is seen as socially determined. (Goffman, 1969; Victor, 1987). This contrasts with the other theories outlined and it is helpful in understanding how old age can become defined through social constructs as a deviant condition.

The influence on social work of postmodernist questioning, where identity is seen as constructed through discourse, is the implication that any construction of ageing, and its impact on identity in older age, should be critically interrogated. Rather than viewing the older person as having an unchanging self, social workers can be aware of the multiple identities to which older people relate and how these identities are constructed (M. Hughes & Heycox, 2005, 2010). K. Healy argues that postmodernist questioning can encourage social workers to recognise a range of perspectives surrounding issues and the multiple narratives involved so that identity is not perceived as fixed. The aim is not to establish the truth but to recognise the ambiguities and differing perspectives of a particular social situation (K. Healy, 2005, p. 210). Fawcett critically reviews the constructed meaning of older age through commonly used terminology such as "care," "protection" and "vulnerability" to argue that social work has a pivotal role in challenging modernist deficit-orientated practices in the context of services for older people where there can be a focus on individual pathology, on assessment and prioritisation of risk (Fawcett, 2012).

The competing tensions surrounding constructions of ageing are evident in the Australian context where research has shown that social work with older people is perceived by social work students as lower status employment and less complex (M. Hughes & Heycox, 2005). They go on to argue that ageism in social work students and the social work profession is an ingrained aspect associated with older age being constructed as physical decline and a disease that needs to be cured rather than experienced. They put forward that critical reflective practice can assist in tackling ageism within the social work profession. Other strategies include participation in courses on ageing and developing educational and mentoring programs. This brings to the fore Tulle-Winton's question as to whether the discourse surrounding the promise of more positive subjectivities achieved through successful ageing is an ambiguous project as it is caught between "resisting the mask of ageing and reaffirming the continued cultural repression of the declining body, and, by extension, of the ageing self." (Tulle-Winton, 1999, p. 282) This is because, paradoxically, successful ageing can be viewed as a technique of regulation which denies older people the right to bodily dysfunction.

As explored previously in this chapter, new discourses have emerged which impact on social work practices, such as identification of and management of risk and the technology of case/care management. What is significant is that from a postmodern perspective these in turn can be seen to send messages to older people negatively positioning them as someone to be

"managed," contradicting the message of being an active consumer with choice. As Powell argues an ambivalence at the centre of neoliberalism is that, on the one hand, older people are to be "managed" by administrative powers such as professionals while, on the other hand, older people are left to govern themselves and take self-responsibility (Powell, 2006, p. 127). These disparate and contested messages to older people provide a repertoire of discourses upon which they may draw to construct their identity. Phillipson and Biggs highlight that with the eradication of a predictable framework for an ageing identity there may be an emergence of "no-identity zones" which fail to sustain an authentic framework for supporting experiences of older people. Phillipson and Biggs argue that a secure position is needed by everyone, whether young and fit or frail and demented (Phillipson & Biggs, 1998).

It has been argued here that the modernist message regarding identity in old age is that it is fixed in relation to values underpinning participation in the workforce. Postmodernist questioning shows that identity in older age can be a contested area where there can be many tensions and ambiguities. The various theoretical perspectives that impact on how identity is constructed in older age have been explored. These highlight what may be seen as challenges in social work practice as social workers, in their daily work, encounter many tensions and disparate notions regarding ageing.

### **2.3 Summary**

To summarise the literature reviewed in this chapter it has been argued that, whilst older people form a diverse group, how identity is shaped can be dependent on dominant discourses surrounding public health and welfare policy. It has been argued that contemporary policies of neoliberalism, such as marketisation and privatisation, have a defining impact on the way old age is constructed and in turn these policies variously influence social work practice. To support these arguments the shift in discourse from grand narratives and progress to pluralism and difference was explored by presenting an overview of structural developments in health and welfare services since the Industrial Revolution. The shift in discourse from reason and certainty to uncertainty and complexity was examined through literature predominantly surrounding two fundamental concerns in contemporary social work practice; the rise of the modernist conceptualisation of risk, and developments made in social workers' understanding and approach to ethical issues. Lastly, literature with a

focus on the shift in understandings from fixed identities to subjectivity is particularly relevant to understandings of the "self" by those growing old, where the modernist message regarding identity in old age is that it is fixed in relation to values underpinning the ability to participate in the workforce. Postmodernist questioning shows that identity in older age can be a contested area where social workers in practice encounter the many tensions and ambiguities. Chapter Three moves to a narrower focus on a group of older people, upon whom these structural policies impact directly; those with the label of dementia and whose ability to make their own decisions is challenged.

## Chapter Three

### **3.1 The influence on social work practice of how shifting dementia and capacity discourses have shaped social action**

In Chapter Two it was argued that neoliberal health and welfare discourses shape the meaning of old age and influence social work practice. This chapter moves to a narrower focus on a group of older people upon whom these structural policies impact directly. This is because they are identified as occupying the space between the private and the public, or the "social" area. Here the state enters the world of private relations because this group are attributed as having a disability called dementia in contemporary western societies. As raised in the Introduction to this literature review, in conjunction with the succession of health and social welfare policy reforms over the last thirty years, there have been parallel discourses that reflect changes in the way what is given the label of dementia, and any subsequent perceived loss of decision-making capacity, are understood and conceptualised. Also, as observed in the Introduction to this thesis, critical questions are raised about what it means to be a person with dementia in the Australian context if decision-making is challenged. The primary research question regarding social work challenges in socio-legal encounters underpins these questions.

This chapter examines the literature that aims to understand the impact of how dementia and capacity discourses are constructed and the three major shifts of understandings in these discourses. The ideas and concepts of modernism and postmodernism are again used as a framework to aid in the analysis. The shift in discourse from grand narratives and progress to pluralism and difference is particularly relevant in understanding changes in how the concept of dementia is constructed. The shift from reason and certainty to uncertainty and complexity provides a focus for exploring shifts in understandings of capacity. Thirdly, the shifts in understandings from fixed identities to subjectivity is relevant to the people who are the focus of this study.

This framework is used in order to argue that from the social work perspective how dementia and capacity are understood, and what informs these understandings, in complex social situations are crucial as these understandings can dominate the interactions of those involved.

As raised in Chapter One there are many different and disputed meanings attached to the word dementia. It is reiterated that the word is used here to refer to perceptions by someone that there is some change of abilities that affect decision-making in an older person although this definition is not exclusive to dementia.

### **3.1.1 Grand narratives and progress to pluralism and difference**

#### **3.1.1.1 The modernist message: dementia is a disease to be cured**

It is argued here that the essence of the modernist message regarding dementia is that it is a disease and, as such, can be cured and this provides hope for sufferers. This is congruent with the belief in grand narratives and the underlying notion of progress that reflects that the world is being made into a better place by people's actions. Since dementia is constructed as a disease or illness, people with dementia may therefore become objects of scientific discourse. In common with methods to find out the cause of other illnesses through positivist empirical research, if the underlying structure of the brain can be understood, organic origins will account for understanding the truth about dementia (Forstl, 2005). There is seen to be a cause and effect relationship where, once the cause is found it can then be fixed. This section therefore looks briefly at contrasting beliefs about dementia before the Enlightenment, explores the modernist constructs surrounding dementia, including the origins of the classifications of dementia, and the social actions that resulted from modernist ideas of understanding dementia.

In the overall historical context, modernist ideas about dementia contrast with dominant beliefs in previous societies. As raised in the Introduction to this thesis, since the Greek and Roman times writers and philosophers have referred to the changing abilities of older people. What is significant is that these were generally perceived as a natural consequence of growing old and uncontrollable. Lacey (1999) states descriptions of "senility" in older people have been noted in history since at least the Greco-Roman era where the "child-like" state of some older people, and terms describing dementia such as "demence" and "dotage," appeared (Lacey, 1999, p. 102). Demence is the origin of the word dementia. For Forstl (2005), in the Renaissance concepts began to be developed about beliefs regarding the origins of dementia and its consequences, these being the loss of memory and lethargy, "foolishness" or "dotishness." Dementia in these times was described as a "passion of the mind when a man's



perception and understanding of all things is taken away" (Cosin, 1592, cited in Forstl, 2005, p. S3).

A noteworthy exception to dementia being a natural consequence of ageing was raised in the Introduction to this thesis, in that Cicero, the Ancient Roman philosopher, thought that an active intellectual life could postpone what he saw as mental decline in older people (Karenberg & Forstl, 2006). Another exception to dementia being viewed as uncontrollable by people occurred in what is described by Berchtold and Cotman (1998) as the medieval interlude, where in the "middle ages" the Church became a powerful influence and its beliefs dominated what was accepted as knowledge. What may be viewed as dementia today was seen as madness or punishment for sin (Berchtold & Cotman, 1998, p. 175). Layman (1989) argues that dementia within this context was not distinguished from other behaviour that was labelled as madness. However, he argues that by the end of the seventeenth century and into the Enlightenment madness was increasingly seen as an organic physical disease no longer involving individual responsibility for action. Within the context of notions about progress, this view could be viewed as a more humane direction.

The nineteenth century was seen as a time of "advance" in health care. Knight outlines how belief in progress could be seen as justified through discoveries such as how blood circulates, anaesthesia, causes of infectious diseases and other diseases such as leprosy and typhoid. Public health measures were introduced, resulting in better health in the general population (Knight, 1998). The concept of madness was transformed into the concept of mental illness. This was encouraged by the scientific discovery of third stage syphilis being found to produce neurological breakdown, which was the first classification of a mental illness (Lyman, 1989). Lyman describes how the first classification of dementia was "dementia praecox" or "early senility." As "senility" in old age was considered normal only early "senility" was considered an illness and this definition of dementia, Lyman argues, was a first instance of medicalised deviance as it was a violation of age norms (Lyman, 1989, p. 598). To be able to identify and classify types of dementia led to beliefs that it may be controlled, investigated and eventually cured. This is still a dominant discourse today; for example, a belief that there will eventually be a cure for Alzheimer's disease, which legitimates allocation of large amounts of revenue to research and policy interests that offer hope for a cure (Alzheimer's Australia, 2012). It also reflects the adherence to belief in the idea of one

true knowledge base, where a cause for a disease is waiting to be found that continues into contemporary times.

Lyman argues that a psychiatry text written in 1801 by a director of French asylums, Pinel, is the precursor of the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM). Pinel's classifications comprised of dementia, melancholy, mania and idiocy (Lyman, 1989, p. 598). The concept of dementia being a disease that could be classified was advanced by the discovery, through empirical research on brain cells, of Alzheimer's disease by Alois Alzheimer in 1906. This discovery encouraged acceptance in the larger scientific community of the time that the concept of senile dementia, or Alzheimer's disease, was due to neurodegenerative brain changes and was probably the most common form of dementia (Forstl, 2005). Today, Alzheimer's Australia (2007) states that Alzheimer's disease accounts for between 50% and 70% of dementias and describe it as a progressive, degenerative illness that attacks the brain. Vascular dementia, described as the second most common form of dementia today by Alzheimer's Australia, has origins in its classification as an illness from 1672, when the possibility of curing cerebral softening was raised. In 1881, from a positivist empirical perspective, a large number of significant observations on correlations in elderly people with cerebrovascular disease was made (Forstl, 2005). Today, when viewed as a disease, it is associated with problems of circulation of blood to the brain caused by a number of small strokes (multi-infarct dementia) or stroke-related changes to the brain and as having many pathological and clinical forms (Forstl, 2005).

Other medical classifications of dementia originated through the search for true knowledge about diseases. Forstl (2005) describes how fronto temporal dementia was documented from 1833 including Lewy Bodies disease, Pick's disease, and a dementia associated with Parkinson's disease reported from 1817. Classifications followed, including a dementia connected with vitamin deficiencies, alcohol-related dementia, and Creutzfeldt-Jacob disease, which is a rare, fatal brain disorder caused by a protein particle. From a social constructionist perspective, all these classifications relate to physical deviation from the perceived norm and pay little attention to the attributes of the individual person in their social context.

These modernist constructions of knowledge about dementia had significant outcomes for the people concerned in the social actions that resulted. As raised in Chapter Two, during the nineteenth century, in the context of industrialisation and population growth, there was a

substantial expansion of the number and size of "insane asylums" in western countries. What is significant here is that these "asylums" housed a group of older people upon whom this social action impacted directly, those with dementia. In 1811 the NSW Government established an "asylum" in Castle Hill for the care and treatment of the mentally ill, which included older people with dementia (State Records NSW). It was not until the late 1920s that physical treatments began to be used in these institutions, such as malarial therapy for people who had syphilis (Smark & Deo, 2006). In the USA in the early decades of the twentieth century the trend of institutionalising older people in mental hospitals meant that the number of those sixty-five and older increased from 13,000 to 56,000 between 1900 and 1930 and many of these had dementia (Lacey, 1999). Similarly, in Australia and Britain the institutions were overcrowded and maintained people with dementia (Smark & Deo, 2006).

From the late nineteenth and early twentieth centuries the profession that became administrators of asylums, and subsequently psychiatric hospitals, was doctors (Lyman, 1989). As the twentieth century progressed, older people diagnosed with dementia and whose behaviour was seen to be creating problems for themselves and others were traditionally cared for in psychiatric hospitals, the successors to "insane" asylums, with little therapeutic support or cure, or improvement of their lifestyle, despite the efforts to diagnose and classify dementia as an illness (Lacey, 1999). This mass institutionalisation of people may be viewed as an unintended consequence of ideas that were initially considered humane and would lead to people living better quality lives (Berchtold & Cotman, 1998). However, it also questions the fundamental modernist message that grand theories and a belief that progress, invested in science, will lead to a better world.

With the notion of progress in scientific knowledge from the eighteenth century these new understandings surrounding dementia can be viewed as just one facet which grew out of a dominant scientific empirical and positivist approach to a broad range of human affairs. These understandings of dementia will be referred to in this thesis as "biomedical understandings" as they reflect the key concepts of a specific aetiology, that is each disease has a specific causal agent acting on the physical body (Knight, 1998, p. 139). As K.Healy expresses, the term "biomedicine" is widely used in the biological, medical and social sciences to refer to the dominant contemporary approaches to medicine that derive from the biological sciences (K. Healy, 2005, p. 20). In the literature these understandings are often referred to as the "biomedical model" but "biomedical understandings" is seen as more apt for

this thesis as the focus is on shifting understandings of dementia and capacity discourses within the wider context of health and welfare. Biomedical understandings of dementia may be viewed not as static, but growing and evolving and including a diversity of opinions. However, these views may be seen to centre on certainty and a belief that dementia is an illness with associated decline and a focus on what a person can no longer achieve. Biomedical understandings are very prominent in Australia and highly influential in social work practice today.

Kitwood, who challenged the key ideas of biomedical understandings using a social constructionist approach, outlined that from his perspective the key ideas of biomedicine are that diseases are deviations from normal biological functioning and so treatment, or social action, focuses on addressing this deviation and correcting it (Kitwood, 1997; Kitwood & Bredin, 1992). However, it is of significance that, as C.L. Estes and Binney point out, biomedical understandings can be distinguished from a biological or scientific model although they incorporate elements of these. They argue there are two aspects of the biomedical understanding of ageing. Firstly, the social construction of ageing as a medical problem with a focus on treatment and management, where old age is linked with illness and pathology. Secondly, the understanding's success comes from aligning and legitimatising itself through its close association with science (C. L. Estes & Binney, 1989, pp. 587-588). Society's confidence in science and a conviction that its knowledge is both accurate, certain and objective may explain the acceptance of biomedical understandings in western countries since its early origins. It also may explain its dominant influence on health policy, research and policy funding priorities, as well as the power of medical practitioners (C. L. Estes & Binney, 1989). Knight highlights that the precedence of the biomedical understanding of dementia in Australia is shown by the relative ratios of spending within governments' health budgets on what could be seen as core concerns of biomedicine (Health Issues Centre 1988; cited in Knight, 1998, p. 139).

### **3.1.1.2 Postmodernist questioning: there are many ways of understanding dementia**

The message of the postmodern concepts of pluralism and acceptance of difference is to reject the notion that dementia can be understood primarily, through grand narratives, as a biomedical phenomenon that charts irrevocable decline related to neurodegenerative changes. Shifts in discourses mean that there may be many ways of understanding dementia which are

dependent on different social, historical and cultural contexts. The advantage of using these postmodern concepts is that it can lead to an understanding that in contemporary Australian society health professionals, older people and their families and people in their social networks can have different belief systems about what dementia is. Taking into account the multicultural mix in contemporary Australia, these beliefs may be very varied. The discussion in this section centres on social constructionist critical questioning of the biomedical understanding of dementia in order to argue there are many different ways of understanding dementia. Then the power dynamics that underpin relationships where there are different understandings of dementia are critically examined.

It is acknowledged that the literature shows there are many ways of understanding dementia, such as normal ageing, spiritual explanations, disengagement theory and psychoanalytic explanations (Downs, et al., 2006). But what is important in contemporary social work practice is recognising the mixture of beliefs encountered, which range from influential biomedical understandings to the new understandings of dementia that originated in the ideas of Kitwood (1989) drawn from a social constructionist approach. The strength of these challenges to taken-for-granted knowledge is that they offer comprehensive insights into a person's individual experience and the focus is on abilities, strengths and inclusion (Downs, et al., 2006, pp. 252-253). The narrowness and evaluative impact of a medical diagnosis is not accepted and illness is seen as a social matter involving the interpretation of a person's experience within contexts of assumptions, norms and values as well as the economic structure of society (Burr, 2004). As Burr (2004) expresses, these social constructionist understandings view medicine itself as subject to social processes and changes. It is acknowledged that beliefs of medical practitioners operate within a culture with norms, values and expectations and there have been shifts in biomedical understandings of dementia alongside of social attitudes. However, this is not to deny that biomedical understandings are still one of the most powerful influences on broader contemporary Australian views of dementia.

Within this dominant discourse of the biomedical understandings of dementia there is some uncertainty due to how complex the medical classification system has become. Krishnan (2007) describes how geriatric psychiatry has to keep up with what he sees as the rapid expansion in scientific knowledge that has been acquired about dementia. He argues for a more advanced classification system for dementia in medicine that has two axes: one for

clinical manifestations and the other for aetiology or cause. Krishnan defines dementia according to the standard medical definition as:

a loss of intellectual abilities of sufficient severity to interfere with social or occupational functioning, always accompanied by memory impairment and at least one of the following: impairment of abstract thinking, judgment or other disturbance of higher cortical function in the absence of delirium. (Krishnan, 2007, p. 4)

However, the issue of memory loss accompanying this description of dementia is a problem for Krishnan; he argues there is controversy as to whether there is evidence that memory impairment need not be an early and essential criterion for a biomedical understanding of dementia. Today it is argued by some, including medical practitioners, that there is an inherent problem in the biomedical classification of dementia as a disease as there is no medical consensus on what factors cause the condition or the use of the labelling system (Forstl, 2005; Harding & Palfrey, 1997; Krishnan, 2007; Lautenschlager & Martins, 2005).

In the last decades of the twentieth century Kitwood (1989, 1997) challenged the assumptions and taken-for-granted knowledge of this biomedical understanding of dementia. He described this understanding as one where the people who are seen to possess the most reliable, valid and relevant knowledge are the doctors. He challenged that in this culture people with dementia are considered significantly different from others because of their organic mental disorder. Kitwood saw biomedical understandings as producing bad care practices that he described as "malignant social psychology" (Kitwood, 1997) as these practices could harm the individual. He argued that when a person with dementia first starts to act in ways that disrupt what is seen as normal social life this is seen as a problem and identified as such by others. Kitwood says that at this point there appears a division between "us" and "them" (Kitwood, 1989, 1997). From this perspective, Kitwood's identification of the treatment of individuals with dementia, such as institutionalisation and marginalisation, can be seen as the social action resulting from a biomedical construction of dementia. However, as Flicker (1999) states, at the time his ideas were criticised by the medical profession who claimed that Kitwood lacked evidence to support his claims which, they argued, were based on anecdotes and sketchy case histories. Also, Flicker outlines that arguments were raised against the style of care Kitwood proposed as it was seen as extremely time-consuming and expensive and would take funds away from other approaches.

Kitwood's main argument focused on the extent to which being a person depends, not only on biology, but also on social interactions. Personhood is a "standing or status that is bestowed upon one human being, by others, in the context of relationship and social being implying recognition, respect and trust." (Kitwood, 1997, pp. 7-8) Kitwood's concept of personhood is today generally accepted theoretically and is related in practice to residential settings and education about dementia. His ideas provided the basis for a shift in focus from hospital style care centred on the priorities of staff and routines, to staff providing care that is created from the individual preferences and uniqueness of each person. Kitwood and Bredin (1997) developed a dementia care mapping tool to evaluate the quality of care, as one of Kitwood's main arguments was that quality of life was linked to the type of care received with an emphasis on independence, wellbeing and empowerment. From the 1980s in Australia, based on Kitwood's ideas, new models of providing residential care grew from a burgeoning awareness of the limitations of therapeutic programmes in large psychiatric hospitals. The first of the new models in NSW were called CADE Units (Confused and Disturbed Elderly Units) that, despite the unfortunate name, provided smaller, more homelike units with individual bedrooms and kitchens, where the environment was easy to negotiate (Fleming & Bowles, 1987). Hostel and nursing home facilities have grown and developed using similar ideas, such as the emphasis on individual needs and staff attention to the older person's feelings rather than rational confrontation.

Plurality of knowledge is reflected in the growing literature base demonstrating that health professionals, older people with dementia and those in their social networks have different knowledge bases and these can be a powerful influence in the interactions between these groups (Adams, 1998, 2003; Adams & Clarke, 2001; Clarke, 1999a, 1999b; Harrison, 1993; J. C. Hughes & Baldwin, 2006; Nolan, et al., 2002). Acceptance of difference in understanding dementia has resulted in newer approaches that endeavour to address the significance of multiple parties involved in a process. These approaches are variously called the "inclusive approach," "partnership approach" or "health care triads" and commonly involve the person with dementia, a person who is identified as the most significant to them, such as a spouse, and the health care professional (Adams, 1998, 2003; Adams & Clarke, 2001; Fortinsky, 2001). These approaches maintain that it is a myth that any single knowledge base, such as a biomedical understanding of dementia, represents all parties involved and it is accepted that power dynamics play a significant role in the relationships (Clarke, 1999a). As Clarke argues, sharing of knowledge may result in better practice but it

can be fraught with moral, ethical and practical problems and at times there is lip-service to participation in decision-making (Clarke, 1999a).

For Adams (2003), triangular relationships result in different roles that can be played by the third person, or health professional, and a combination of alliances and collusions can be formed. The health professional can be a doctor, social worker, nurse or a paid helper. Adams describes a spouse or significant person in the life of the person with dementia as an informal carer. The informal carer and professional can exclude the older person; the informal carer and older person ally against the professional and the professional and older person ally against the informal carer. Use of language is seen as important in these triads as the third person can be disempowered through discourse (Adams, 2003, p. 48). Clarke (1999a) develops the argument that partnerships, such as these triads or between an older person and a professional, can share a mutual appreciation of each other's knowledge but as some knowledge bases are more highly valued or dominant power can be exercised in different ways. Professionals can develop "pseudo-partnership" relationships by the use of monopoly of "expert" knowledge and older people and families can exert power by refusal or noncompliance with expert knowledge (Clarke, 1999a).

That biomedical understandings of dementia are influential in dominant discourses today is further demonstrated by Clarke, who drew on data collected from family and health professionals. Clarke found that whilst family normalised their relationship with the person with dementia, this process was not usually validated by health professionals, who tried to encourage compliance with their model of service provision that emphasised the pathological aspects of the person where dementia was constructed as a disease. Significantly, Clarke found family emphasised the continuance of their relationship with the older person and deconstructed the assumed pathology by professionals (Clarke, 1999b). Similarly, J. C. Hughes and others found that ethical issues differ between professionals and families. They found these differences are reflected in issues such as what are seen as the best interests and wishes of the person with dementia. Professionals talked of the best interests of the person with dementia in isolation of their social context, whereas family members saw the best interests of themselves entwined with the older person. Professionals did not see some issues as ethical that the family did. These were guilt, sense of responsibility and duty. Family also paid closer attention to the way the older person was spoken to and treated as a person (J. C. Hughes, Hope, Reader, & Rice, 2002).



### **3.1.1.3 Influence on social work practice**

What is significant for social work in the message that dementia is a disease to be cured is that, as a result of the acceptance of the dominant modernist ideas of grand narratives and progress, the social action that resulted created a move to a hospital environment as the place where social workers practised and knowledge was acquired (Parton, 1994). Parton, who draws upon a constructive social work perspective using a social constructionist approach based on the work of Gergen, sees the space occupied by social work within this context interrelated with and dependent on a number of more established discourses such as medicine (Parton, 1994, p. 18). So, it may be argued that if a person with dementia is the object of a biomedical understanding, this restricts the ability of social workers to produce a picture of the individual as a subject not immediately visible to others. For Parton, the use of interpretive knowledge for insights and understandings of relationships as primary technologies of practice is therefore limited as there is no real space for private and public mediation (Parton, 1994, p. 18).

The studies referred to previously of Adams (2003) Clarke (1999a) and J. C. Hughes and others. (2002) demonstrate how power dynamics have the potential to marginalise the person with dementia and the views of people in their social contexts. The implications for social work practice are that postmodernist concepts of pluralism and difference are useful in that they question the taken-for-granted assumptions of the dominance of health professional expert knowledge in the processes in which social workers are involved. Parton (1994) argues that the challenge for social work is to accept and interpret differences in knowledge between those involved in social interactions. If knowledge refers to a particular construction of events this can be used to give equal consideration to the multiple interpretations and perspectives in a given situation (Clarke, 1999a). Parton (1994) argues that social work can fulfil the essential mediating role between those who are actually or potentially excluded using a constructionist social work approach. Social workers can work towards making all constructions and interpretations heard and it is possible to reframe situations to create better understanding of the marginalised views (Parton 1994). When considering the primary research question of this thesis, Parton's comments regarding the essential mediating role and the inherent challenges to social work practice are particularly relevant.

A social constructionist understanding of dementia that emphasises the use of language is significant here as in the social processes where social workers are involved meaning is seen as being created when people talk to each other. Each person develops their own meaning and from this it may be viewed that those with power can control the language of the discourse and influence how the world is seen. In Gergen's (1985, 1999) terms the voice of those in relatively powerful positions is prioritised over others. What is important in the social work practice context is that, as Parton argues, it is an emphasis on the process in social work of plurality of both knowledge and voice that are key issues in taking social work professional practice forward in complex social situations that are mostly embedded in continuous change and do not come ready formed (Parton, 2003, p. 1).

Acceptance of pluralism and difference in social work practice situations surrounding a person with dementia where decision-making is questioned means these situations are viewed as fraught with difficulties and require considerable skill to unearth the diversity of views. This is opposed to an approach of being an expert and imparting expert knowledge inherent in the biomedical understanding dementia. Ensuring that the personhood of the individual with dementia is respected can be challenging within the multiplicity of opinions. Social work practice can, as K.Healy (2005) highlights, contribute to the control and surveillance of the people it is trying to assist if the social worker takes a narrow approach based on the discourse of having expert knowledge. Foucault's idea of a medical or clinical "gaze," which was referred to in Chapter Two, is also relevant here in the links that can be made between social constructionism and modernism and postmodernism. For Foucault, discourses, languages and meanings that centre on and increase the power of health professionals, where ageing is medicalised as a social issue, reflect society's acceptance of science as having knowledge that is accurate and objective (Powell, 2006). Foucault's association of knowledge with power demonstrates how divisions can arise in the triads or combinations of people involved in each unique situation. As Fawcett highlights, the play of knowledge and power can be used to draw a dividing line between the knowledge of the expert and that of the service user, client or consumer where the latter's views are downgraded (Fawcett, 2009a, p. 121).

### **3.1.2 Reason and certainty to uncertainty and complexity**

#### **3.1.2.1 The modernist message: capacity is a binary concept**

As highlighted in the previous section, the modernist concepts that flowed from the Enlightenment lead to constructions of dementia which are positivist and based on reason and the certainty of science. These concepts also led to the institutionalisation of people with dementia. It is argued here that this was achieved by significant parallel legal changes that moved who were making decisions about the legal capacity of a person. In the legal system inherited by Australia this decision-making moved initially from a monarch, to the courts and then to professionals. However, underlying both historical developments and the modernist message is the notion that capacity is a binary concept. There is the certainty that people are considered either capable or incapable of all decisions. So if a person is found legally incapable, they cannot make any decisions. As Darzins and others reflect, this fails to deal with people who have partial, fluctuating or some impairment of decision-making (Darzins, Molloy, & Strang, 2000, p. 5).

Historically, in western cultures prior to the Enlightenment a finding of legal incapacity was very wide-ranging and justified quite intrusive curtailments of personal autonomy and rights. The concept of guardianship was recognized in Roman times and common law adult guardianship originated in thirteenth and fourteenth century England (Carney & Tait, 1998; O'Neill & Peisah, 2011). English law articulated notions of protection for those perceived as lacking the ability to care for themselves and guardianship was used to permit the Monarch to manage the lands and profits of estates of two groups of people who were seen as "idiots" and "lunatics" (O'Neill & Peisah, 2011; Sabatino & Basinger, 2000). Carney and Tait (1997) outline how during these times those seen as "lunatics" were treated more generously, as they could have their money managed "for their own benefit" and when they became "well" returned to them; whereas those seen as "idiots" were liable to forfeit their assets to the Crown in return for maintenance of themselves and their households by the Monarch.

In England, this responsibility moved from the Monarch to the Chancery Court, where it was usual to appoint a committee or family member. But these arrangements, as O'Neill and Peisah (2011) point out, only ensured that wealthy people were looked after and others who were reliant on their families and charity often found themselves in prison. However, this change created a fundamental shift where professional power subverted sovereignty and right. The system introduced into Australia in the early days of the colony of New South

Wales was inherited from England. The responsibility to appoint guardians moved from the Governor to the Supreme Court in the *New South Wales Act 1823 (UK)* and in NSW the *Lunacy ACT 1878 (NSW)* contained provisions for the care of people seen as mentally ill and their estates (O'Neill & Peisah, 2011). Guardianship was little used until the 1960s because of the focus on confinement by institutionalisation and the increasing power of the medical profession. As the institution itself made decisions about matters such as treatment and lifestyle, with no need for consent from the person concerned, guardians were mostly not seen as needed (Carney & Tait, 1997; Rees, 2009). In keeping with earlier times, however, property management rights were an issue so they were routinely transferred from the person to a state agency (Carney & Tait, 1997, p. 12).

Foucault's ideas about the new disciplines such as medicine, psychiatry, psychology and criminology, with their practice legitimised by the new knowledge of science, are relevant here as they explain how the disciplines grew to subvert the classical order of rule based on sovereignty and right. From this perspective these professions began to institute a regime of power exercised through disciplinary mechanisms and the stipulation of norms for human behaviour and, as a result, decisions were not made in the courtroom but in the hospital or clinic (Powell, 2006). This growth in disciplinary power was legitimised directly by the positivist search for the organic origins of dementia and the reforms seen as progressive where older people were brought out of shackles in prisons into institutions designed to provide more humane care (Berchtold & Cotman, 1998).

However, as raised in Chapter Two, the literature reflects that people with dementia whose behaviour deviated from the norm did not break free by the use of reason, or the certainty of finding a cure, but came under a different kind of social control (Smark & Deo, 2006). For Smark and Deo, from the Foucauldian perspective, mental institutions in NSW were seen as structures that provided "disciplinary surveillance" which were controlled by state governments through the financing of the institutions (Smark & Deo, 2006, p. 3). Smark and Deo highlight that overcrowding and understaffing in these institutions led to them being custodial rather than therapeutic. Similarly, Powell argues that social control moved to hospitals where accounts were constructed of the classification of the type of dementia a patient suffered from by connecting signs and symptoms. People who were considered to be unable to make their own decisions were subjected to the highest levels of control and surveillance (Powell, 2006). For Lacey (1999) the most striking paradigm shifts that occurred

in the twentieth century include the first sixty years where there appears to be no "expert" who recommended active therapeutic involvement with people who had a diagnosis of dementia. Lacey (1999) describes how in the next decades therapies such as reality orientation and behavioural therapy were attempted in institutional settings but milieu therapy was reported to have more success as it stressed the importance of positive staff interactions with residents.

### **3.1.2.2 Postmodernist questioning: capacity can be varied**

Underpinning the marked structural changes in western societies originating in the early 1980s, there were changes in the way decision-making capacity was viewed and conceptualised. Where there was certainty in that a person either had capacity or did not, and who made this decision, there has been a shift towards an understanding of capacity as being varied, which has profound impacts by creating uncertainty and complexity. In the Australian context, the notion of capacity is now based on a person's ability to make a specific decision, such as where to live. If the ability to make a decision is challenged, who then makes this decision on behalf of the person, and on what basis it is assessed the person cannot make the decision, can be fraught with difficulties. This section briefly explores international legislative reforms, which grew out of the shifting discourses surrounding the concept of capacity, before moving to focus on the legislation and relevant literature that has a direct focus on guardianship as a socio-legal encounter in the Australian context, where the boundaries in time and space of this study are located. The contested area of how capacity may be assessed is then addressed before examining literature directly relating to guardianship from professions other than social work.

In many western countries reform of guardianship laws took into account the varied nature of capacity and respect for autonomy and self-determination of the individual (Gove & Georges, 2001). One of the central debates in the international literature regarding the contemporary legislation was to balance the ethical values of autonomy or choice with paternalism or protection (Carney & Tait, 1991; B. Woods & Pratt, 2005). Introduction of new legislation created many grey areas of uncertainty. Capacity moved from a clear binary legal concept to a situation where, as Sabatino and Basinger argue, no matter how articulate, detailed or comprehensive the legislative definitions, incapacity determinations for all but the clearest cases depends on a weighting process, that is a consideration of medical, social and a

combination of very practical variables relating to the need for state intervention (Sabatino & Basinger, 2000, p. 119).

This notion of varied or area-specific incapacity can create confusion and uncertainty within both professional and private individual and family contexts when an application for guardianship is being considered (Bennett & Hallen, 2005; Schiemer & Anetzberger, 1999). There is complexity as, if a person's decision-making is in question, the focus for every decision can be on whether the person has capacity to make that particular decision. As raised by K. Sullivan, health professionals can appear to differ widely in their understanding of capacity and different thresholds applied when making recommendations (K. Sullivan, 2005, p. 94). Decisions therefore can relate to a particular point in time and the type of decision being made, such as financial or health, how complicated the decision is and how much information the person has been given, and if they understand the particular information (Attorney General's Department, 2008, p. 21). It is recognised under these reforms that a person may not be able to manage their finances but be able to make decisions such as where and how they want to attend to their personal care or where they may wish to live. From the legal perspective, there is also an underlying presumption of capacity unless proved otherwise.

From the 1980s in Europe many countries rewrote their legislation including Austria, Germany, Denmark, Scotland, England. and Wales (Gove & Georges, 2001; Jones, 2001; Wilkinson, 2001). However, Carney and Tait challenge that reforms in some countries did little to change the position of those served by the new legislation and cite examples such as Germany, where superior court rulings insisting on the procedural protection of a personal hearing were largely ignored (Carney & Tait, 1998, p. 149). Japan also initiated major law reforms to establish a new system of guardianship which took effect in early 2000 (Arai & Homma, 2005; Mizuno & Nanba, 2003).

In the United States of America state-specific legislation established the legal requirements for guardianship and Kane (2001) describes how the process of appointing a guardian can be cumbersome and expensive. Kane notes that most states recognised partial or limited guardianship but few courts appointed guardians with limited decision-making (Kane, 2001, p. 93). Similarly, Kapp says that a guardian with unlimited decision-making powers is often appointed after the courts accept evidence on decision-specific incapacity (Kapp, 2004, p. 85). Kapp also outlines how most people in the U.S.A. tend to "bumble through" and make

informal arrangements rather than pursue costly legal court proceedings. When the formal process is undertaken, it is usually for the benefit of a third party, such as a service provider, financial institution or family member (Kapp, 2004, p. 87). Kapp discusses whether professionals in the United States should be encouraging more guardianship applications or supporting individuals to work out problems. This is interesting because Australian legislation specifically says that it has to be proved that problems cannot be solved informally before an application for guardianship is accepted.

As happened in other countries, Australia rewrote its guardianship laws in the late 1980s. This was on a state-by-state basis so there is no uniform legislation (Bennett & Hallen, 2005). Carney and Tait (1998) describe how the purpose of the new laws was to make guardianship an institution of last resort with a genuine respect for individual autonomy. Australia's laws are unique, in that the new legislation was entrusted to specialist multidisciplinary tribunals rather than courts. The Northern Territory is the only state where a local and supreme court administers guardianship legislation. In general, most states require the establishment of the presence of a "disability" and of "incapacity," in addition to other factors. For example in Victoria the *Guardianship and Administration Act 2000* defines disability as an "intellectual impairment, mental disorder, brain injury, physical disability or dementia" and incapacity as "that the person is unable by reason of the disability to make reasonable judgements in respect of all or any of the matters relating to her or his person or circumstances". In New South Wales the *Guardianship Act 1987* defines disability as "intellectual, physical, psychological or sensory disability; advanced age; mental illness or person otherwise disabled" and incapacity as "because of a disability, is totally or partially incapable of managing his or her person" (Bennett & Hallen, page 484).

Carney and Tait outline how the philosophy behind the new tribunals was one of promoting access to justice and overcoming economic and psychological barriers associated with courts. The tribunals were to be more "user-friendly," operate informally and assume primary responsibility for eliciting evidence by engaging in inquisitorial styles of hearing rather than a passive adjudication, as in courts (Carney & Tait, 1998, p. 148). This is another unique feature of the Australian model, as three presiding members make up the tribunal, a legal member, professional member and community member. For the presiding members of the tribunal it is not a constant occupation as with, for example, a presiding magistrate in a court.

As the legislation in NSW is the most relevant to this study this will be the focus of discussion. Fleming and Bowles (1987) note how pressures in the 1980s from several different areas converged to provide a shift in discourse that forced change in NSW. These included changes in the interpretation of the *Mental Health Act 1958* when a ruling changed the status of people with dementia. These people were found not to be suffering from a disease, and it was said that in NSW before a person can be mentally ill it must be demonstrated that his or her condition must be characterised as a disease. Therefore, people with a diagnosis of dementia could not be admitted to psychiatric hospitals and must be discharged from them. This ruling was in the context of a new *Mental Health Act 1983* which reinterpreted the 1958 Act. This is interesting in that the legislation challenges the grand narrative of modernism that dementia is a disease.

A second pressure was the Richmond Report (Fleming and Bowles, 1987) which reviewed psychiatric hospitals in NSW and recommended the establishment of local community services as an alternative to large institutions. Important recommendations were that services for older people be based on multidisciplinary community-oriented services. These services were to be provided in an integrated manner and linked to regional acute health services. Thirdly, a review of nursing homes and hostels in 1986 found inappropriate care was often provided for elderly people and emphasized the need to tailor the level of care to the level of need (Fleming & Bowles, 1987, p. 26).

NSW moved to new guardianship legislation in August 1989 with the enactment of the *Disability Services and Guardianship Act 1987 (NSW)*. The Act was renamed the *Guardianship Act* in 1993 (O'Neill & Peisah, 2011). This Act is administered in conjunction with the *Protected Estates Act 1983 (NSW)* which provides the legislative framework for decisions regarding capacity to manage finances (Attorney General's Department of NSW, 2006). Current practice in NSW dictates that if a legal decision-maker is perceived by someone as necessary, applications are made to the Guardianship Tribunal of NSW. Of all the yearly applications to the tribunal annual reports show that a diagnosis of dementia is given as the cause of primary disability in approximately 45-50% of cases (Guardianship Tribunal of NSW, 2006/2007, 2010/2011). This tribunal requires evidence that there is the presence of some type of disability and, due to this disability, the person is not capable of making his/her own personal lifestyle decisions in specific areas, such as accommodation or receipt of services, and/or financial decisions. It must also be established that there is a need



for a legal alternative decision-maker to be appointed, and this will be in the best interests of the person concerned. At least two health professional reports are necessary, including a medical report. The tribunal can appoint a legal guardian and/or financial manager who may be a relative or friend, or a public guardian for decisions on lifestyle issues, and/or NSW Trustee and Guardian (formerly the Office of the Protective Commissioner) for management of finances. That it has to be demonstrated that all informal options to resolve the issues are exhausted and, in instances of guardianship, demonstrated that a need exists, places responsibility clearly with family and/or community services to find some resolution before an application is lodged.

This stipulation of need adds to the complexity and uncertainty of these socio-legal encounters as need is subjective and evaluative and open to many interpretations (Darzins et al., 2000). Similarly, the requirement that applications to the Guardianship Tribunal of NSW should be a last resort raises the issue about who is defining what the last resort is and from what perspective. This is a substantial shift in discourse from the modernism concepts of reason and certainty which resulted in a person being declared by a medical practitioner as being incapable of making decisions in all areas of life.

An important aspect of the NSW legislation is the concept of the "person responsible" who is identified informally to fulfil legal requirements for medical consent. This "person responsible" can also have additional responsibilities such as making decisions about services and accommodation options. That this person can be identified acts as a filter to the guardianship process and reduces the need for applications. The "person responsible" is not necessarily next of kin, but may be spouse or other relative, neighbour or a significant person in the life of the person with dementia. This concept allows decisions to be made informally and social workers can help identify this person and support them, alongside the older person, in making their decisions. However, as opposed to the notion of next of kin being automatically identified to make decisions, it is not always clear-cut who the "person responsible" is and this can add to uncertainty, conflict and ambivalence in these situations.

With the amendments made to the Guardianship Act in 1997 it became possible for a person to appoint an enduring guardian. In a similar way to how enduring powers of attorney are drawn up, a person may now appoint an enduring guardian to make lifestyle and health care decisions should they be perceived as losing the capacity to make their own decisions at some time in the future. If there is any significant dispute, the Guardianship Tribunal can review,

confirm, revoke or vary the functions of the enduring guardian, as is the case with enduring powers of attorney (Office of the Public Guardian, 2005). In practice, many solicitors are now drawing up an enduring guardianship at the same time as a power of attorney and this can be influential in decision-making as it may be viewed as legal validation to those making difficult decisions and can advance the philosophy that the wishes of the individual older person be adhered to. However, people do change their minds so this can add to contested issues and ambiguity and there can be confusion about the powers of the tribunal to override the powers of an existing enduring guardianship and/or power of attorney.

Whilst it can be argued that changes in legislation result in uncertainty and complexity, particularly in the notion of the variable nature of capacity, assessing decision-making capacity in practice can be further complicated as, in the Australian context, there is no standard assessment framework and a diversity of opinions as to how capacity should be assessed (Attorney General's Department, 2008; B. Collier, Coyne, & K. Sullivan, 2005; Darzins, et al., 2000; Hall, 2009; Moye, Butz, Marson, & Wood, 2007; Moye & Marson, 2007; Parker, 2003; Webber, Reeve, Kershaw, & Charlton, 2002). Webber and others (2002) point out there is no agreed-upon method for assessing financial competence in use in Australia and argue the current measures do not provide adequate information. Another opinion is put forward by Darzins, Molloy and Strang (2000), who argue that decision-making involves a mixture of cognitive and functional abilities. In this model what they describe as mainly cognitive decisions, such as making a will and power of attorney, should be assessed by measuring mainly cognitive function, whereas personal care decisions, which they argue are functional, should be assessed by measuring mainly functional capacity. However, Carney argues that transfer of powers of decision-making should be judged in terms of an older person's functional abilities only, being the extent to which they are able to manage adequately in society as distinct from their theoretical capacity to reason and evaluate or the cognitive aspect (Carney, 1995, p. 516). Alternatively, Parker (2003) argues that physicians are often called on to say whether, in their opinion, a person has decision-making capacity for legal purposes, such as refusal of treatment. Parker argues this gives power to medical practitioners in settings that are not purely medical but also moral and legal. Parker contends that there is a consensus amongst medical practitioners when judging patients' decision-making capacity. That is, decisions are made in accordance with the seriousness of consequent risks. He argues that a risk-related standard is incoherent and that a rigorously applied procedural standard will minimise paternalistic medical interventions.

To add to these contested issues in assessing capacity, the use of formal testing to measure capacity is also questioned by some. Testing, such as neuropsychological testing and the Mini Mental State Exam, is challenged as it is viewed that it may negatively position the person being tested and this has the potential to cause harm to the confidence and self esteem of the person being tested (Sabat, 2005, 2006). Sabat (2005, 2006) who takes a social constructionist perspective, argues that testing can be seen to be undertaken from a positivist position where application of professional expertise may isolate the individual from relationships. Instead, he argues that attention should be given to the meaning-making behaviour of the older person. There is a growing body of literature that supports the idea that decision-making is done in the context of relationships, not as purely autonomous individuals (D. O'Connor & Purves, 2009). J. C. Hughes and Baldwin (2006) argue that in making difficult decisions people can be considered not only individual autonomous people but also as mutually dependent and connected by their relationships within which decisions are made. Therefore, if the focus is just on the individual with dementia and not their connecting relationships, then this is inadequate as in decision-making there are inevitably broader relationships involved. (J. C. Hughes & Baldwin, 2006, pp. 36-40). For J. C. Hughes and Baldwin, what they describe as perspectivism, "where an ethical decision cannot be made blind to the points of view of those who have a legitimate interest in the case" (J. C. Hughes & Baldwin, 2006, p. 83), can help to prevent exclusion of the person with dementia.

While the majority of literature from other professions, such as law and medicine, shows that Australia's Guardianship Tribunals have been generally successful (Bennett & Hallen, 2005; Carney, 2003; Carney & Tait, 1997) emerging difficulties have been identified such as sufficient funding and access to the tribunals. Some argue that in effect too much success without equivalent developments in other policies can produce negative consequences such as difficulties relating to the lack of less restrictive alternatives within and outside the guardianship system (Carney, 2003; Carney & Tait, 1991; Tait & Carney, 1995). For Chesterman, national policy developments are necessary to provide clearer guidelines regarding the need for substitute decision-making when people occupy residential facilities. Chesterman also argues for the need to development national guardianship principles, as each state has different legislation, and identifies developments in the health and welfare sectors that pose challenges, such as increasing risk consciousness and risk aversion among service providers (Chesterman, 2013, pp. 26-27).

From a legal perspective, Carney and Tait, who are the most prolific authors regarding guardianship in the Australian context (Carney, 1995; Carney, 2003; Carney & Tait, 1991, 1997; Carney & Tait, 1998; Tait & Carney, 1995), acknowledge that of all the social situations that potentially may need guardianship applications only a small percentage eventuate. They quote an unpublished study where 300 cases of social workers in Victoria were examined. Only sixty of these were considered serious enough to be possible subjects of a guardianship order and eventually only half of these proceeded. Of those that proceeded, another half withdrew before completion. The driving force in taking cases to the tribunal was the view that income and property needed to be protected. Carney and Tait identify social workers as filters or gatekeepers since social work practice emphasises conservation of existing relationships, individual potential and the promotion of individual rights (Carney & Tait, 1991, p. 68). Other intermediate options raised are policy filters, future planning, access to advocacy and appointment of a third party independent person for those older people who do not have anybody they can identify as the "person responsible" (Tait & Carney, 1995).

Carney (2003) notes the strong preference in contemporary public policy in Australia which encourages advance planning, such as implementation of powers of attorney or advance care directives, as a means by which people may avoid the need for guardianship in the future. Carney relates this to structural issues and the evolution of neoliberal policies where governance operates by the rising ideas of mutual obligation and reciprocity in public policy and contractualisation and privatisation of services (Carney, 2003). Carter takes this further at a theoretical level and sees Foucault's work on governmentality, where responsibility is shifted onto the individual, being another explanation for the change in public policy where government is able to transfer uncertainty and risk to the individual while maintaining some control (Carter, 2010, p. 151). Carter argues that a legal approach is grounded in concepts of modernity, where a single set of rules may be applied to everyone in a consistent, predictable way. However, she views postmodern concepts as underpinning and more relevant to the social relationships of those involved in particular situations. Carter argues that guardianship is established under legislation where its primary processes are legal. A guardian is appointed by a tribunal and subsequently accountable through a tribunal. However, at the same time, when a guardian applies decision-making on behalf of a person they are operating in a complex social context where there may be little consistency and predictability (Carter, 2010).

From a medical perspective in an Australian study, Peisah, Brodaty and Quadrio (2006) describe the dynamics of family conflict in fifty cases that were presented to the Guardianship Tribunal of NSW. The findings of this study show that perceived unfair distribution of financial support, inheritance issues and control of money is a frequent theme in applications. In common with the literature on alliances referred to in the first section of this Chapter, they found family alliances including the older person an important aspect in disputes. Also, they draw attention to the need and potential for family-centred work which addresses family dynamics and interpersonal conflict.

In older research studies, undertaken by the nursing profession in the USA, some insight is given into what prompts a family member or professional into making the decision to plan for a legal decision-maker (Kjervik, Miller, Wheeler, & Weisensee, 1999; Kjervik, Weisensee, Anderson, & Carlson, 1998; Kjervik, Weisensee, & Anderson, 1993). To summarise, these studies investigated the primary events or "triggers" that prompted the seeking of a substitute legal decision-maker. What are described as emotional/cognitive events were the most frequently mentioned category of trigger events. These included memory loss, forgetfulness, inability to manage finances, getting lost, neglecting nutrition, hygiene and not attending to health care or taking medications. The other two most frequently mentioned categories were physical, for example strokes and falls, and situational, e.g. lack of family member if spouse died. Whilst this literature does not involve the older person, or examine interconnecting relationships, attention is drawn to the differences in the level of concern expressed surrounding these trigger events. Professionals expressed significantly more concern than family members.

### **3.1.2.3 Influence on social work**

The modernist message of capacity being a binary concept may be viewed as historically influencing social work practice in the direction of treatment and therapeutic relationships, with little or no role in decision-making surrounding capacity issues. As raised previously in this chapter in comparison to contemporary times the number of social workers in practice with people with dementia was extremely low. Allen argues that many social workers based their practices upon logical positivism, psychoanalysis or the empiricist tradition of behaviourism. So "reality is out there and can be discovered by an objective observer." (Allen, 1993, p. 32) This modernist positivist message, based on the notions of reason and

providing certainty, may be viewed as resulting in the emphasis on treatment and therapeutic relationships. In social work practice this is shown in textbooks where, when describing theory from a psychosocial therapy perspective, one of the challenges was seen as "to demonstrate in a scientifically acceptable way the differential results of our activities ... and it is essential that we continue to focus on well-designed thoroughly conducted outcome studies." (Turner, 1974, p. 106) However, alongside this dominant discourse some social workers, such as Allen, saw that a constructionist paradigm was highly congruent with social work values as the influence of the social context and an individual social worker's values could shape the descriptions of what were identified as problems (Allen, 1993, p. 31). Another opposing voice was raised by Rodwell, who advocated against rejecting a more interpretive approach to a person in their environment, which she saw as the position of many social workers in the 1920s, 30s and 40s. For Rodwell, positivism was epitomised in a classical text by Bertha Reynolds, which rejected old practices of improvement of the social worker so they may work cooperatively with clients, as this was seen as inconsistent with the forward advance of social work in becoming scientific (1990, pp. 27-28).

It is also of significance that some creative work was achieved by social workers in the 1960s and 70s who rejected the notion of passivity in working with people with dementia. In the U.S.A. an approach to treatment included the development by a social worker, using empirical research designs, to decide whether an older person had a disability that was accessible to therapeutic intervention. What transpired from this was that residential staff developed plans for nursing home residents' care that included supporting the residents' strengths and using social histories in individualised ways. Another social worker developed a model that was based on providing care that considered the patient's reality or subjective experience using Erikson's stage theory of development with humanistic-centred therapeutic techniques (Lacey, 1999, p. 113).

As discourses shifted to an understanding of capacity as being varied, there has been a growing body of literature across professions, such as nursing and medicine, which is relevant to social work practice. This literature surrounds ethical decision-making with people with dementia and grew in parallel with the advances made in understanding ethical issues in contemporary social work practice discussed in Chapter Two (Darzins, et al., 2000; J. C. Hughes, 2006; J. C. Hughes & Baldwin, 2006; J. C. Hughes, et al., 2002; D. O'Connor & Purves, 2009; D. O'Connor, Purves, & Downs, 2009). Reflecting uncertainty, J. C. Hughes

and Baldwin argue that in this area "morals are messy: ethics is everywhere"; the major theories and principles of ethics can conflict and there are no easy solutions to the moral dilemmas involved in making difficult decisions (J. C. Hughes & Baldwin, 2006, p. 15). They argue that sometimes the consequences of an action need to be considered at the same time as giving weight to the importance of maintaining a relationships. For J. C. Hughes and Baldwin (2006), if decisions need to be made, whatever they are associated with, these decision are informed by value judgments on what is felt to be the right or wrong course of action. They see ethical issues as ubiquitous. Some are minor, such as a family member wondering if they are doing the right thing if they take over doing a household chore the person with dementia usually does. Others are critical and have major impact on lives, such as the ethical dilemmas raised where legal action, like seeking a guardianship or financial management order, is perceived as necessary.

As raised in the Introduction to this thesis, in Australia there is a growing body of literature about decision-making with people with dementia in areas closely surrounding the legal framework of guardianship. Issues raised concern decision-making regarding finances and asset management on behalf of older people through measures such as enduring powers of attorney (Setterlund, Tilse, & J. Wilson, 2002; Tilse, 2000; Tilse, Setterlund, & J. Wilson, 2002; Tilse, J. Wilson, & Setterlund, 2009; Tilse, et al., 2005; J. Wilson, Tilse, Setterlund, & Rosenman, 2009). J. Wilson and others note that this is a complex area of social work practice in which a range of ethical, legal, financial and socio-cultural aspects intersect but it is underdeveloped (J. Wilson, et al., 2009, p. 166). Similarly, Tilse and others argue that from their research older people's assets, a term used in a broad way to encompass all the financial resources of an older person, can be a contested site. They conclude that current provision is insufficient to protect older people from financial abuse or to assist with managing assets well (Tilse, et al., 2005, p. S51). In other areas that impinge on this study, Squires and Barr draw attention to the need for future planning and suggests plans should be made by an older person while they are able to make a will, grant enduring power of attorney, appoint an enduring guardian and make an advance care directive (Squires & Barr, 2005). Substitute decision-making, such as those described above, could be viewed from the postmodernism concepts of complexity and uncertainty as ways of society trying to create the order and certainty of modernism.

To turn to the social work literature directly relating to guardianship issues, the idea that decisions are based on values in practice situations is supported by three particular social work studies from the USA which relate to events preceding guardianship. Iris (1988) found that societal attitudes and beliefs about ageing have great impact on the guardianship decision-making process rather than a need for guardianship. Crampton (2004) argues social work practice can be preventative and stop unnecessary applications for guardianship that can cause unnecessary emotional pain to those involved. Schimer and Anetzberger (1999) compared the application of guardianship legislation in three geographically diverse areas of Ohio. Their findings suggest that there was general agreement in understanding concepts of incapacity but professional differences in value orientation affected how these concepts were applied in given cases. Professionals in the study, particularly social workers and nurses, often differed from each other regarding issues of protection and lifestyle choices. Nurses were more willing to disrupt the client's lifestyle if doing so would ensure their protection while social workers placed emphasis on preserving lifestyle choice. Whilst these studies originate overseas, the issues raised may be seen as significant to the Australian context. For example, social workers often work in multidisciplinary teams.

Soon after the implementation of the new legislation Logan (1991), Chief Social Worker with the South Australian Guardianship Board, attempted to address the balance in what he saw as the lack of discussion about the new legislation surrounding adult guardianship in the social work literature. He highlighted that there would be an impact on social work in that as a profession it was in a position to critique adult guardianship arrangements, give advice and support to older people and their families, as well as make decisions about applying for guardianship and supplying information to tribunals. From his position he noted concerns that families saw their legal rights as "next of kin" eroded, the legal responsibility of service providers was not clear in practice and he argued that social workers as a group could have been given more direction to the changes that occurred. He also drew attention to an important difference between Victorian and NSW legislation; Victoria established an Office of the Public Advocate to carry out independent investigations for the Guardianship and Administration Board as well as acting as a guardian of last resort (Logan, 1991).

While, as Logan (1991) argues, the literature may not reflect a strong social work voice it may be viewed that in other ways there has been a stronger participation by social workers through avenues such as members of guardianship tribunals (Guardianship Tribunal of NSW,



2006/2007, 2010/2011). Also, O'Neill and Peisah (2011) draw attention to the way the NSW legislation was drawn up. They state it was largely the work of an interdepartmental working party which had representatives from many government departments and councils such as the Mental Health Co-ordinating Council and NSW Council for Intellectual Disability. Consultations of the draft Bill were conducted with many non-government agencies. The Victorian legislation, which preceded NSW, had a strong influence (O'Neill & Peisah, 2011). From these many community and government agencies it could be concluded that many social workers participated.

### **3.1.3 Fixed identity to subjectivity**

#### **3.1.3.1 The modernist message: dementia is a gradual loss of mind**

For the group of older people who are the focus of this study, those with dementia, the modernist messages about fixed identity may also be linked with an identity associated with "loss of mind," or what Aquilina and J. C. Hughes (2006) describe as "the living dead." For Aquilina and J. C. Hughes modernist messages regarding loss of mind in dementia reflect the observations that the "self" is lost slowly as the illness progresses. They refer to scientific and popular literature which reflect this concept such as *Alzheimer's Disease: Coping with a Living Death* (R. Woods, 1989) and films such as *Iris*, which depicts the deterioration of the author Iris Murdoch. From social constructionism perspectives this reflects the concept of having a "fixed identity" where the self is self-contained and unitary (Burr, 2004, p. 104). This section looks at the modernist message of fixed identity through an exploration of the "care for the carer" approach to people with dementia as it may be argued that the resulting dominant discourse of a construction of dementia as one of "loss of mind" is that the person concerned requires the care of another.

The implications of the modernist understanding of personality as being fixed have been discussed previously in this chapter where the person is seen as a passive victim and if they became a problem to society institutionalisation was the social action that resulted. What is significant here is that the literature emerging from the 1980s shows two parallel theoretical approaches developed from Kitwood's work on personhood. The first is the "care for the carer approach." This is one where some argue the possibility of excluding the person with dementia is still present. For Downs, Clare and Mackenzie they connect this approach to the

biomedical understanding of dementia where the person with dementia can still be viewed as the passive victim when professionals see no possibility of engagement with the person. Instead they engage with the "carer." The implication for the individual's family being that they are perceived as carrying the burden of being carers (Downs, et al., 2006).

This approach puts the "carer," often a spouse, child or other family member, at the centre as services and financial support are aimed at helping them to maintain the person with dementia. D. O'Connor and others argue that studies of communication between people with dementia and their carers have traditionally focused on the care-giving aspects of the relationship and this has resulted in a narrow understanding of the relationship as one-way activity (D. O'Connor, Phinney, Smith, Small, & Others, 2007). Fawcett sees the terms "carer" and "cared for" as modernist orientations that divide people into two distinct groups while the words take on universal meaning. The "carer" is able and has qualities that enable them to provide care, whereas the "cared for" is dependent (Fawcett, 2009a, p. 126).

This approach has been very influential and is incorporated into provisions made through economic and social structures in Australia, such as carers' pensions and allowances and residential and community services, including respite support groups and counselling. It is not to be denied that people close to a person with dementia need recognition and support as there can be significant challenges. However, the "carer" is seen as the dominant person and the "expert" in expressing the needs of the person being cared for (Adams, 2003; Downs, 1997). The second theoretical approach developed from Kitwood's work on personhood is one that follows social constructionism perspectives. Here dementia occurs within a psychological and social frame of reference and what is important is that there is a belief that there is a sustained private sense of self not a steady loss of personality and identity to the point that no person remains.

### **3.1.3.2 Postmodernist questioning: the self can be sustained**

As noted in Chapter One, Burr uses the term "subjectivity" to refer to social constructionists concepts regarding personhood or selfhood. It replaces the traditional psychological term "personality" where identity can be seen to be fixed (Burr, 2004, p. 204). Kitwood's person-centred approach to dementia means that it is important to understand the person's experience of living with the label dementia rather than making assumptions (Kitwood, 1997). As

Downs, Clare and Mackenzie argue this approach has significant implications for both the person with dementia and their family members. Rather than assuming a loss of self, the implication is that there are on-going, evolving relationships with others. It is also acknowledged that carers are not inevitably victims but, with support, can have the opportunity to renegotiate their relationships (Downs, et al., 2006, p. 246). It is argued here that postmodern questioning implies that people with dementia sustain a sense of self.

Postmodern literature conveys that for a person with dementia the self persists within a social frame of reference. What is important is that there is a belief that there is a sustained sense of self (Adams, 2003; Cowdell, 2006; Downs, 1997; Downs, et al., 2006; Epp, 2003; Harrison, 1993; J. C. Hughes, et al., 2006; D. O'Connor, et al., 2007; B. Woods, 1999). J. C. Hughes (2001) argues that what may be viewed as negative consequences associated with a diagnosis of dementia may be mitigated by an approach that respects this and supports personhood. He calls this view of the person a "situated-embodied-agent view" where the person is embedded in a history and culture and, he argues, whilst the person's agency might be whittled away, if personhood is part of a life-history and engagement with others, as well as a bodily form, then it still makes sense to talk of the person (J. C. Hughes, 2001, p. 90).

This understanding of dementia highlights the use of language and constructed meanings, including use of the concept of social positioning. Burr (2004) states that positioning in social constructionism acknowledges the active way in which people try to locate themselves within particular social interactions through the use of language (Burr, 2004, p. 113) or "in interaction, practice of locating oneself or others as particular kinds of people through one's talk." (Burr, 2004, p. 204). Sabat (2006) argues that the negative positioning of people with dementia can therefore serve to weaken their moral and personal attributes and help to create narratives about them. He develops a social constructionist view of the different selves that provide a clear understanding of the importance of language and social positioning for a person with dementia. For Sabat, selfhood is expressed in a variety of ways in public discourse and can be analysed into three different forms, which are called self 1, self 2 and self 3.

Self 1 can be preserved, after the loss of most abilities and when language can no longer be used, by using gestures. This self is the self of personal identity and expressed as "I" "me" and relates to ownership of experiences, obligations and responsibilities.

Self 2 is comprised of a person's physical and mental attributes and beliefs about those attributes. These can include hair colour, sense of humour, sadness, anger, embarrassment etc. In dementia it is possible for others to focus on the loss of attributes, not those that endure. For example, a person can enjoy company but be unable to remember events. Self 2 attributes can be historical but new self 2 attributes can come from issues associated with the diagnosis of dementia. So, a person can have historic attributes of being a teacher, having religious beliefs and having brown hair. New self 2 attributes would include recent events, such as a diagnosis of Alzheimer's and having grey hair.

Self 3 is comprised of the various different social personae which are constructed in the variety of situations in which individuals live their lives. Lives are constructed with the cooperation of others, e.g. roles, unique behaviour with family and spouse. This identity is the first that may not be maintained by others for the person with dementia and alters the way the person with dementia feels they are allowed to act (Sabat, 2002b, 2006).

### **3.1.3.3 Influence on social work**

The social constructionist view of selfhood has significant implications for social work practice. For example, to understand the complexity of decision-making attention must be given to trying to preserve the selfhood of the person with dementia and to the way the person is interconnected in their relationships. This may be viewed as one of challenges in social work practice that the research question of this thesis is designed to address. This approach questions potential assumptions in social work practice in socio-legal encounters. Of particular significance is the area of service provision where entry to the home can challenge personhood and interconnecting relationships and service providers may also become applicants to a Guardianship Tribunal.

The question of whether services have been tried is raised by the Guardianship Tribunal of NSW in most cases before accepting an application, as legal guardianship is considered a last resort and services are viewed as an option that must be tried. How decisions are made by people with dementia and their spouses and families regarding services is therefore pivotal and relates to the concept of subjectivity or selfhood, or how the sense of self is preserved and the associated language used by service providers. There is often a general assumption by professionals that services are "good" for both the older person and their family (Brodaty,

Thomson, Thompson, & Fine, 2005; Nelms, Johnson, Teshuva, Foreman, & Stanley, 2009). Research shows that there can be multiple reasons for not using services, such as not being informed of what is available or the characteristics of the service itself, i.e. inconvenient times and cost (Brodaty, et al., 2005); or social isolation, low mood of the older person and identification of high levels of stress in family members (Nelms, et al., 2009).

Recent empirical research studies on the acceptance and use of formal services highlights that decision-making regarding services is a joint decision between an older person and their family member or significant person (D. O'Connor & Purves, 2009). Purves and Perry (2009) undertook case study research of an individual family and concluded that to understand the complexity of decision-making attention must be given to the way in which the family itself is understood, as those concerned can have similar and different needs. This involves the perceptions of the older person. In analysing decision-making, Keady, Williams and Hughes-Roberts (2009) introduce the concept of "bridging" as a metaphor for changes in ongoing relationships and the decision-making processes. The notion of bridging involves the person with dementia, in the context of their family relationships, losing balance, finding balance and then keeping balance. Their participants, who engaged strongly in the decision-making process, were embedded in their relationships.

Other empirical studies show that there are often highly complex issues, grounded in the interconnectivity of relationships, for both the older person and their family involved in services coming into the home. D. O'Connor and Kelson (2009) warn that despite language that might include words such as "dignity" and "respect" to preface how the older should be treated, the framing of services invariably draws predominantly on health and safety needs and not personhood needs. Lloyd and Stirling (2011) found that there can be "ambiguous gain," in that there are unintended outcomes as a result of accepting services. This can include reordering of domestic spaces with the needs of the system providing services and a loss of mastery over the material and symbolic boundaries of the private space of a home. They also found that family members, who they interviewed, felt failure within themselves for accepting services and had a desire to protect the person receiving care from psychological distress. Services were also a disruption to the stable interpersonal relationships and maintenance of personal identity of the person identified as receiving care (Lloyd. & Stirling, 2011).

## 3.2 Summary

The literature reviewed in this chapter highlights why it is important for social workers to understand changing dementia and capacity discourses in order to build effective working relationships. In the space between the private and public, in which social workers practice, it has been shown that there is the potential for diverse and competing understandings of dementia which reflects an underlying mixture of beliefs. It is therefore important to undertake research that explores how this mixture of beliefs play out in individual social situations such as socio-legal encounters. Despite the growing understandings reflected in the literature regarding personhood, it may be argued that for contemporary Australian health professionals the scientific positivist approach, and associated biomedical understanding of dementia, is still a powerful influential discourse. These include understandings that there is a change in, or complete loss of, the person who has been given the label of dementia and a focus on the individual in isolation of their interconnecting relationships. Similarly, the legal discourse is powerful and in contemporary society guardianship legislation and varied concepts of capacity are not well understood. The social work profession itself is comprised of people with diverse knowledge bases, beliefs and values and how comfortable individual practitioners are with the rejection of certainty varies.

The literature reviewed in this chapter also shows that research on how individual social work practice situations play out in socio-legal encounters, where a legal alternative decision-maker is perceived as needed, is critical but under-researched. Literature from other professions, such as medicine and law, point clearly to the need for research into how filters for guardianship and financial applications in Australia work. It is embedded in legislation in the state of NSW that an application for guardianship or financial management should be a last resort but this leaves a void where it may be argued roles and responsibilities of professionals and families are unclear and individual situations are open to negotiation, collaboration and/or conflict. Ethical and moral dilemmas may be experienced as abundant where notions of the right way forward can be multiple and diverse.

In this study a social constructionist lens will be used to analyse and interpret case studies which focus on a person with dementia and their interlocking professional and personal relationships in individual socio-legal encounters. The perspective used is one that agrees with a particular relativist position of social constructionism consistent with the argument that language generates the reality known by individuals. Social workers in health and welfare

contexts are entrenched in the discursive structures available to them and this makes the perspective particularly relevant to interpret and critically interrogate the different understandings of those caught up in individual socio-legal encounters. This social constructionist framework will be used to assist in understanding how the taken-for-granted biomedical knowledge of dementia may be challenged and how lack of capacity to make decisions in socio-legal encounters is perceived.

Chapters Two and Three have raised many issues that may be viewed as potential challenges in social work practice in contemporary health and welfare contexts. Chapter Four outlines the methodology of this study, which is designed to answer the primary research question regarding these challenges in social work practice with older people, their families and other professionals in socio-legal encounters.

## Chapter Four

### 4.1 Introduction

Chapters Two and Three have examined literature on how social welfare systems have a dominant impact on how old age is constructed and how dementia and capacity discourses have been constructed and have changed. The implications for social work practice of these interrelated areas have been examined. This literature is relevant to the overall aim of this study, which is to critically examine social work practice in complex and disputed situations where an alternative decision-maker is perceived as necessary for a person with dementia. The purpose of the research was to enable social workers to better understand the dynamics involved in these socio-legal encounters and provide knowledge that could be used for more effective practice. In order to achieve this it was viewed as pivotal that the perceptions of all the participants in these unique individual social situations were understood. With this aim and purpose of the study in mind the researcher selected methods that would enable an in-depth investigation of the meaning and individual experience of all participants in socio-legal encounters.

In this chapter the methodology of the study is outlined. The chapter is divided into several sections. After this introduction, which includes an account of the choice of the theoretical perspectives and framework, the research questions are presented. In the third section the research study design is outlined. The fourth section addresses the research process of data collection by introducing the participants and outlining the instrumentation used. The fifth section covers data analysis and the sixth section ethical considerations. The seventh section addresses the trustworthiness of the research. The eighth section comprises a summary of the Chapter.

The choice of using theoretical perspectives drawn from social constructionism was the first dominant influence on the direction of this research. This decision was made at the time the researcher undertook an initial literature review. Clearly there were many different theoretical perspectives that could have been chosen, such as symbolic interactionism or phenomenology (Crotty, 1998). However, for the researcher, the key assumptions of social constructionism, especially the critical stance of questioning taken-for-granted knowledge, opened up new



ways of understanding and appreciating what is accepted knowledge. This meant that the researcher's taken-for-granted knowledge surrounding dementia and capacity was challenged and questioned. In turn this led to new insights surrounding clinical practice as well as the direction of the research.

The level of critical interrogation that social constructionism promotes can be linked to perspectives which shape the contemporary theoretical base of social work, such as a strengths perspective or anti-oppressive practice. K. Healy (2005) highlights the strengths perspective as identifying and using an individual's and community's strengths, rather than a deficit-orientated approach. This can be viewed as crucial in providing a way to challenge a biomedical focus on individual pathology. However, some argue that this perspective does not recognise the structural barriers faced by service users (K. Healy, 2005). The anti-oppressive perspective, by contrast, focuses on an approach that identifies social structures as shaping understanding and, therefore, responding to structural injustices is a priority (K. Healy, 2005). However, as K.Healy (2005) highlights, although anti-oppressive practice challenges social workers to recognize the cultural and structural context of practice there are some limitations to the approach. K.Healy argues there can be a focus on minimal intervention, no way of prioritizing the needs of individual services users and a reliance on a structural analysis of power relationships that does not recognise the individual context of people (2005). Significantly, K.Healy draws attention to the issue that both the strengths perspective and anti-oppressive practice theory can be categorised as reflecting modernist ideas in that there can be a singular underlying truth or way in working with service users (K. Healy, 2005, p. 191).

The framework chosen for the analysis of the literature review was therefore developed using key concepts from social constructionism with connections being made to both modernism and postmodernism. This dominant influence on the research arose at a later stage in the process, when it became necessary to present the complex and extensive material gathered in reviewing the literature into a cohesive form to present a structured literature review. Postmodernist perspectives may be viewed as drawing from many of the concepts of both the strengths perspective and anti-oppressive practice. However, a focus on analysing the shifts in dominant discourses means that concepts of modernism may be interrogated and postmodern techniques used, such as recognising and exploring a range of perspectives surrounding a specific socio-legal encounter. Social and institutional contexts are highlighted,

oppression may be recognised, deficit-based practice can be challenged and the notion of discourses can be used to analyse an individual social situation within the broader social and institutional structural context (K. Healy, 2005).

In regard to understandings of dementia, what was central in following this theoretical direction was the work of Kitwood (1989, 1997), who took perspectives from social constructionism and applied them to challenge the taken-for-granted biomedical knowledge of dementia. Particularly influential in the early stage was the literature that built on Kitwood's work, for example the literature on personhood and selfhood by authors such as Sabat (2002b, 2006) and Downs (1997). Similarly, literature by authors such as D. O'Connor, Purves and Downs (2009), and J. C. Hughes and Baldwin (2006), which challenged the taken-for-granted knowledge surrounding ways of viewing autonomy in decision-making, provided new ways of viewing social work practice and the direction of the research. For these authors decisions are viewed as being made by people interconnected in their relationships and, as Hulko and Stern highlight, a person-centred approach opens up the opportunity to take into consideration cultures that do not value the individual over the collective and where individual autonomy is not part of taken-for-granted knowledge (Hulko & Stern, 2009, p. 71).

During the data collection and analysis phase of the research another strong influence emerged. What became evident in this process was the importance of the impact, variously on all participants, of contemporary health and social welfare policies. What emerged from the data, but had not been fully anticipated, was the dominant role of service providers and their agency contexts and the underlying power dynamics in the relationships formed. The literature reviewed at this stage that was helpful was the material that focused on perspectives where the central idea was that older age is a socially constructed event. Here, authors such as Powell (2006), Biggs and Powell (2001), and Phillipson and Biggs (1998) were influential in the direction taken. The strong links to the analysis drawn from social constructionism used as a theoretical basis in this thesis is evident in this literature. This literature also raised the notion that Foucault's ideas can be used to understand the construction of old age and the inherent power dynamics, which reflects the links between social constructionism and modernism and postmodernism. At the macro level, this literature provided a wider perspective on ageing within which the concepts of dementia and decision-making capacity are understood and conceptualised.

The material in the literature review covered many difficult concepts to link together. The dominant influences arose at different times during the process of the research and links between these influences had to be identified, clarified and refined. To group key concepts from social constructionism, with connections being made to both modernism and postmodernism, into the three significant areas arrived at was a challenging and difficult task.

Clearly, from the initial stages of this study, the development of these specific theoretical perspectives point to an underpinning epistemology, or understanding of knowledge, of constructionism. Crotty describes a range of epistemologies, including positivism and constructionism, which influence the way the research is done (Crotty, 1998, pp. 8-9). He outlines that positivism would direct research to identify objective truth whereas constructionism points to a different direction, where meaning is not discovered objectively but constructed through exploring processes that lead to meaning-making (Crotty, 1998, pp. 8-9). What is significant is that a certain epistemological stance directs the way the research is undertaken, its theoretical perspective and methodology. The specific approach of social constructionism, as outlined in the Introduction to this thesis, is inherent in the epistemological stance of constructionism. Consequently, the methodology used in the research study, designed to explore the research questions, is in keeping with this.

## **4.2 Research Questions**

The primary research question has been outlined previously in this thesis. To reiterate, it is: *In a contemporary Australian health and welfare context what are the challenges in social work practice with older people, their families and other professionals in disputed, complex and uncertain situations where a legal alternative decision-maker is perceived as necessary?* From this primary research question what Mason (2002) describes as the "big" research questions which the study was designed to explore were assembled. These are:

1. What is the process of interaction and negotiation around issues that may necessitate an application for guardianship/financial management?
2. What are the values and tensions behind these negotiations and subsequent decision-making?
3. What is the impact in these situations of how dementia is understood and what assumptions are made in these understandings?

4. What is the impact in these situations of how capacity is understood and what assumptions are made in these understandings?

### **4.3 Research study design**

Qualitative research methods were chosen for this study as these methods were considered appropriate for studying the processes involved in the complex social environment of decision-making, especially where it is important to interpret meaningful human actions and the individual perspectives that people give of themselves or others. Qualitative research methods also flowed from the underlying epistemological stance. As Mason (2005) argues, qualitative methods are usually used when the object of study is some form of social process, meaning or experience which needs to be understood and explained in a rounded way rather than using, for example, causal patterns (Mason, 2002, p. 134).

A case study design was used to explore the answers to the research questions. As Stake (2000) highlights, a case study design is defined by an interest in individual cases and what can be learnt from specific cases. In this thesis these are specific socio-legal encounters. Stake argues that the qualitative case researcher tries to preserve the multiple realities; the different and contradictory views of what is happening in a particular case (Stake, 1995). For Yin, the distinctive need for case studies arises out of the need to understand complex social phenomena and the more the research questions seek to explain some present circumstance, or how or why some social phenomenon works, the more the case study method will be relevant (2009, p. 4). As Denscombe argues, the advantage of the case study design was that the focus on a set of research case studies allowed the researcher to deal with the subtleties and intricacies of the complex social situations and explore relationships and social processes in a way that could not be achieved through other methods (Denscombe, 1999, p. 31).

Robson (1995) defines a case study to be a "strategy for doing research which involves an empirical investigation of a particular contemporary phenomenon within its real life context using multiple sources of evidence." (Robson, 1995, p.146) The contemporary phenomenon in this research was guardianship, or the appointment of an alternative legal decision-maker, within the context of the socio-legal encounters of the participants. Alston and Bowles (2003) argue that a case study design is particularly useful in social work settings because it allows analysis which will give insights into the wider target group and the findings can assist in the

development of insights into social work practice. It was the researcher's experience that in social work practice each socio-legal encounter is complex and diverse and gives rise to specific issues within the encounter. What the case study design provided was a way of exploring the individual perspectives of those involved, and what they wanted, in one unique socio-legal encounter. Interviewing participants not involved in the same socio-legal encounter, would not capture the underlying dynamics involved. For example, individual interviews to investigate the individual experiences of groups of participants, such as family members or social workers, not involved in the same encounters.

In this study a set of five individual "socio-legal encounters," or "research case studies," were undertaken and explored to provide insight and understanding into how decisions were made around issues that arose out of the circumstances surrounding guardianship. These two terms are used interchangeably in this thesis, and for simplicity the term "encounters" only will sometimes also be used. The study used cross-case analysis; the aim was to understand each case individually and then the processes and outcomes across cases (Miles & Huberman, 1994, p. 173). This approach allowed for consideration of the research case study as a whole entity, looking at how decisions were made within the encounter, such as the understandings of dementia and capacity, and then turned to a comparative cross-case analysis. The advantage was that in studying the process of how decisions were made by all participants in one encounter led to the discovery of concepts that could be explored in further socio-legal encounters. The study did not have universal access to complex socio-legal encounters, so sampling was small and purposeful. The aim was that the first case studied would provide evidence to produce theory about the process involved in the encounter. This aim was achieved. This theory then guided the choice of subsequent cases whether it was to try and find the same or different results. For example, the first socio-legal encounter gave insight into the power dynamics of decision-making surrounding the perceived need for a legal guardian to make a decision regarding entry into a nursing home for the person who was the focus of the encounter. This data was then compared to subsequent research case studies where, for example, decision-making surrounded different issues, such as the impact of financial considerations.

Generally, this case study approach does present challenges in terms of deciding which case becomes the key reference point to explore identified concepts in other cases. As Stake (2006) points out, the selection process in multi-case studies often begins with cases already

at least partially identified and the challenge is to discover commonalities and/or what is dissimilar and then to decide whether to focus on one or both of these aspects. In this research it was fortunate that the first socio-legal encounter, which is termed research case study "G", was in fact the first case that was referred to the researcher by a social worker to assess suitability for inclusion in the study. This particular socio-legal encounter offered the potential to interview participants from the different categories of people, such as person with dementia, social worker, service provider, spouse, as well as documentary analysis in the form of Order and Reasons for Decision by the Guardianship Tribunal of NSW. Research case study "G" was the first encounter in which interviews were conducted and which provided a rich theoretical framework to assist in identifying both commonalities and differences in the subsequent cases. In this respect the research developed from this specific socio-legal encounter. However, a limitation of this approach is that it was opportunistic and reflects the difficulties of negotiating access to potential socio-legal encounters.

The case study approach also allowed for the use of a variety of research data collection methods, such as interview and observation, to capture the meanings which the participants attributed to the socio-legal encounters. In parallel with the use of multiple data collection methods the approach also fostered the use of multiple sources of data, such as use of documents and human participants, which facilitated the validation of data through triangulation. These methods of data collection added to the rigour of the study.

Denscombe highlights that there can be disadvantages posed by a case study design in that the boundaries of the case can prove difficult to define and negotiating access to case study settings can be a demanding part of the research process (Denscombe, 1999, p. 39). The researcher's personal position, outlined in the Introduction to this thesis, was an advantage in both of these areas. Knowledge from extensive clinical experience provided some confidence in drawing up the initial case boundaries set out below, although these were redefined during the research process. Past associations were an advantage in gaining access to participants as the researcher had, before the research was carried out, been employed in the organisation. Bryman puts forward that one of the greatest problems with case studies is associated with the generalisability of the findings as it may not be said that one case or a few single cases are representative and can be applied in other cases (Bryman, 2004). However, as Robson argues, it is the analytic generalization that is important in case studies, not statistical generalisation (Robson, 1995, p. 161). This study made no claims of generalisability, rather the purpose was

to enable social workers to better understand the dynamics and the processes involved, and understand how social workers manage the competing views of dementia and capacity. Multiple case sampling, however, as undertaken in this study, adds confidence to findings in that the generalisation is from one case to the next on the basis of a match to the underlying theory (Miles & Huberman, 1994, p. 29) As Miles and Huberman argue, if a finding holds in one case and again holds in a comparable case but does not in a contrasting case the finding is more robust (Miles & Huberman, 1994, p.29).

With reference to previous studies there are strengths and limitations in using this case study design approach. The strengths include a more holistic way of looking at the impact of health, welfare and legal systems on the interactions in individual cases. Methodologies of previous studies have investigated health care triads (Adams & Clarke, 2001, Adams, 2003) or conducted interviews with groups of respondents, such as family members, people identified as carers and professionals, not participating in the same interaction or encounter (Kjervik et al, 1998; Iris, 1988). Similarly, regarding financial management, asset managers assisting older people manage assets were interviewed as well as older people having their assets managed (Tilse et al, 2005; J. Wilson et al, 2009). Also some studies have focused on one particular category of participants such as professionals (Green & Sawyer, 2010) or conducted multi-disciplinary focus groups (Schiemer & Anetzberger, 1999). The social constructionist framework of this study enabled the multi-systemic issues in the individual socio-legal encounters to be captured and examine the way health, welfare and legal systems are constructed within these encounters. This approach may be seen as unique in that the findings will contribute new knowledge in the area.

A limitation of the study was that although endeavouring to interview the person with dementia, this was only possible in one individual case. A second person, who was to be interviewed, died before the interview was conducted. This may reflect the complexities involved in taking this particular approach. There is a gap in the literature, particularly in the Australian context, where research with a case study approach has been attempted. Gilmour and others (2003) included people with dementia in a study exploring the issues surrounding risk of a person with dementia living alone and was able to interview ten people with dementia. However, these were not in the same interactions with the other participants interviewed who were family members, district nurses, care staff and general practitioners. Likewise, another study which gave attention to looking at individual cases used a

methodology which focused on documentary data only. Peisah and others (2006), focused directly on guardianship in the Australian context and examined documentary information in applications to the Guardianship Tribunal of N.S.W and the Reasons for Decisions made by Tribunals in thirteen individual cases. As put forward by them their findings were tentative and there is a gap in formal knowledge about family conflict and a need for further understanding this difficult area of clinical work.

In keeping with a case study design the boundaries of the socio-legal encounters needed to be defined. These boundaries became more explicit in the process of the research, as the practicality of access to participants was encountered. The research case study was the unit of analysis. The focus, or what Miles and Huberman (1994) describe as the "heart" of the case study, is the person with dementia. In the research proposal the boundary or context around this person included possible participants from three main groupings:

- Social worker: referred to a social worker who provided a social work service to the person with dementia.
- Family/significant people: referred to a spouse, child, other relative, friend, neighbour or other individual significant to the person with dementia. For convenient reference in carrying out the research these people were referred to as a family member or significant person. In the actual research process, spouses were the people who were interviewed. It may be viewed as a limitation of the study that other relatives, such as children, were not interviewed.
- Other professionals: referred to people such as coordinators of home support services (referred to as 'service providers'), professional direct care workers employed by these agencies, geriatricians and neuropsychologists. As previously highlighted from the initial research case study, the most dominant "other" professional was found to be a service provider.

The criteria for inclusion in this boundary in each research case study was that these participants had influence in the life of the person with dementia when negotiations took place surrounding the need for a legal guardian. The geographical boundary is New South Wales, Australia, as the particular legislation in Australia is state-specific. As Miles and Huberman point out, "you cannot study everyone, everywhere, and there are limits on the choices involved" (Miles and Huberman 1994 p.27).



## **4.4 Research process**

### **4.4.1 Data collection: participants**

The research was carried out in collaboration with the Manager of the Social Work Department and Senior Social Worker in the Department of Geriatric Medicine of a large metropolitan teaching hospital in Sydney: Westmead Hospital. Following initial negotiations a letter was written to the Senior Social Worker of the Department of Geriatric Medicine with a summary of the proposed research study attached (see Appendix 1). The purpose of the letter was to gauge the interest of the social workers in the study. The information sent was discussed at a departmental social work meeting, after which it was relayed to the researcher that there was agreement that it was a valuable project and would be supported by the social work team.

After the research was approved by the Human Research Ethics Committee, Westmead Campus (see Appendix 2) and ratified by the Ethics Office of the University of Sydney (See Appendix 3), a meeting was held to launch the research and attended by the researcher and social workers from the Department of Geriatric Medicine. These social workers practised within the hospital and in community settings. The purpose of this meeting was to inform the social workers about the research study and invite them to volunteer to participant by contacting the researcher if they were involved in a suitable research case study. Social worker participant information sheets and consent forms were distributed (see Appendix 6).

At this meeting it was outlined that a suitable case was considered to be one which:

- Was considered typical in that it was complex and arose from the perceived need for a legal decision-maker for a person with dementia by a party involved in the process.
- The perceived need was such that an application for an alternative legal decision-maker may be lodged within a short time frame (i.e. 2 months) or an application had been lodged.
- Access to other participants in the research case study was a possibility through the social worker as, ethically, the researcher could not contact them directly. It was hoped that in addition to the social worker there would be at least one family member or other professional involved, as well as the person with dementia.

Access to other participants proved to be a sensitive area from the perspective of the social workers. Concerns were expressed about the sensitive issues leading up to a guardianship tribunal hearing when families were mostly in crises. There were also issues raised about approaching the person with dementia to be included in research, such as giving informed consent. To remove barriers from participation in the research these issues were resolved by encouraging the social workers to participate in an interview with the researcher. A decision could then be made by the individual social worker about the appropriateness of approaching a family member or the person with dementia to participate and at what time this would be the most appropriate. The consent process for the person with dementia was explained. This process is outlined later when discussing instrumentation. Over the following months the five research case studies evolved through the voluntary participation of individual social workers from this department. A total of thirteen interviews were undertaken between 14.4.2009 and 17.10.2010.

It is acknowledged that practicalities of access to participants resulted in uneven inclusion of participants in the cases. This was anticipated as a difficulty and eventuated in practice. However, the first research case study provided a wealth of in-depth data. This was so extensive that a decision was made to refer to this as the "central research case study" for analytical purposes. During the research process attempts were made to "write up" these research case studies in order to present them, and this proved difficult for the researcher because whilst summarising there was a tendency to impose interpretation or start analysis. Nevertheless, the cases are presented here in short summary form after being introduced in diagram style in the following pages. It is hoped that these diagrams will provide the reader with an easy reference to help assimilate the material in the rest of the thesis. The case studies are of Graham, Edward, Maria, Jane and Albert. All of the participants associated with each study are identified using the first letter of the case study's name. For example, the social worker in Graham's case study is referred to as Social Worker G and the service provider in Maria's case study is referred to as Service Provider M.

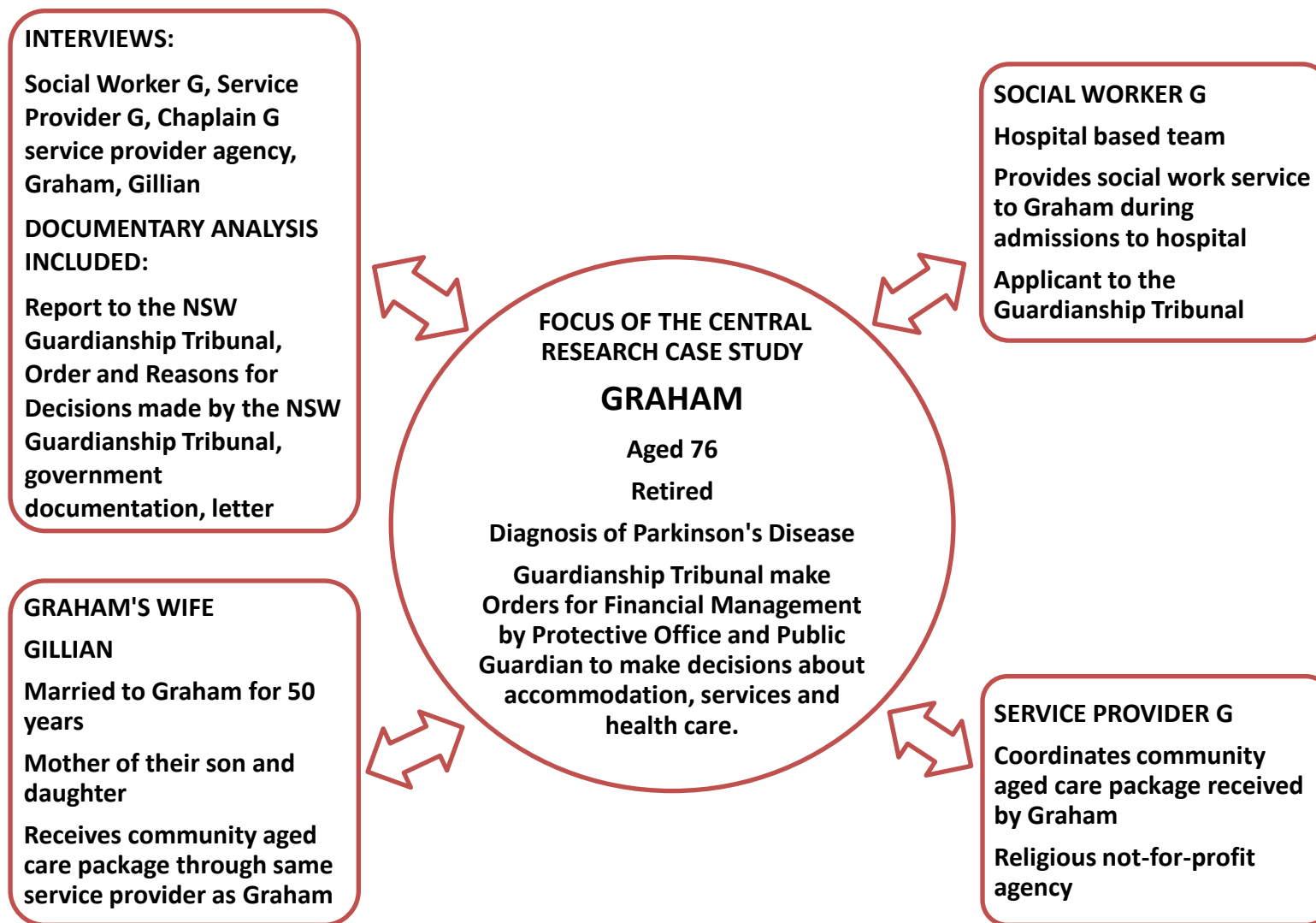
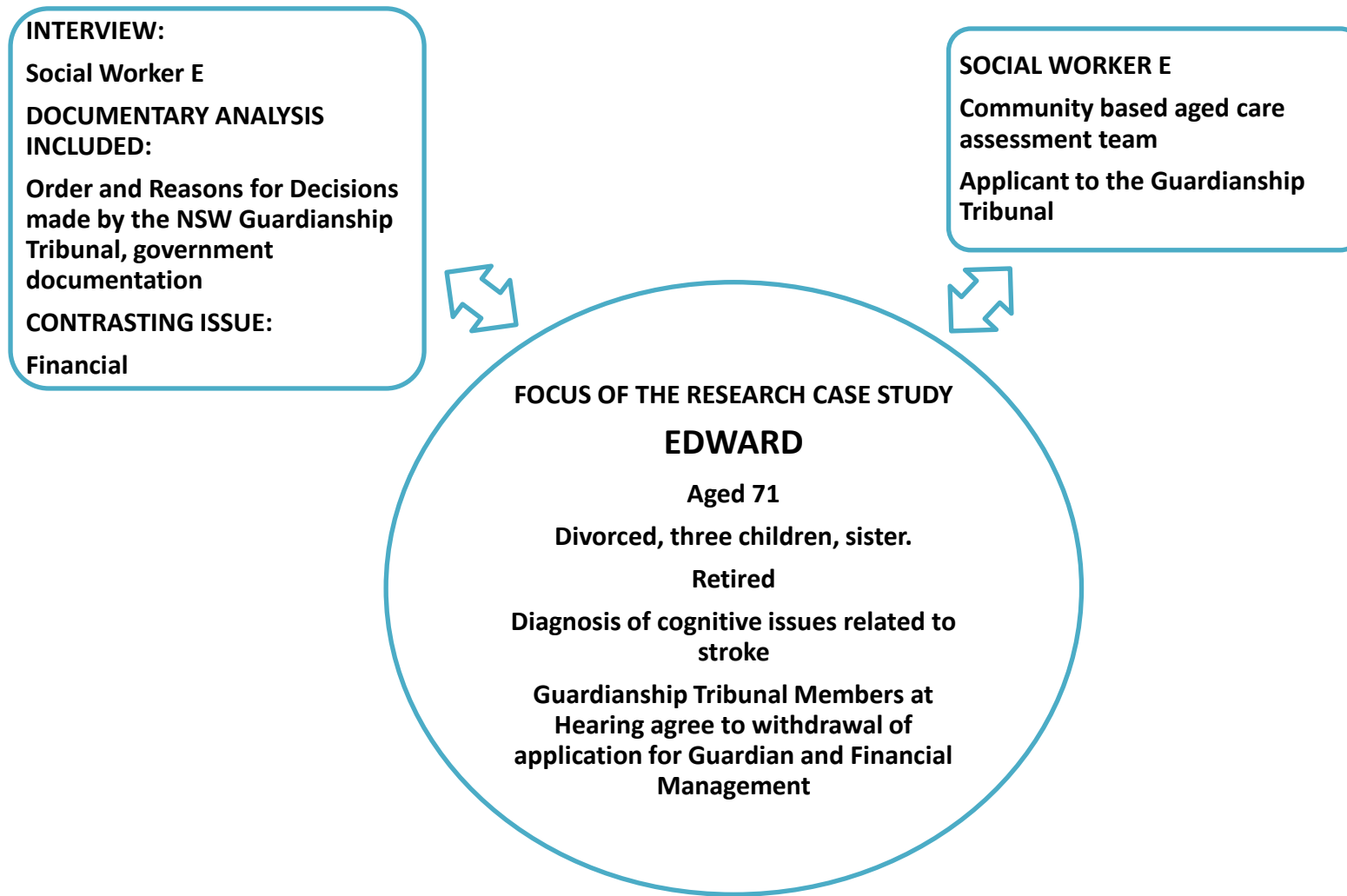


Figure 4.1a: Research case study of Graham



**Figure 4.1b: Research case study of Edward**

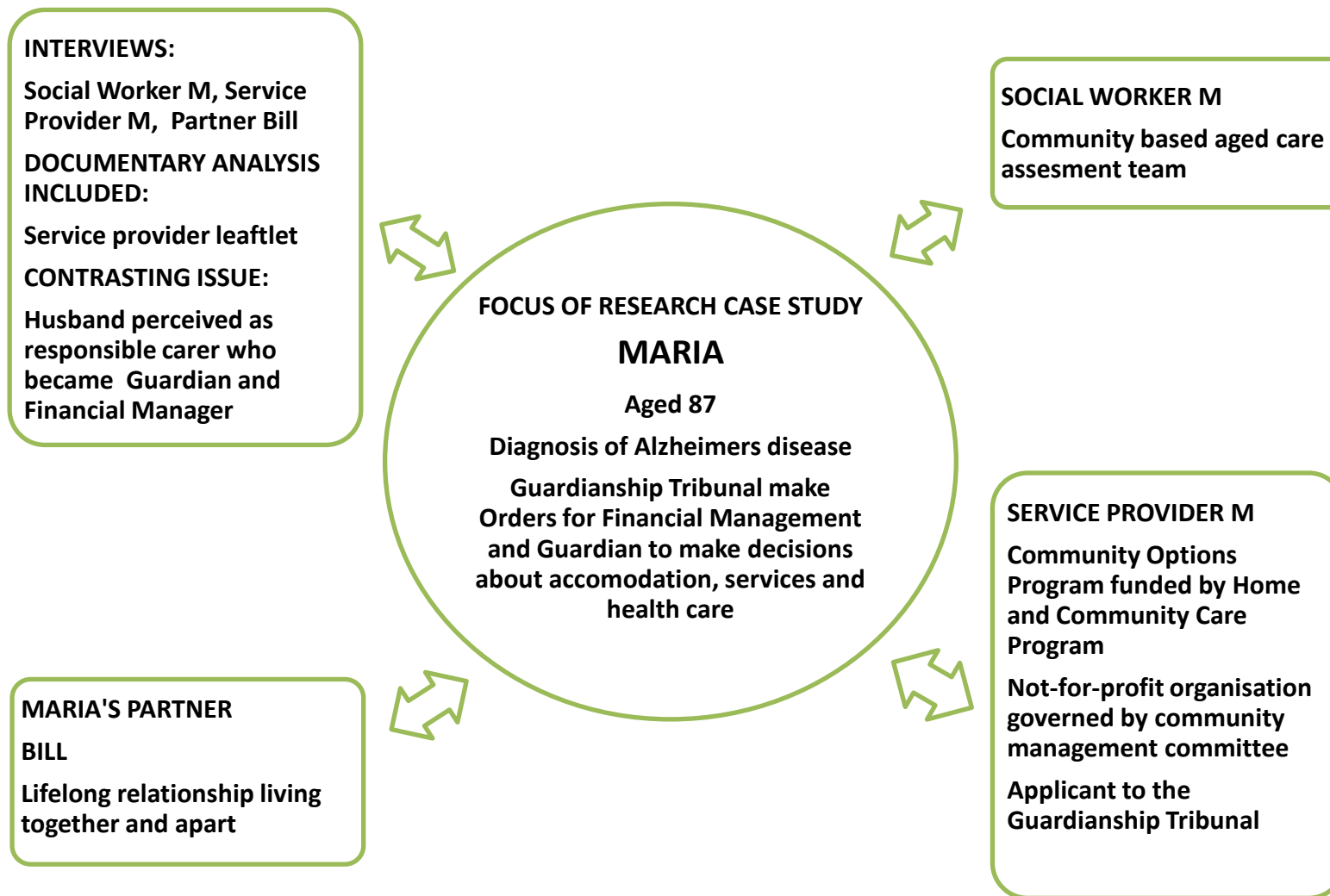
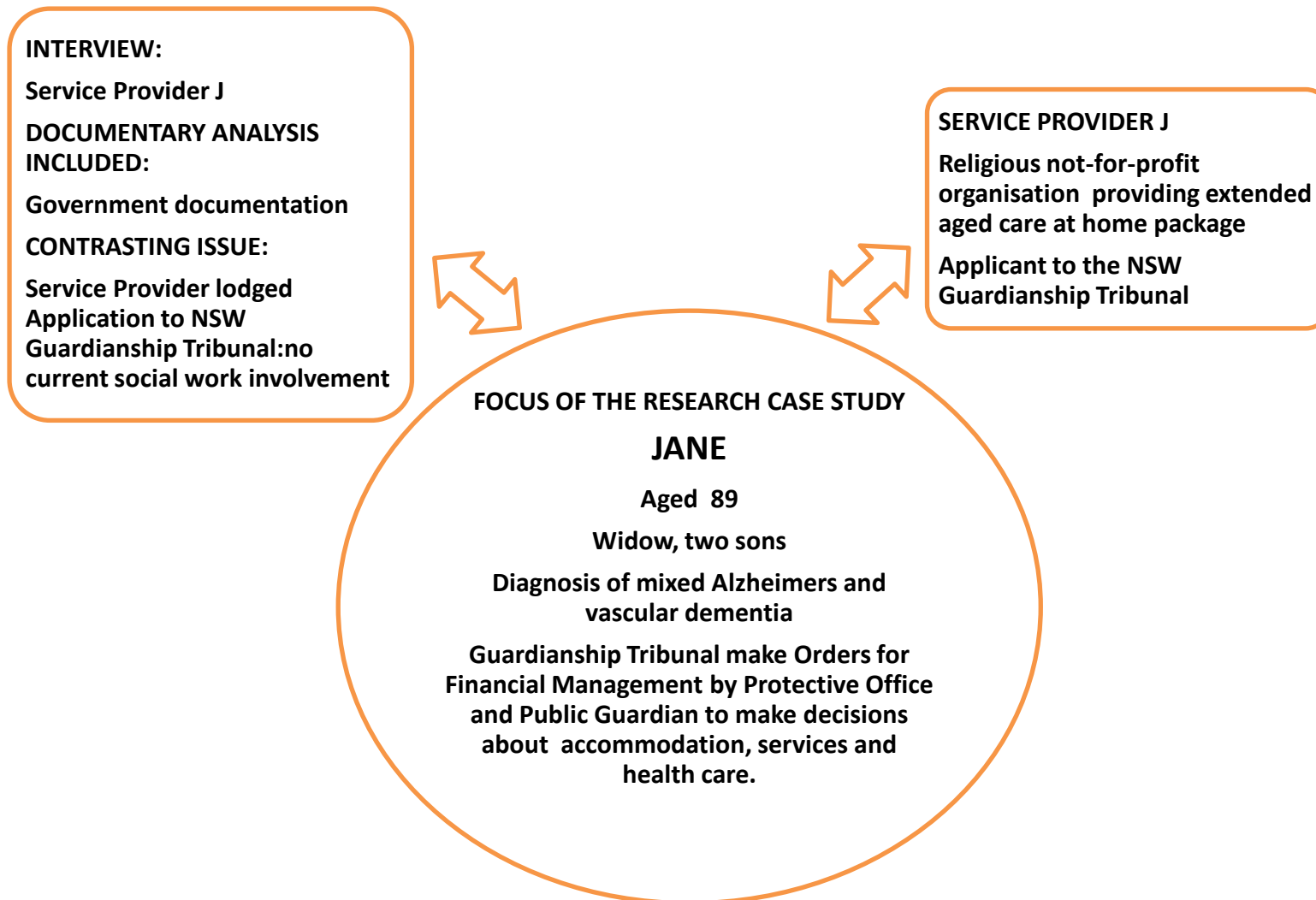
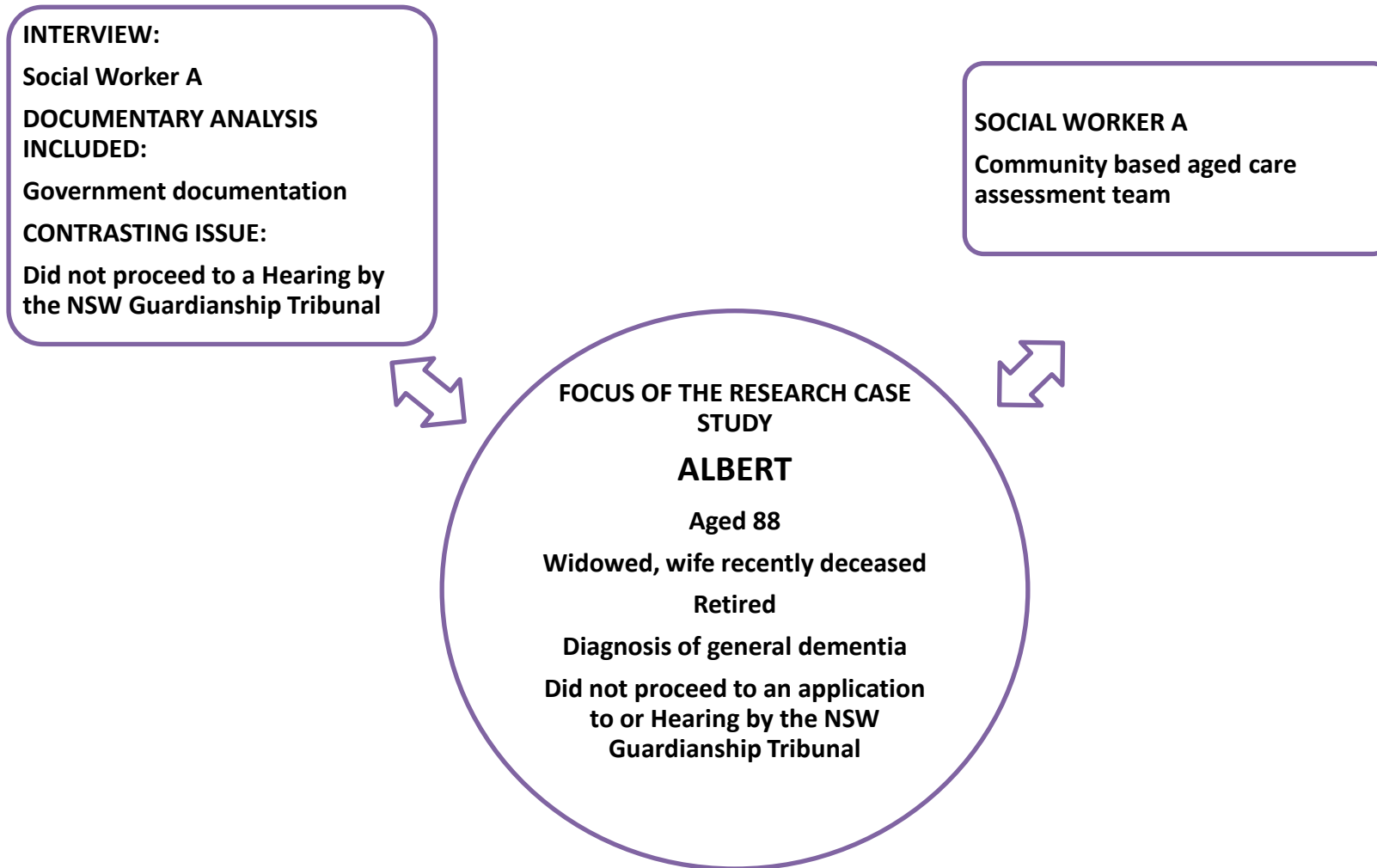


Figure 4.1c: Research case study of Maria



**Figure 4.1d: Research case study of Jane**



**Figure 4.1e: Research case study of Albert**

## **4.4.2 Summaries to accompany diagrams**

### **4.4.2.1 Graham**

Graham was a 76 year old man born overseas. He came to Australia with his family of origin as an 18 year old. He was retired, and living in his own home with his wife Gillian. The couple had irregular contact with their two adult children and grandchildren. Graham's diagnosis was that of Parkinson's Disease and associated cognitive issues. He was considered suitable for inclusion in the study as changes in his cognitive abilities were compatible with those identified as within the jurisdiction of the Guardianship Tribunal of NSW. Graham's socio-legal encounter occurred during a hospital admission. His history included multiple admissions to hospital over a short period. Following one admission he was discharged to a nursing home but then returned to his own home and was readmitted to hospital. The Guardianship Tribunal of NSW made an Order for Financial Management by the Protective Office (now NSW Public Trustee) and appointed the Public Guardian to make decisions about accommodation, services and health care. Graham then moved from the hospital to live permanently in a residential aged care facility.

Five interviews were conducted over a three month period with the hospital social worker, Graham and his wife Gillian, a service provider and a chaplain.

Document analysis included the Order and Reasons for Decisions made by the Guardianship Tribunal of NSW; correspondence between the service provider and geriatrician; a service provider report to the Guardianship Tribunal and government documentation including Australian National Audit Office (2006/2007) Administration of the Community Aged Care Packages Program and Department of Health and Ageing (2006) Aged Care Assessment Guidelines.

### **4.4.2.2 Edward**

Edward was a 71 year old man born overseas. He came to Australia as a single young man. He was retired and lived in his own home with his son. His son entered a rehabilitation program and Edward did not want to remain at home alone. Edward was divorced, had three children, a sister and an ex-wife. He had contact with his three children but they had their own issues which prevented an active role in the socio-legal encounter. Edward's diagnosis



was that of cognitive issues related to a stroke. He was considered suitable for inclusion in the study as changes in his cognitive abilities were compatible with those identified as within the jurisdiction of the Guardianship Tribunal of NSW. Edward's socio-legal encounter occurred while he lived at home and then in respite care in an aged care facility. At the Guardianship Tribunal hearing the social worker, who was applicant, withdrew the application for guardianship and financial management as it appeared that it would not be successful. Edward remained in a residential aged care facility as a permanent resident after the hearing. A contrasting issue to the central research case study was that Edward's family were in conflict regarding financial issues.

One interview was conducted with the community aged care assessment team based social worker.

Document analysis included the Order and Reasons for Decisions made by the Guardianship Tribunal of NSW and Department of Health and Ageing (2006) Aged Care Assessment Guidelines.

#### **4.4.2.3 Maria**

Maria was an 87 year old woman who was born overseas. She came to Australia in the 1950s. Since the early 1960s she lived at various times with her long term partner, Bill, also from the same overseas country, who she met in Australia. Bill returned to live with Maria six years before the socio-legal encounter after a period of approximately four years separation. They had no children or relatives in Australia. Maria's diagnosis was moderate/severe Alzheimer's disease which identified her as being within the jurisdiction of the Guardianship Tribunal of NSW. She was considered suitable for inclusion in the study due to this diagnosis. Maria's socio-legal encounter occurred while she lived in the community with Bill. After a hearing by the Guardianship Tribunal of NSW an Order was made for Financial Management and a Guardian to make decisions about accommodation, services and health care. Bill was appointed her private financial manager and guardian. After the hearing Maria moved from her own home to live in a residential aged care facility. She died within three months. A contrasting issue to the central research case study was that Maria's partner was perceived as a responsible carer who became her private guardian and financial manager.

Four interviews were conducted over a six month period. Two with the community aged care assessment team based social worker before and after the hearing; Maria's partner Bill and a service provider.

Document analysis included an information leaflet from the service provider agency.

#### **4.4.2.4 Jane**

Jane was an 89 year old widow who was born in Australia. Her husband died in 2002. She lived in her own home with her son. She had two sons. Jane's diagnosis was that of mixed Alzheimer's and vascular dementia. She was considered suitable for inclusion in the study due to this diagnosis, which identified her as being within the jurisdiction of the Guardianship Tribunal of NSW. Jane's socio-legal encounter occurred while she lived in the community with her son. After a hearing the Guardianship Tribunal of NSW made an Order for Financial Management by the Protective Office (now NSW Public Trustee) and the Public Guardian was appointed to make decisions about accommodation, services and health care. Jane then moved from her own home to live in a residential aged care facility. A contrasting issue to the central research case study was that the service provider lodged the application to the Guardianship Tribunal of NSW and at the time of the socio-legal encounter there was no social worker involved in the process.

One interview was conducted with the service provider.

Document analysis included: Australian National Audit Office (2006/2007) Administration of the Community Aged Care Packages Program.

#### **4.4.2.5 Albert**

Albert was an 88 year old man born overseas. He came to Australia post World War II with his wife. Albert had no children. Albert's wife died immediately prior to his socio-legal encounter. His diagnosis was that of a general dementia. He was considered suitable for inclusion in the study due to this diagnosis, which identified him as being within the jurisdiction of the Guardianship Tribunal of NSW. Albert's socio-legal encounter occurred while he lived alone in the community. Albert's socio-legal encounter did not proceed to a

Guardianship hearing. He was admitted to hospital and made his own decision to move directly to an aged care facility. This was the contrasting issue to the to the central research case study.

Two interviews were conducted with the community aged care assessment team based social worker, before and after Albert moved to live in an aged care facility, over a period of eleven months.

Document analysis included: Department of Health and Ageing (2006) Aged Care Assessment Guidelines.

Total number of interviews: 13

Total number of documents: 7

In the initial research design a separate retrospective review and analysis of documents was envisaged as being undertaken. This was included in the application to the Human Research Ethics Committee at Westmead Hospital, where it was requested that the researcher collect for analysis Orders and Reasons for Decisions by the Guardianship Tribunal of NSW received by the social workers within the Department of Geriatric Medicine at Westmead Hospital. These were to be different socio-legal encounters to those included in the research case studies outlined above and to be a completely separate strand in the data collection and analysis. To this end the social workers from the Department of Geriatric Medicine gave the researcher ten Orders and Reasons for Decisions received from the Guardianship Tribunal. However, once data collection started in the research case studies described above, the breadth and depth of the data collected led to abandoning this separate document analysis. This was because the material collected through the five research case studies was complex and diverse and it was thought that a separate document analysis would prove to be unwieldy.

#### **4.4.3 Data collection: instrumentation**

Three separate methods were used to collect data in the research case studies. These included semi-structured interviews with participants, document collection, maintaining a journal and writing memos.

##### **4.4.3.1 Semi-structured interviews with participants**

In keeping with qualitative research, semi-structured interviews were designed to gather the accounts and experiences of the social workers, spouses and service providers who participated. The format for the design of these interviews was based on Mason's (2002) ideas for planning qualitative interviews. This was, firstly, to develop the "big" research questions, outlined previously, and from these research questions develop smaller or mini-research questions. From these an overall loose structure and interview guide was drawn up. Interview cards for the main topics and specific issues to be covered were designed and used. These cards gave flexibility and prompts for the interviewer about the key issues and questions. With each participant, lines of enquiry could be followed by the researcher specific to the interview and areas of focus could be covered by the participant without necessarily

having to draw on a particular card. Two similar but modified interview guides, and associated cards, were used; firstly, for social workers and professionals and, secondly, for family and significant people (see Appendix 4 and 5). This approach was chosen because Mason's procedure provided a structure that enabled a flexible but rigorous plan to be drawn up to interview the diverse participants where some issues needed to be followed up in more depth depending on the participant. During the interview process this procedure proved valuable in that cards could be used as prompts to direct interviews but not dominate the flow of the interview.

This method was also chosen in preference to other methods, such as focus groups, because interviews allowed privacy to discuss sensitive issues and exploration at the individual level of experiences. Interviews also allowed the participant to choose the venue of the interview. For the two spouses, the interview took place in their homes. Social workers and service providers were interviewed in a variety of settings, including an interview room in the Social Work Department of Westmead Hospital, a private room at a service provider's agency and cafes. The interviews were tape recorded and transcribed, taking out all identifying data. All participants signed Participation Information Sheet and Consent Forms (see Appendix 6 and 7).

There were very sensitive issues involved in interviewing/observing the person with dementia. Until recently, the perspectives and subjective experiences of people with dementia tended to be overlooked in research (Hubbard, Downs, & Tester, 2003). Slaughter and others (Slaughter, Cole, Jennings, & Reimer, 2007) highlight that informed consent can be a problematic area, but assuming people with dementia are unable to participate in research reinforces negative stereotypes. These ethical issues are taken up later in this chapter but the position taken here was that if the study failed to include the perceptions of the person who is the focus of the study, the study would not be inclusive; respect for personhood and valuable data would be lost. However, in data collection techniques safeguards were built in to try to prevent any harm. A disappointing aspect of the study was that only one person with dementia was interviewed, Graham in the central research case study, as access proved difficult to the others for various reasons. For example, Maria was to be interviewed but unfortunately died before this could take place.

The original research design envisaged two methods of obtaining consent from the person with dementia. Firstly, consent would be sought from whoever was seen as the authorised

representative, guardian or "person responsible." This could have been a legal guardian, family or a significant person (Slaughter, et al., 2007). Please see Appendix 8 for example of the Participant Information Sheet and Consent Form for "person responsible." Secondly, consent would be sought through a participatory research method, or a method for process consent with persons who have dementia, outlined by Dewing (2007). Dewing argues this method presents a person-centred and inclusionary approach to consent that values the interests of all parties involved (Dewing, 2007, p. 13). The method contains five elements. Firstly, background preparation is needed. Secondly, the basis for consent needs to be established as capacity can be seen as situational and variable. It may be that an adapted informed consent process could be used. Key factors include that the researcher knows the person's usual presentation and level of wellbeing, how a decrease in the level of wellbeing may be triggered or recognised, and how the person usually consents to other activities within their day-to-day life. The third element is when the researcher feels confident enough to seek an initial consent from the person with a diagnosis of dementia for the specific research. Notes should be made about location, time, information given and evidence to account for how consent is given for inclusion in the research. Fourthly, initial consent needs to be monitored. Lastly, feedback and support is needed, such as if the person with dementia needs support to make the transition back from the research context and feedback to others with permission of this person. The method requires observation techniques, as well as an unstructured interview schedule (Dewing, 2007).

This structure was followed in interviewing Graham. Social Worker G initially discussed participation in the research with Graham and she formed the view that he understood the information given and was able to decide whether to participate or not. Background information was gathered through Social Worker G and notes were maintained. An initial discussion took place with Graham to enable the researcher to give information and explain the purpose of the study, and ask Graham if he would like to participate. The researcher made the decision that he was able to provide consent to voluntarily participate and a Participant Information Sheet and Consent Form was left with him to read, which he subsequently signed. The interview was conducted in a private room in a ward at Westmead Hospital. See Appendix 9 comprising the interview guide. Graham's wife was also asked to sign the consent form for the "person responsible."

#### **4.4.3.2 Document collection**

Orders and Reasons for Decisions by the Guardianship Tribunal of NSW summarise, from the tribunal's presiding members' perspective, the circumstances that made a hearing necessary, the views of the person with dementia and their family and significant people, and professionals, so that disputed issues are documented and underlying values and tensions can be seen. They also give a rationale for the tribunal's decisions and include what is seen as evidence that the person with dementia is not able to make their own decisions in a particular area, e.g. accommodation, and there is a need for a legal decision-maker. These are unique documents that meet the criteria used by Bryman (2004) for evaluation: authenticity, credibility, representativeness and meaning. The existence of these documents made it an attractive method for document analysis in the research case studies. As Hodder (2000) argues, what people say is often very different from what people do and a study of material culture is of importance for qualitative researchers who wish to explore multiple and conflicting voices. The researcher endeavoured to collect as many of these documents as possible connected to the research case studies.

#### **4.4.3.3 Journal and memos**

A main journal was kept throughout the research to record significant events and what were considered important information and dates in the development of the study, such as the progress of ethics approval and the start of the interview process. This journal also included reflective notes and observations. During the interview stage of the process a notebook was maintained to record field notes in order to document observations, impressions and reflections as soon as possible after each interview. Issues that were thought relevant at the time and would not be picked up by a tape recorder were noted, such as non-verbal communication, telephone calls and observations. A separate notebook was maintained to record the interview process of the person with dementia. The journal and memos were also transferred into the appropriate section of the computer-supported qualitative data analysis software program NVivo 7, which was used in the data analysis stage. Further notebooks were maintained, recording ideas and issues discussed in the regular meetings between the researcher and her joint supervisors.

## **4.5 Data analysis**

Two main complementary tools were used in the data analysis: a thematic network analysis as outlined by Attride-Sterling (2001) and the computer-supported qualitative data analysis software program NVivo 7. Attride-Sterling's thematic network analysis tool draws on core features that are common to many approaches in qualitative analysis (Miles & Huberman, 1994; Strauss & Corbin, 1998). This thematic analysis seeks to find the themes salient in a text at different levels, and thematic networks aim to facilitate the structure of these themes. It offers a web-like network as an organising principle and it makes clear the procedures that may be used in going from text to interpretation. From a purely chronological stance the technique was developed based on some of the principles of argumentation theory put forward by Toulmin (1958). Toulmin describes argumentation as the progression from accepted data through a "warrant" to a "claim." This thematic network analysis tool was chosen because it employed recognised and established techniques and facilitated the analysis in a methodical way to add to the rigour of the study. For the researcher, the technique was a means of exploring the connections between the explicit statements and implicit meanings in people's discourse. The tool did not overtake the material but enabled the material to be developed in a useful way and provide a conceptual framework. The tool was also useful as it allows the "how" of the analysis to be explained to others and adds transparency to the research.

The thematic networks facilitated the extraction of, firstly, basic themes or the lowest-order premises evident in the text. Secondly, organising themes where categories of basic themes are grouped together to summarise more abstract principles. Thirdly, the global theme or a super-ordinate theme encapsulating the principle metaphors in the text as a whole. The texts referred to include interview transcripts and documents. The process followed the six steps put forward by Attride-Sterling (2001). These are detailed below.

### **4.5.1 Step One**

Coding the material. Codes were devised by going through the data, identifying the most pertinent constructs and shaping them into a set of initial basic codes. After an initial reading and marking manually by colour-codes, these were transferred into the software program NVivo 7. These codes, now nodes in NVivo, were based on issues that arose from the text



itself and theoretical interests guiding the research question. For example, there was a theoretical interest in the concept of risk. In this first step of coding, six basic codes/nodes emerged surrounding risk. See Appendix 10 for outline of nodes and tree nodes.

#### **4.2.2 Step Two**

Identifying basic themes. The nodes were grouped into fourteen clusters, or tree nodes. Each node's text segments were re-read within the clusters. Basic themes for each cluster were abstracted from the coded text segments and then refined so that the boundaries were specific enough to be discrete and broad enough to encapsulate a set of ideas contained in numerous text segments. Nvivo 7 was used to organise the nodes into tree codes. Once clustered into tree nodes these basic themes were then reframed into what Toulmin (1958) called statements of beliefs. These statements of belief back the warrant, which is the organising theme and detailed in step three. They are a renaming of the original tree nodes. Taking the example of the six nodes in the cluster surrounding the theoretical interest in risk, after re-reading and interpretation of the text, the tree node *constructions of risk* was refined into the basic theme *of risk is fluid and constructed differently* as a statement of belief about the data in this tree node. See Appendix 10 for an outline of the nodes and tree nodes.

#### **4.5.3 Step Three**

The first thematic network analysis network was constructed. See Appendix 11: Figure A11.1. The themes identified in step two were assembled into similar groupings and interpreted into middle order organising themes on the basis of shared issues. Five organising themes were initially identified. Returning to the example of the basic theme in step two, *risk is fluid and constructed differently*, this basic theme was assembled into a similar grouping with two other basic themes that reflected statements of beliefs about the data. These were: *critical events force and justify decisions* and *capacity is legal and situational*. This organising theme was identified as *risk and capacity is fluid and situational*, which is one of the warrants, or principle and premises, on which the global theme claim is based. The global theme is the super-ordinate theme that brings together the organising themes to present an argument, or a position or assertion about the given issue, which in this instance is decision-making with people with dementia in circumstances where a legal decision-maker is

perceived as necessary. In this early stage of the network analysis in this study it was that: *power, responsibility and risk are critical concepts in understanding different domains of interaction and decision-making.*

#### **4.4.4 Step Four**

In this step the researcher went back to the original text and used the network as a tool which brought together data and interpretation. This thematic network analysis tool allowed the material in the networks to be described and concepts explored by taking each network in turn and then moving material within an individual network or across the network. This assisted in exploring underlying patterns that began to emerge and material could be moved around with ease using NVivo 7. This step provided direction to begin to draft the analysis. In the practical process of undertaking the analysis, this step was seen as a breakthrough in marrying up interpretation of the data and the theoretical underpinnings of the research.

#### **4.4.5 Step Five**

The network's main themes and patterns were refined, summarized and rewritten. In practice this process involved reduction of the number of organising themes. Overall, ten different thematic network analyses were sequentially drawn up while working through the material. See Appendix 11, which comprises these thematic network analyses that were refined during the process. The final thematic network analysis is presented in Figure 5, Chapter Five.

#### **4.4.6 Step Six**

Findings in the summaries of each thematic network were pooled together into a cohesive whole and presented in Chapters Five, Six and Seven. Attride-Stirling (2001) uses this step to relate back to the core theoretical assumptions of the research and refer to the original research questions. In practice in this study during the 5 steps outlined above the theoretical perspectives and research questions were interwoven throughout the thematic network analysis process.

Data analysis began after the first interview and continued simultaneously with data collection. Data was transferred into NVivo 7 as soon as practicable after the initial manual

coding. This proved a convenient tool for data storage as the program is focused around the concept of a case. The program was also helpful in working with the data as it provided strategies for development of the coding system, visualising the ideas and patterns in thematic networks and making links between ideas and concepts. It also allowed for within-case analysis as well as cross-case analysis. Memos were made in the program on each tree node and nodes within each tree to store reflective thoughts. Annotations or comments about particular segments of text were made in the documents as the analysis progressed.

#### **4.6 Ethical considerations**

As raised in the Introduction to this thesis, the researcher is an experienced social worker and interviewer with two decades of clinical experience in social work with people with dementia and their families and is currently a practising social worker in this field. This experience has implications in that knowledge and values were brought to the research study that could impact on the connection between the researcher and the participants. This is acknowledged as both an asset and a possible limitation. Sensitivity to the data collected, a sound knowledge of interview techniques, empathy with people with dementia and their significant others, and knowledge of issues and resources can be seen as positive. However, the researcher also brought underlying taken-for-granted knowledge to the research from this clinical practice. For the researcher, reflexively examining her own taken-for-granted knowledge has been embedded in the research process. This created an awareness of the strength of the dominant biomedical discourse in social work practice and a concern about how the social work participants would view the interpretations of the data collected from them by using a social constructionist understanding that challenges their taken-for-granted knowledge. As Minichiello and others highlight, the danger of being an "insider" researcher, or someone who has a special knowledge of their own group, is that the researcher might probe for information from research participants and then make different interpretations from the participants (Minichiello, Aroni, & Hays, 2008, p. 190). This was a dilemma that was overcome by maintaining the integrity of the research process by straddling the role of "outsider" researcher, who developed concepts and theories from the material provided by the participants, with "insider" social work status. This approach of straddling the two roles also

assisted the researcher in overcoming the drawback of being an "insider" of not wanting to appear critical of those with whom relationships were already formed.

A further limitation of the insider status of the researcher was that this could affect how much participants were willing to disclose and their perceptions about confidentiality and anonymity. Full written informed consent was obtained and confidentiality was stressed both verbally and in the Participant Information and Consent Sheets. This was critically important where multiple interviews took place in an individual research case study. All identifying details were removed when the interviews were transcribed so participants remained anonymous in any written material associated with the research or presentations of the data. As outlined previously in this chapter the sampling method ensured that participation in the research was voluntary as social workers were invited to contact the researcher if they wished to discuss being recruited and had a specific case in mind. Also, access to further participants in the research case study was through the social worker so the researcher did not approach these participants directly. All participants were informed that they could withdraw from the research at any stage.

As an "insider" the researcher had prior knowledge of one particular research case study. The personal position of having provided a social work service to Jane some years previously was given careful thought before the decision was made to include Jane's research case study. At the time of the research data collection the researcher had no direct social work involvement and was not employed by Westmead Hospital. It was considered feasible to include Jane in the research after an approach was made to the researcher, as it was thought that the complexities of her social situations and contrasting issues could provide valuable data. Pragmatically, as is often the case in small, purposeful sampling, the research design did not allow for easy access to a large number of cases where it would be possible to pick and choose. In practice the service provider interviewed was unknown to the researcher, as the link was made through a colleague from the service provider's agency, and insider knowledge was helpful regarding Jane's historical context. Despite lengthy and extensive social work involvement prior to the research by at least four different social workers based in both the hospital and community aged care assessment team, at the time of carrying out the research there was no social worker involved in the application for a guardian and financial manager for Jane. This, in itself, provided an interesting contrasting case.

The research aimed to ensure that no harm was experienced by the participants. The need to include people with dementia in research studies is becoming well established. Over the last decade there has been a growing body of research which has begun to document the subjective experience of living with dementia and examples of methods used in research including interviews, observation, conversational interviews and reminiscence work (Cowdell, 2006; Hubbard, et al., 2003; D. O'Connor, et al., 2007; Wilkinson, 2002). As referred to previously, strategies to prevent any harm to participants with dementia included the participatory research method to obtain consent outlined by (Dewing, 2007). The initial research design outlined strategies such as pausing or discontinuing the interview if strong emotions were expressed by either the person with dementia or family member. If the issues raised caused distress it was envisaged that participants would be supported through this and, if they expressed the need, appropriate referrals made. In practice, all participants contributed fully within the interview and from the free flow of the interviews it was clear that issues surrounding the need for a legal decision-maker were viewed as a central issue by professional participants in their clinical work and were life changing events in the private lives of the other participants. All participants appeared to appreciate the opportunity to give voice to their experiences.

As outlined previously, prior to commencing the study ethical approval was sought and granted by the Human Research Ethics Committee, Westmead Campus (see Appendix 2) and ratified by the Ethics Office of the University of Sydney (see Appendix 2). The study was also approved by the Research Governance Officer, Sydney West Area Health Service, for the research to be conducted at this specific site (see Appendix 2). This was required for the research to be assessed as suitable for the specific site and the suitability of the investigators for the proposed research. As required, annual reports were submitted to the Human Research Ethics Committee, Westmead Campus, throughout the research process. Whilst this route to gain ethics approval was lengthy and demanding in terms of both process and documentation, the benefit was access to participants that could not be achieved by another route.

#### **4.7 Trustworthiness of the research**

A number of different stances are taken in relation to assessing the quality of qualitative research (Bryman, 2004; D'Cruz & Jones, 2004; Guba & Lincoln, 1982; Lincoln & Guba,

1985). Guba and Lincoln suggest four criteria to assess the trustworthiness of research; credibility, transferability, dependability and confirmability to ensure that trustworthy research be reconsidered beyond positivism but with equal rigour. These criteria are consistent with those in quantitative studies, that is reliability, internal validity, external validity and objectivity. The four criteria for qualitative research are based on the paradigm that assumes the existence of multiple realities rather than one absolute truth. Multiple realities can only be understood in holistic terms where context is essential to theorizing (D'Cruz & Jones, 2004). As such these criteria are particularly relevant to this research where case studies are analysed through the social constructionist lens to understand the different perspectives or realities of participants. The study's trustworthiness is demonstrated by internal cohesion where the social constructionist framework is used to interpret data and the questions asked are designed to gather the multiple realities of participants in their social contexts.

Looking at each criterion in turn, credibility relates to the emphasis on multiple accounts of social reality, that the research is carried out according to good practice and that the analysis is believable (Bryman, 2004). The use of perspectives from social constructionism supported accounts of multiple social realities. These were embedded in this study from its inception including the formulation of the research questions that were designed to seek out individual perceptions. The relationship of the researcher to the study has also been addressed in the thesis. The findings of the research were disseminated by the researcher at a number of professional forums. While the purpose of these presentations was to disseminate the findings of the research, not respondent validation, this provided the opportunity to gather impressions as to whether the findings were congruent with the clinical practice experience of the social workers who attended these meetings. There was a range of responses including an appreciation of the theoretical approach; that the research case studies were meaningful in that the knowledge was applicable to other contexts, and that the findings were challenging in that they posed more questions to consider. Generally there was a thoughtful response, however, some of the concepts introduced, such as the use of professional power, were more difficult to relay in these types of forums. As Bryman states, there can be practical difficulties in presenting a researcher's analysis, which was made in the research context of the development of concepts and theories, to both participants and wider audiences, when the inferences were initially designed for research purposes (Bryman, 2004, p. 274).

Transferability is the second criterion proposed by Guba and Lincoln (Guba & Lincoln, 1982; Lincoln & Guba, 1985). This refers to the extent knowledge can be transferred to other contexts. As referred to previously when discussing dissemination of the findings, it appeared that many of the social workers who attended the meetings were able to transfer the knowledge gained in the research case studies to apply to their own practice. At a wider level decision-making with people with dementia is a broad topic, as is complexity in casework practice, and the knowledge gained in this study is relevant across different professions and contexts. Thick descriptions were used in the analysis, which Guba and Lincoln argue provide others with a baseline for making judgements about the possible transferability of findings to other settings (Guba & Lincoln, 1982; Lincoln & Guba, 1985).

The third criterion is dependability, where researchers adopt an "auditing" approach towards data gathering. Journals, memos and notebooks have been kept to provide evidence of record keeping. All interview transcripts have also been kept, as well as data on the software program used. Similarly, stages in the thematic network analysis have been kept and presented in Appendix 11. The fourth criterion is confirmability, where the researcher has acted in good faith. It has been acknowledged that the researcher brought certain values and taken-for-granted knowledge to the research which were continually reviewed and critically appraised through researcher reflexivity. It is acknowledged that from a social constructionist viewpoint it is not possible to separate values from how the research question is understood and addressed.

D'Cruz and Jones (2004) highlight that a particular strategy for achieving trustworthy research is triangulation, or combining multiple methods of data collection and not relying solely on interviews. In keeping with the case study design this research uses a variety of data collection methods, such as semi-structured interviews, observation, document collection, journaling and memos all of which were analysed in the data interpretation and the presentation of the findings.

#### **4.8 Summary**

This chapter has outlined the methodology of the study. An account of the theoretical perspectives and social constructionist framework was presented and the research study design outlined. The research process of data collection and instrumentation used was

delineated and the five case studies introduced in diagram and summary form. Data analysis, ethical considerations, and the trustworthiness of the research have been expanded on. An analysis of the findings of this study are presented in the following three chapters in an integrated way in the context of the preceding literature review chapters.



## Chapter Five

### 5.1 Introduction

This is the first of three chapters that present an analysis of the findings of this study in an integrated way. As outlined in Chapter Four, the analysis is based on the thematic network analysis described by Attride-Sterling (2001). Each of these three chapters will focus on a distinct organising theme that supports the global theme. The global theme is an assertion about the socio-legal encounters that endeavours to encompass the principal metaphors in the data as a whole (Attride-Sterling, 2001). In the analysis issues that emerged from the three global themes show that what encapsulates the meaning constructed by the participants in this study is that they are engaged in *Power Plays and Contestations*. The assertion here is that power plays and contestations at the interface of decision-making in socio-legal encounters reveal that the individual contexts of the research case studies are evolving, where different players participate by bringing their own perspectives, and in this process alliances are formed which reflect underlying dynamics of power. At this interface there are many diverse and contested issues, such as constructions of risk, capacity, protection and responsibility which are critical.

Relating this assertion or global theme back to the primary research question of this study, it may be argued that the challenge in social work practice with older people, their families and other professionals in these disputed and uncertain situations is to unravel the power plays and deconstruct the contestations in socio-legal encounters. Also, in returning to the four research questions posed aimed at understanding the processes of interaction and negotiation, the values and tensions behind these negotiations, and questioning different perceptions of dementia and capacity, this global theme shows that links can be made to these questions about underlying power plays and contestations in which participants engage. The challenge for social work practice, it may be argued, is to ensure that all the participants' views on critical contested issues are taken into consideration in decision-making and any resulting action is shaped by the unique context of specific socio-legal encounters.

This chapter comprises the first organising theme that supports the global theme: *deals from disparity*. This centres on the contextual influences affecting decision-making where the

individual participant is embedded in a professional or private context and there are inherent power dynamics. Chapter Six comprises the second organising theme: *constructions and reconstructions*. The focus of the analysis is on how individual knowledge bases that support the process of decision-making differ and change. This is highlighted through knowledge expressed about dementia and the person who is the focus of the socio-legal encounter, as well as the impact of critical events and constructions of risk and capacity. Lastly, the focus of Chapter Seven is the organising theme: *ethics and messy morals*. How ethical dilemmas involve balancing responsibilities and rights in socio-legal encounters is explored where negotiating responsibility for action can limit the rights of the person with dementia. Protection can be viewed as multi-layered and diffuse in balancing these responsibilities and the context of the individual socio-legal encounter can intensify the need to balance responsibilities and rights. The final thematic network analysis in diagrammatic form follows in Figure 5. This Figure demonstrates the progression of the interaction of the themes and how the network patterns were refined as concepts were explored. See Appendix 11 for a detailed evolution of the other nine different thematic network analyses which were sequentially drawn up while working through the material.

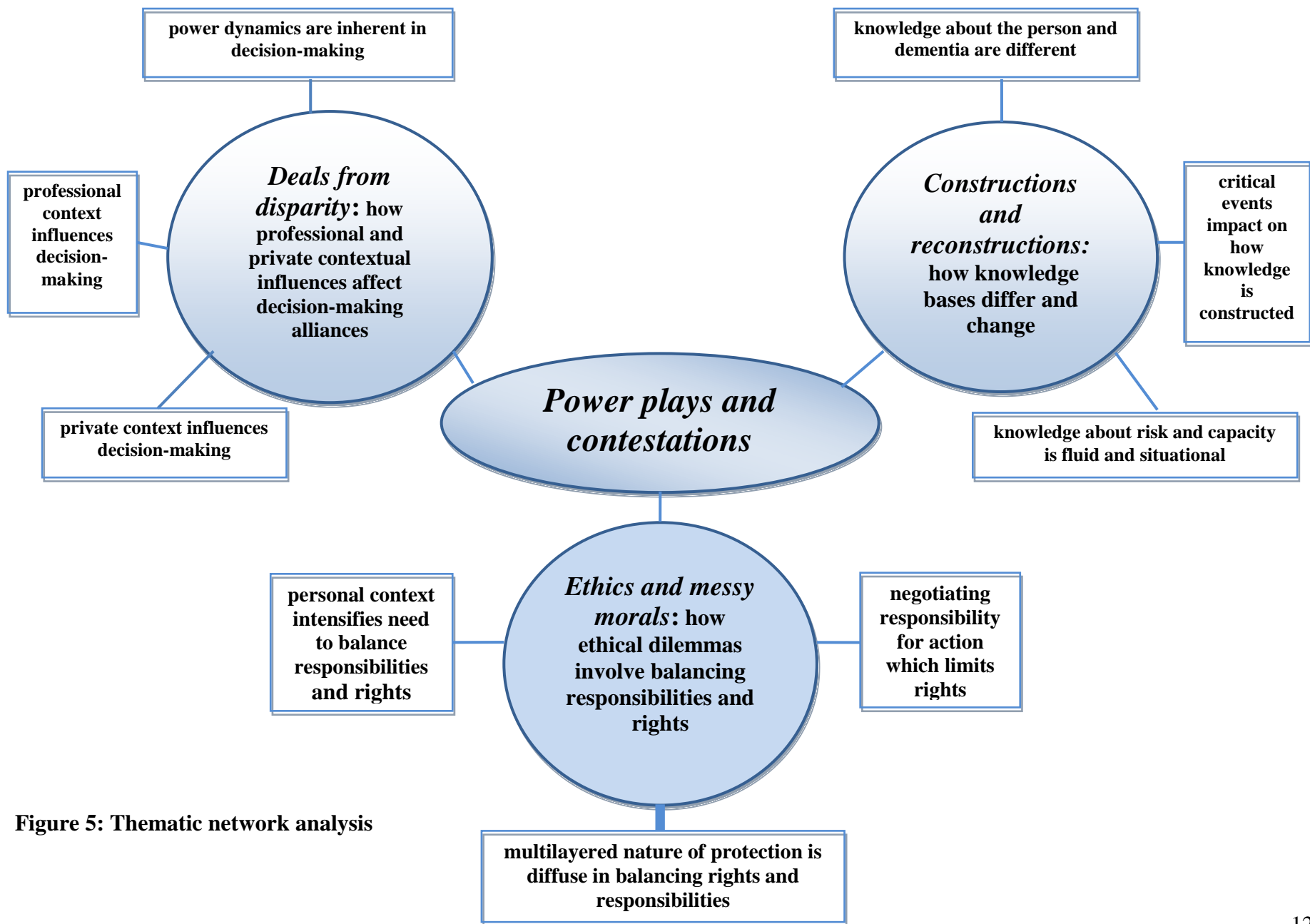


Figure 5: Thematic network analysis

## **5.2 Organising theme: deals from disparity – how professional and private contextual influences affect decision-making alliances**

This organising theme reflects the experience of the participants interviewed regarding the process of interaction and negotiation around decision-making and the values and tensions behind the process of an application for guardianship/financial management. Consequently, this organising theme relates primarily, although not exclusively, to the first and second of the four research questions the study was designed to explore. The first research question centres on the history of the process, who was involved or left out, who initiated and maintained interaction and the relationships formed around decision-making whereas aim of the second research question was to uncover the values and tensions behind decision-making in order to understand different perspectives.

An exploration of the three themes that support this organising theme provide the structure of this chapter. These basic themes are statements of beliefs regarding the characteristics of the data (Attride-Sterling, 2001, p. 289). These are that:

- Power dynamics are inherent in decision-making.
- Professional context influences decision-making.
- Private context influences decision-making.

There is some crossover in the analysis of these basic themes to provide an integrated presentation of the organising theme. However, within each basic theme the findings of the study are presented before moving to discuss these in relation to the relevant literature.

It is important to note that social work practice in the research case studies was consistent with what Parton and O'Byrne describe as characterised in terms of indeterminacy, uncertainty and ambiguity (Parton & O'Byrne, 2000a, p. 44). In this study decision-making was complex and reflected that there are no easy solutions in social situations that are uncertain. In this respect the research case studies fall into the category referred to by Webb (2006) as "wicked" problems as there were interrelated components of organisational complexity and strong moral dimensions. In wicked problems issues are not easily defined, complex judgements are needed, there are no clear stopping rules or objective measure of success and solutions can be better or worse not right or wrong

(Webb, 2006, pp. 192-193). Therefore decisions made by the individual participants cannot be evaluated as "right" or "wrong."

### **5.2.1 Power dynamics are inherent in decision-making**

In explaining the decision-making process alliances were formed during the negotiations, reflecting underlying power dynamics. It is necessary to clarify use of the term "alliance" as this concept is central to the findings and analysis of the data. In Chapter Three it was highlighted that newer approaches to interactions have grown out of the perceived need to develop a professional approach where all participants are included in the interactions and to try and address the acceptance of differences in understanding dementia. What is useful in terms of this study is the term "alliance," which is used to draw attention to the collusions that can develop in the interaction between professionals and the older person and their family. This term reflects one of the dictionary meanings of "alliance," that of "a joining of efforts or interests by persons, families, states or organisations" (The Macquarie Dictionary, 1991, p. 45). So the term is adopted here to describe the interactions of participants as it reflects the agreement, either open or implicit, between two or more participants made in order to advance their common goals in the process.

As referred to in Chapter Three, there are potentially a variety of combinations of alliances that may be formed in any complex social situation but what is significant is that the findings of this study demonstrate that there were differences in how decisions were made between categories of participants. The participants in each research case study can be separated into two different categories: professional participants, who were social workers and service providers, and private participants, who comprised the individual who is the focus of the research case study and their family members. They can therefore be viewed as situated in professional or private contexts within each socio-legal encounter. These different contexts produced different influences in decision-making. The professional participants' context influenced decision-making as it included the impact of policies and legislation, or the professional background and agency context of the social worker or service provider. Alternatively, private participants were situated in a context where the person who was the focus of the research case study had a unique historical and social situation where a spouse, family, or neighbour was significant in the process of decision-making. The sense of the person who is the focus of the research case

study making efforts to sustain their sense of self was paramount in this context. In this study alliances were formed within these two contexts, for example, between two professionals, or across the contexts, such as between a professional and a family member.

Starting with Graham's socio-legal encounter, Social Worker G practised in a ward environment where professional expert knowledge dominated and there was an expectation of compliance to this knowledge. This context was influential in her practice and decision-making. She referred frequently to the team within which she practised and used the word "we" to describe how the team made their decisions. To compare with the other socio-legal encounters, where the social workers practised in a community environment in an ACAT, there were margins for more flexibility and autonomy in decision-making but the context was not perceived as being as cohesive as the ward team environment. One community social worker described how she experienced support in her practice:

*What I find very difficult in my situation is that I have three supervisors, I have a deputy supervisor, and I have a team leader, and I have the manager. I have three people that I could go and talk to. If I go to my supervisor, I actually find that she is quite good to talk to, but she has no authority. And her and the team leader, immediately you go and talk to them they go: "let's see what the manager says". So in many ways I feel like, well I have to skip these two, and go straight to the head to get my information. Or to get my authority. And when I do that, the manager is very, very good. But I'm skipping the line of authority and it's a delicate balance there. (Social Worker A)*

This community practice environment also placed more emphasis on the narrative that was perceived by the social worker, and retold to her supervisors, as this was the basis of decisions made, as opposed to the ward team context where other team members had more direct contact with the older person and their family. This narrative could then become a crucial element in defending or justifying action. However, in the ward context Social Worker G's decision to lodge an application for guardianship was seen as a team decision, which she described:

*...we actually had a case conference where we had, so myself, the geriatrician from the hospital, the geriatrician from the ACAT team, the CACP coordinator, and the physio and the OT here from the hospital. So we all sat around and talked about what our concerns were, could we think up any other options, and as a group we decided it was time to put in the application. (Social Worker G)*

This team decision, which at this stage of the process included an alliance with Service Provider G, placed Graham and his wife in a powerless negative position, where their views, that they wished to remain at home together, were marginalised. The marginalisation of these views may also be interpreted to reflect values where the accepted bio-medical understandings of dementia was that medical opinion, and associated opinions of those in the allied health field, should be taken into account and acted on by "patients." Priority was given to physical safety over emotional health in very detailed descriptions by Service Provider G and Social Worker G to justify the decision to apply for a guardian and financial manager based on risk factors such as inadequate hygiene and diet, lack of mediations, and remaining on the floor, which was described as "falls." These may be seen to focus on individual pathology and the need for Graham and his wife to change their lifestyles according to Graham's physical decline.

What are described by professionals as "falls" are, for Graham, a preference. He said:

*I sit on the floor. It's convenient. I can't fall over, see... You can't stand for long, you get tired, see. Up and down like a yo-yo. You see if I sit on the floor it solves the problem and there's no pain that interferes and I can eat my breakfast. ... In bed it's no problem because you are lying flat out, see, but sitting the nerve is sometimes crushed and really reacts and very painfully. (Graham)*

The "team decision" to lodge an application for guardianship and financial management was based on the perception that current community services could not support Graham at home and the only alternative was residential care. This reflects the lack of resource options and the limitations in the current provision of aged care services at an institutional level outlined later.

A significant contrasting issue between Graham's central research case study, in a ward environment, with the other socio-legal encounters played out in a community environment, was in terms of the power of medical authority vested in a geriatrician.

While ultimately the geriatrician's authority was prioritised and accepted by all players, discussions within the community environment appeared to have space to challenge this medical advice. In comparison to the central research case study and Social Worker G's perception of team responsibility, Social Worker E in Edward's research case study had a perception of individual professional responsibility for Edward. She related that the geriatrician's perspective was that Edward was able to make his own decisions regarding his financial affairs and lifestyle. However, in Social Worker E's narrative, she felt that if she withdrew her services she would be perceived as aligning with Edward's sister who, at a later stage in the evolving process in this encounter, took responsibility for Edward's financial affairs. Initially in the research case study there was no family member who was willing to take responsibility for Edward's financial management. When his son went into a rehabilitation program, Edward did not want to remain in his own home by himself. However, Edward's ex-wife expressed concerns to the social worker about his sister taking responsibility for his financial affairs. These concerns centred on inheritance for her children. So, contrary to the geriatrician's opinion, Social Worker E opted to submit an application for a decision to be made about appointing a legal guardian and financial manager by the Guardianship Tribunal. At the hearing the medical authority, vested in the geriatrician, was accepted and Social Worker E withdrew her application. She said:

*Anyhow, it was actually the Guardianship Tribunal that in the end encouraged me to pursue this and I said that I feel more comfortable, even though I think in some senses the application is dead in the water and I'm probably not really wanting to see the public guardian or the OPC [Office of the Protective Commissioner] take over and overturn her power of attorney or enduring guardianship. I was finding it very ethically difficult that in actual fact, if I withdrew the application and said why, I was becoming the decision-maker. (Social Worker E)*

The dilemma for Social Worker E was that by deciding to form an alliance this decision is powerful in that she implicitly provides legitimacy, through professional power, to the person with whom the alliance is formed in the family. In her view, initiating an application and bringing the parties together at a hearing was a more transparent process of decision-making.

At the professional level, the dynamics of power are remarked on by Social Worker E. She said:



*I disagreed with the geriatrician because I guess I still kept seeing this man who didn't have a really good grasp of his finances, was very vague about them and was also unable to do anything about – equally as he was unable to pay his electricity bills or renovate his house, he was unable to sort out his finances. He was unable to negotiate with banks. (Social Worker E)*

This disagreement regarding capacity with the geriatrician means that Social Worker E was aware that medical opinion would be upheld at the Guardianship hearing and reflected the underlying balance of power. The different perceptions of capacity between the two professionals is pertinent to the research question regarding how capacity is understood and the assumptions made in the understandings. For Social Worker E, her notion of capacity was linked with direct observation and knowledge of Edward's daily living situation over a period of time. Similarly, Social Worker E's dilemma regarding forming an alliance with Edward's sister, or with the geriatrician, is significant in relation to the research question regarding the process of interaction and negotiation around the issues posed in this unique socio-legal encounter where values centre on financial matters.

In this research case study Edward made the decision to enter a residential aged care facility, initially on a short term basis, after talking with his family. So this decision was made within the context of his private family relationships. This was actively supported by Social Worker E and created a cohesive alliance between Edward, his family, and Social Worker E on the issue of accommodation. However, it brought to the fore conflict in the family regarding financial and inheritance issues where decision-making was more problematic.

The dynamics of power in Edward's research case study were revealed at a personal and family level, as well as the professional one. At the personal level, Edward's sister and ex-wife were both perceived by Social Worker E as powerful. She said:

*his sister was such a powerful and dominant force – I suppose that was also another feature of the whole thing. Whilst I got on quite well with her, she was a very powerful woman, a very strong woman and she did direct him, and he just followed along. (Social Worker E)*

and

*interesting to see the females, like the sister and the wife were actually very similar people ... in terms of their dominance and their power. They were powerful women, very forthright, had quite solid decisions.* (Social Worker E)

What is interesting about these statements is that they demonstrate underlying power dynamics. Where family members are perceived as powerful, impact on decision-making by a social worker can shape the resulting action. However, even where family members are perceived as powerful this does not necessarily mean they will take responsibility for an application to the Guardianship Tribunal. Nevertheless, it is clear that in answer to the first research question regarding the process of interaction and negotiation around issues that may necessitate an application for guardianship or financial management, perceptions of family power are relevant.

In the professional context alliances between social workers and service providers produced either tension or cohesion in the decision-making process and revealed underlying power dynamics. This occurred as social workers and service providers, situated in different agencies, participated by forming alliances in the variety of social situations in the socio-legal encounters. These included strong family support, absence of a family member or a family member was not perceived as "responsible," or in the presence of conflicting family relationships.

In Maria's research case study the differences in the professional experience of Social Worker M and Service Provider M was a factor that was handled in a cohesive way between the two professionals. Service Provider M said:

*I think ... [Social Worker M] was, at the time, in the learning stage of this. I think it was maybe the first one she had to do. So I was actually advising her of the processes. And I think she was actually getting something different from her manager, what the course may be which, I said, "we can actually do this" and "you can actually do that" and she got back to me, "you're right ..."* (Service Provider M)

In the evolving decision-making process Maria's spouse, Bill, became a part of this alliance, despite early and continuing ambivalence. This created a wavering but powerful alignment of relationships between the two professionals and Bill.

A powerful alignment is demonstrated between Service Provider G and Social Worker G just prior to Graham's Guardianship Tribunal hearing. Service Provider G's agency withdrew the package of care provided to Graham, due to perceived high physical risk factors, and Graham had no choice regarding a move to another service provider. This withdrawal of services is a powerful action that added to the argument made by Social Worker G to the Guardianship Tribunal that Graham could no longer remain at home as he did not have any services. This draws attention to the importance of the role of service providers in socio-legal encounters and their involvement in the process of interaction and negotiation. One of the ambiguities in the central research case study was that both Graham and Gillian spoke positively of the direct care workers and Service Provider G. This highlights, for them, the importance of direct personal relationships. Gillian says:

*Everybody has been very kind and they've looked after us very well. But we still would like to be together. (Gillian)*

Graham also perceived the carers coming into the home as helpful. However, he is very clear about identifying the most powerful voice he thought was being heard. He said:

*Dr... [geriatrician practising in the hospital] has decided he wants me in a nursing home and he wants someone to look after me from outside... he's the head man of the tribunal. He's got to appoint someone to be my guardian. (Graham)*

Adding to Graham's lack of choice in this central research case study, the perception that Graham did not have a responsible carer with whom Service Provider G could form an alliance to make decisions was an issue for Service Provider G. In the underlying dynamics of power this was another aspect that placed Graham in a powerless position. In contrast in Maria's research case study Bill is seen as a responsible carer and therefore from the professionals' perspective it was possible to form an alliance with him. Service Provider G described Graham's wife, Gillian, as having mental health issues and from her first interview with the couple described them as a "very peculiar case". She said:

*Gillian said that she had, and this is what I don't understand either, the day I first interviewed her, I said "have you eaten today?" And she said "no". She doesn't seem to be able to, other than getting take away, doesn't seem to think to feed herself. And she is obviously not starving because she is not underweight or anything. But it's very strange that she doesn't think to feed herself. And we go in*

*and feed her every day. We get the ... meals and put them in the freezer for her. Open the fridge it's always chocked with food, always. Fruit, vegetables it just that she doesn't do anything with them. (Service Provider G)*

In contrast to this, however, Service Provider J, whose agency provided both high and low care packages, stated that her agency does not have a policy that the service user should have a family member or other significant person who was perceived as responsible. She accepted the referral of Jane and her son, although she perceived Jane's son as not being a responsible carer. This, however, still places Service Provider J in a powerful position in the decision-making process.

The analysis of the data in this theme is pertinent to literature reviewed. Overall, the data supports the proposition put forward by Hulko and Stern (2009) that power features prominently in relationships and interactions between service providers and the recipients of services, particularly when there is a difference in age and perceived cognitive abilities.

The cohesive element to the support Social Worker G expressed while practising in a ward environment, and the consequent team decision, is congruent with Powell and Biggs' (2001) argument, raised in Chapter Two, that key Foucauldian concepts of genealogy, discourse and power/knowledge can be applied to those who are labelled "old." Here, power is seen as being operated by professionals through institutions and face-to-face interactions and is constituted in the discourses. The power of the professional discourse, as portrayed by the team decision, is that it is perceived as the "true" discourse and effectively destroys the legitimacy of other competing discourses (Biggs & Powell, 2001, pp. 5-7). Similarly, the deficit-oriented approach, such as the listing of Graham's perceived physical risk factors may also be interpreted as reflecting the expert "gaze" and discourse of dependency. Biggs and Powell argue that Foucault's concept of the medical "gaze" where discourses, languages and ways of seeing shape the understanding of ageing into questions that centre on, and increase the power of, the health professions while restricting other possibilities (Biggs & Powell, 2001, p. 3).

The findings are also congruent with the literature discussed in Chapter Three, regarding formation of alliances and partnerships (Adams, 2003; Adams & Clarke, 2001; Clarke, 1999a). However, this study adds new knowledge regarding the complexities in forming

alliances beyond those involved in a triangle. Adams (2003), referred to in Chapter Three, discussed a triangle of three types of collusive alliances that may exist across professional and private contexts between an older person, family member and a professional where a third party is excluded by an alliance between the other two parties. This study builds on this work in that there are multiple players situated in different agency contexts. Adams (2003) also suggests that there are three identified roles of professionals; mediator, suppressor and exploiter within a triangle of relationships. However, again in the research case studies the complexity presented by the number of participants means that these roles are more dynamic than comprising a triangle. For example, in the central research case study Social Worker G and her hospital-based team acted as suppressor towards Service Provider G and her agency, who consistently argued and lobbied the hospital over a period of months and put forward the view that Graham was physically unsafe at home and action should be taken for him to go to residential care. It is not until a critical event, a severe burn, forces an alliance between them that the power dynamics altered and realigned.

The data from Graham's central socio-legal encounter also supports the argument that people's dignity can be subservient to resource allocation through market forces discussed in Chapter Two, which can prevent an individual from articulating their own needs (Lloyd, 2004). Graham, instead of having choice between providers and a package of care to meet his needs, was eventually excluded from service delivery.

Before moving to the next basic theme, it has been shown here that there are complex underlying power dynamics inherent in the five socio-legal encounters and these affect the alliances made in the constantly changing process of decision-making. This research study takes some of the concepts on alliances referred to in the literature further by applying these concepts to complex case studies where many players are interacting. Some of the challenges in social work practice have been identified in the processes in the research study cases such as recognising power dynamics and possible alliances that may be formed within and across the professional and private contexts, the contrasting impact of a ward or community environment on the individual social worker's perceptions, the role of service providers in the interactions and negotiations, and the significance of how a family member who is identified as a main carer by professionals is perceived.

### **5.2.2 Professional context influences decision-making**

Professional participants had a variety of different roles, professional backgrounds, and agency contexts which influenced their decision-making process. Although practising under the same public legislation and policies, different interpretations of these were revealed. The social workers and service providers in the socio-legal encounters did not specifically say that they practised case management techniques. However, in a document included in the analysis, in Maria's socio-legal encounter the role of the Community Options Program was described as "to provide case management/care coordination to people with complex care needs including people with dementia" (Midwest Community Care Inc., 2011). Similarly, services provided by a community age care package are identified as being "CACP case management" (Department of Health and Ageing, 2006, p. 18) whereas the role of the ACAT was seen as one where the overall care needs of frail older people were assessed in order to gain access to services. Here clients, significant family members and service providers, need to be involved in the "assessment and care planning process" (Department of Health and Ageing, 2006, p. 1). What is significant is that case management or a care planning process has diverse meanings in the two different professional contexts of the social workers and service providers and this presents one of the challenges this research was designed to explore.

Until 2013, in Australia the *Aged Care Act 1997* and its *Principles*, an Act of Federal Government, provided the legal framework within which the social worker participants in this study practised (Department of Health and Ageing, 2006). This Act governed residential care and aged care packages where the main areas of regulatory control were funding services, allocating aged care places to approved providers, assessing client eligibility and other areas such as handling complaints. One of the main roles of the social work participants was assessment of eligibility for the services provided by these packages in the home, and for residential care. If approved for a package of care by a delegation process, which was guided by principles and interpretation of these principles in legislation, the person approved was referred to a service provider to provide the direct home support. In the research case studies there was no continuity between what is assessed as needed by the social worker as part of an ACAT, and what is provided in the aged care package by the service provider.

The three service providers who provided aged care packages in the research case studies also practised within the guidelines and principles of the *Aged Care Act 1997* where the aged care packages program was administered by the Federal Department of Health and Ageing. However, Maria's research case study contrasts to this as the legal framework within which the service provider practised is *The Home and Community Care Act 1985*, which governed the provision of support services to older people who live at home. This program was administered by the State Government, the NSW Department of Ageing, Disability and Homecare. Service Provider M's agency was a Community Options Program. As such this program allowed the agency to assess potential clients and allocate their services on a prioritised basis within their budget. This contrasts to access to care packages which are restricted to those assessed as eligible by the ACAT which included the social worker participants in this study.

All four service provider agencies were large social welfare organisations that delivered multiple programs alongside of the aged care packages and community options program, such as residential care, in-home respite programs, domestic assistance and dementia support. The two community care packages and one extended aged care at home package in the current study were provided by agencies of differing religious denominations in the private not-for-profit sector. The fourth agency, the community options program was a not-for-profit organisation governed by a community based management committee drawn from the local community and elected annually by the general membership. Each social welfare organisation had its own culture, organisational structure and policies which led to complexity at the interface of decision-making between the social workers and service providers and affected the alliances formed through different expectations of the role of the social worker and service provider.

The individual service provider's case management role was coordination of the management and delivery of direct home support within the care package or community options program. As outlined in an audit by the Australian National Audit Office in 2006 the Department of Health and Ageing had very limited information on how providers deliver case management services because the program was run "at arm's length" (Australian National Audit Office, 2006/2007). So how individual providers understood and discharged their responsibilities determined the quality of the program and although the providers are required to perform care planning, care coordination and case

management on an individual basis, it is very unclear what this means and is open to wide interpretation in practice. This results in variable quality across the system.

Within this system of welfare provision a contrasting issue in the socio-legal encounters was how the role of the social worker was perceived by the service provider. In the research case studies of Graham and Albert, the responsibility for taking action to limit an individual's ability to make their own decision regarding accommodation was expected of the social worker, thereby positioning them as an enforcer. Service Provider G's perception of the role Social Worker G was that she and the treating hospital team were responsible for taking action to lodge a guardianship application due to perceptions of high risk factors in Graham's life at home. In Albert's research case study Social Worker A described how the service provider referred back to her, as enforcer. She said:

*CACP [Community Aged Care Package] Coordinator continually have said "you've got to do something." I know, or I feel in myself, that this is an unsafe situation. He's not only at risk of neglect by himself, but of, well it's not a financial abuse yet... (Social Worker A)*

Albert's neighbour and his deceased wife's friend also turned to Social Worker A to "do something":

*Because I've had the friend saying "You've got to do something." The next door neighbour is a physio in aged care and says "You've got to do something." (Social Worker A)*

This reflects assumptions regarding the differing roles and dynamics of power in the alliances but also at a societal level that social work practice can be seen as controlling people in the interests of social order. This also brings to the fore a key link with ethical issues which is the focus of the third global theme presented in the findings and analysis of this study. However, as discussed later, not all the service providers perceived the responsibility for initiating an application for guardianship as the role of the social worker, which reveals the variability in practice contexts. Service Provider A and Service Provider M both took responsibility for lodging applications. However, for Service Provider M this was after lengthy negotiations with Maria's spouse and Social Worker M. Social Worker E, whilst not in negotiation with a service provider, took responsibility for



lodging an application. Service Provider J was in a unique contrasting position as there was no current social worker involved.

Another factor in the decision-making process for professionals was that within the Australian policy context described previously, the services offered by the service providers' agencies were what was available from the agency's perspective, not what was perceived as needed by the consumer - the person who was the focus of the research case studies and their family - or the social worker. In Graham's central socio-legal encounter this was particularly relevant as what was offered to Graham in the community aged care package did not meet his needs by enabling him to remain at home and he had no continuity in changing from a low care package to a high care package.

Service Provider G's agency did not provide high care packages and she saw her service as being inadequate in meeting Graham's support needs from her first interaction with Graham and his wife, Gillian. However, Graham had been assessed as needing a low level of care by the assessor hospital team and this referral was accepted by her agency, so this placed her in a difficult situation. She said that, due to a boundary mistake, Graham was assessed by another coordinator, and she:

*...ended up with him and he was signed on without me actually knowing. (Service Provider G)*

In efforts to maintain Graham at home Service Provider G referred back to the hospital assessment team for a reassessment to get a high level package of care allocated to him. But once he was approved as needing a high level of care, two other service providers refused to accept the referral for a high level package as he was perceived as not having a responsible carer and also because of the presence of occupational health and safety issues. Service Provider G said:

*When the EACH [Extended Aged Care at Home] provider assessed of course I had had the carpet steam cleaned and I had everything looking nice when she arrives. And of course the carer is in there doing the shopping etc.... The EACH package only had to look after him. No, they just said it was a big OH&S [Occupational Health and Safety] problem... she said that, because they get a lot of takeaway food ... because of his diabetes and the bathroom was not set up properly for showering, because he is noncompliant with his diet, yada, yada, yada, they won't come in and*

*I followed her up the driveway and she said, you know, "it's an OH&S problem for you too ... it's just been good luck that you haven't had an accident." I said "it's more than good luck." And she said, well "I would say it's more good luck than good management." So I just looked at her and turned around and went away because I was very annoyed at her. And to think we had been struggling for three months to get this person to say no. (Service Provider G)*

The irony is that the wellbeing of the workforce was prioritised over the wellbeing of the individual. However, as outlined in the guidelines derived from the legislation, the purpose of the agency was to provide direct assistance of home help, personal care and management of social and safety issues that arise at home. The factor common to all packages was described as being that they will provide a coordinated package of care to meet the complex needs of the individual (Department of Health and Ageing, 2006, p. 18).

The different agency contexts and perceived professional roles also influenced how the service provider made the decision to apply for guardianship. In the central research case study Service Provider G did not see an application for guardianship, and coordination of this, as her role. Her action was to lobby the hospital and community social workers to do this. As outlined, she felt that the resources of her service were not suitable:

*I kept saying we were there because of humane reasons, that really they were a mental health issue, until they became a certain age and then instantly a community aged care package. Well, they weren't really, never. (Service Provider G)*

Until the critical event for Graham, a severe burn resulting from a hot water bath, forced an alliance between Service Provider G, Social Worker G and the treating hospital team, Service Provider G was placed in a negative position where she was vulnerable and powerless. Prior to this event Graham had been admitted to hospital multiple times over an 18 month period. Service Provider G said:

*...because he burnt himself the last time at home. And this was the ninth time [admission to hospital]. Last time they had managed to get him to a nursing home, and the Director of Nursing kept on ringing me going ... because she tried to get some sort of tribunal going but no-one was coming to the party then. And it wasn't until Dr [geriatrician] decided, let's fix this problem. And I think when he hurt*

*himself in the bath that was the leverage for them to say well maybe he's not cognitive you know, maybe he's not making informed decisions. It's like, hello, I've been saying this to you... (Service Provider G)*

In contrast with this, Service Provider J was clear in her role regarding taking responsibility for an application for a legal decision-maker to be appointed and this placed her in a more powerful position:

*I'm the case manager. It's my responsibility to do it. (Service Provider J)*

In Jane's socio-legal encounter, Service Provider J was the applicant and she formed an alliance with a hospital community geriatrician for supporting documentation to present to the Guardianship Tribunal. This was a cohesive alliance where Service Provider J took the initiative regarding the application. As with Graham's central research case study medical authority vested in a geriatrician and detailed accounts of physical risk were dominant in the decision of the Guardianship Tribunal to appoint a legal guardian to make decisions regarding both Jane's accommodation and a legal financial manager. Service Provider J said that she did not have the resources to enable Jane to remain at home as she frequently "wandered" looking for her son.

Lastly, within the context of the service providers' agencies, the professional backgrounds of service providers varied and so differing expertise was brought to each research case study. This professional background can be influential in decision-making where there is no consistent role in who should be the applicant to the Guardianship Tribunal and agencies had differing organisational expectations of their employees. Both Service Providers G and M had certificates from welfare courses through the Department of Technical and Further Education. However, Service Provider G's actions revealed that an application for guardianship was not seen as her responsibility, whereas Service Provider M was willing to take on the role as applicant and negotiated with Social Worker M around this. In contrast to this, in Jane's socio-legal encounter Service Provider J was a registered nurse with an experienced history in working as a coordinator of aged care packages and this agency had a policy of employing experienced registered nurses to coordinate both their community aged care packages and extended aged care at home packages. Service Provider J took pride in her agency:

*I mean, we've got some really, most of ours are pretty difficult. They've come to us for a particular reason. They know that we'll put the big hours in. They know that we'll put all the equipment in. They know that we'll try hard to make it work.*  
(Service Provider J)

Service Provider J related that extended aged care at home packages have a professional nursing component in the service provision as they are designed to meet the needs of people who require higher levels of care. Community aged care packages do not have this provision as they provide a lower level of care and so an individual agency, at the time this study was undertaken, can employ from whatever professional background they view as appropriate.

With reference to the literature, Chapter Two highlighted the argument by Biggs and Powell (2001) that there is a growing reliance on complex systems of managerialism, leading to social workers becoming risk-assessors and enforcers. This study generally supports this assertion. The perception of social work can be about controlling people in the interests of social order (Banks, 2006; Howe, 1994). In Chapter Two, the double perspectives of social work benevolence and social control (Biggs & Powell, 2001) or external coercion and personal cure (Howe, 1994) were identified as pertinent to the primary research question of this thesis concerning the challenges in social work practice in socio-legal encounters. These contradictory characteristics are evident in the findings of this study and the notion of the social worker being perceived as enforcer draws attention to this challenge.

The confusing system of welfare provision to older people in Australia outlined in the data in this theme has some strengths and weaknesses which are outlined in a report by the Productivity Commission produced in early 2011, whose brief was to systematically review the social, clinical and institutional aspects of aged care in Australia and develop options for reforming the funding and regulatory arrangements across residential and community aged care (Australian Government: Productivity Commission, 2011, pp. 3-4). This report acknowledges that there has been an increase in the range and quality of care and support available to older people, and the workforce is generally appropriately skilled and dedicated although there are shortages. However, consistent with the findings in the five research case studies reported on in this study the Productivity Commission also found that there are delays in care assessments and provision, discontinuous care across

packages of community based services, quality of care is variable and choice of provider is not an option for consumers (Australian Federal Government: Productivity Commission 2011).

In this study social workers and service providers in the socio-legal encounters did not specifically say that they practised case management techniques, however many of the issues arising for them are consistent with the critiques of neoliberal reforms discussed in Chapter Two. These include being situated in contexts where there has been a move away from an emphasis on helping, trusting relationships to a service orientated approach. The impact of where the needs of people and their dignity become subservient to privatisation's market principles (Connell, Fawcett, & Meagher, 2009b; K. Healy, 2009; T. O'Connor & Sacco, 1993; Phillipson, 1994; Powell, 2006). In this study the aged care assessment team social workers, whose role was to assess and coordinate care plans, saw a gap between these plans and what was put in place as a package of care by service providers. In Service Provider G's example what was implemented was viewed as inadequate by the aged care assessment team.

In the service provider agency contexts, a critical and differing bottom line was the availability of resources to provide services. As noted in Chapter Two, M. Hughes and Heycox argue that a contemporary challenge in the Australian context is that though governments have a reduced role in delivering service, they still exercise control by providing funding to service providers, setting terms of service contracts and requiring agencies to compete with each other in the tendering process (M. Hughes & Heycox, 2010, pp. 8-9). They describe the impact of this being that workers may be more concerned with service delivery and competition than with lobbying and advocacy. This is consistent with the research case studies as service providers can accept or reject cases that are referred to them by the ACAT. This demonstrates how competing agencies can self-select cases, and in the central research case study reject a case that is considered to have perceived risk factors that are too high from the agency's perspective. There is no obligation on service providers to provide a service to those who are referred.

The disparity in service providers' professional backgrounds is congruent with what Healy describes as an increased reliance on, and transfer of responsibility to, the non-government sector evident in new public management and the employment of staff based on abilities to perform specific tasks (K. Healy, 2009, p. 403). Significantly, K. Healy

argues that these tasks can centre on risk reduction and the standardisation of risk assessments where the individual worker's capacity to engage with problems and find solutions is downplayed. This is congruent not only with the findings and analysis in this section but also regarding different and changing knowledge bases presented in the second global theme where there are key links between the modernist notions of risk and risk assessments and the process of decision-making.

Before moving to the next basic theme, what the research case studies show is the organisational complexity and fractured nature of services which influences how decisions are made by both service providers and social workers within the professional context. This clearly presents a challenge in social work practice in socio-legal encounters and as such addresses the first of the subsidiary questions in this study regarding the process of interaction and negotiation around issues that may necessitate an application for guardianship/financial management. The significant role of service providers is also brought to the fore. This organisational complexity and fractured nature of services also revealed tensions and/or collaborations in the alliances formed. The implication for social work practice is that in complex social situations where services are involved assumptions cannot be made about individual professional roles and negotiation is necessary in each individual case. This is significant in addressing the second question posed in this research as attention is drawn to the values and tensions revealed in the process.

### **5.2.3 Private context influences decision-making**

In the analysis of the previous basic theme the emphasis has been on how decisions are made in a professional context. This basic theme, that the context of family relationships influences decision-making, concentrates on the influences on decision-making from the private context of family relationships and the person who is the focus of the research case study. Here, it will be seen, decisions are commonly made through personal knowledge built on shared understandings of personal experience and needs.

Private contextual influences in decision-making are particularly relevant in explaining how the differences and commonalities between cases are accounted for in the overall analysis. As outlined in Chapter Four Graham's research case study was selected as the

central encounter from which to identify commonalities and differences in the subsequent encounters. The differences identified in initial case selection were lack of family support, or perceptions by social workers and service providers of family support not being responsible; financial and inheritance issues; who lodged the application for guardianship or financial management, and the progression of the encounter to a hearing. These differences generally accounted for the precipitating factors for the hearing but in the overall analysis it was found that many commonalities were reflected in different ways. For example the significance of family engagement is a commonality evident in all encounters played out in different ways. Graham's wife was perceived as not making responsible decisions and his two children were not engaged in the encounter. Edward's family were supportive but were unable to make decisions. Maria's encounter revealed strong support in the form of her partner. Jane's son was perceived as not responsible and other family support absent due to family conflict. Albert had no family support as his wife had recently died.

Similarly the relevance of how support services engaged with those in the private context is a commonality played out in different ways. Service Provider G was engaged with Graham continuously for a period of twelve months before the hearing and Social Worker G had intermittent contact with him during this time culminating in the current hospital admission when the hearing took place. Social Worker E was engaged with Edward for approximately three months before the hearing. She felt she could not refer to services due to the condition of his home. Maria had a history of intermittent contact with services. Service Provider M had been engaged for approximately eight months before the hearing and Social Worker M for three months. Jane's provision of services by Service Provider J's agency was the most consistent in all the encounters, where she had progressed from a CACP to an EACH. The CACP was co-ordinated by another employee of the agency whereas Service Provider J had co-ordinated direct services to Jane, as an EACH, for two years prior to the hearing. Social Worker A had been engaged with Albert for approximately nine months before he was admitted to hospital and moved to a residential facility. The service provider in this encounter was not interviewed but had been engaged tenuously for an approximate period of seven months before his admission to hospital.

For service users, assessments for support services at home by professionals meant opening up to the scrutiny of others their relationships, living preferences, values and beliefs. In the research case studies a variety of professionals entered into private lives. These included social workers, service providers who coordinate the assistance given, paid carers who provide this assistance, dementia support workers, home modification workers, Meals On Wheels workers, occupational therapists, physiotherapists, geriatricians, and ambulance workers. These professionals brought their own perceptions and built their own narratives about what was happening in the individual case studies.

In Maria's research case study Service Provider M described how she organised Maria's support services to assist Maria and her husband, Bill:

*We brokered the personal care first of all for three days a week ... we got the occupational therapist to come in, and they looked at the shower and made recommendations to home mods. ... I referred them to a laundry service and that was helping Bill a great deal because he wasn't happy to wash the sheets every five minutes ... We spoke about a personal alarm as well ... Because Bill sometimes left Maria by herself and he would go off, so even although she had no idea what to do it was something ... I organised some respite as well, I referred to a dementia respite service but they didn't have any vacancies so I organised some brokered short term respite to go in, and that was great, it was the same service that provided the personal care. And so we were monitoring how those services were going. And then once the dementia respite service started, actually, Bill found it difficult, or Maria found it difficult, because she, I don't quite know the reason why, she ended up following Bill around rather than staying with the care worker, so we couldn't understand that. (Service Provider M)*

However, for Bill, the services offered by Service Provider M meant that he was also open to regulation of private matters:

*They sent someone on Mondays, one hour, for her to have a shower. On Wednesdays they had somebody here that came for three hours to have a shower and then one who came here actually just sat here with Maria. And then I could go do shopping and things like that, you see. And then on Friday they had ... there was one hour. That was the arrangement, it was actually pretty good. But, you know, it*



*makes your life very regimented ... We had Meals On Wheels, I had to sit each morning waiting for Meals On Wheels. You know, after you've had your freedom, sitting there and somebody brings the meals.... We did eat it, I mean it wasn't that good, but we did eat it. (Bill)*

For Bill another unexpected consequence of the decision-making process also meant that, as he was appointed Maria's legal guardian and financial manager, he had to begin to deal with more public regulation of private matters. Although Maria received a pension, Bill had never applied for one and they had maintained their finances separately. Financially he provided more in the relationship. He explained how, because of the expectations of the regulating bodies his and Maria's finances were now pooled together as a couple and he was required to apply for a pension. In applying, Centrelink required that, as he was eligible for a small pension from his country of origin, he must apply for this. When he received the papers to fill in he needed to list his employment history in that country and places where he had lived for the first ten years of his working life. This caused him great stress. Combining finances also meant that as he had acquired more money than Maria, he had less to spend on a move to an independent living unit in a retirement village. He said that after living intimate but separate lives:

*Anyway, I finished up being a spouse ... so I got the guardianship and the financial management and I was actually quite pleased, until they sent me all these papers. Oh my God, they're swamping me with papers and all the orders of what I have to do ... they said you've got to preserve the capital. My will says everything goes to Maria and her will says everything goes to me. So to preserve her capital, it only goes to me. And I don't care if it runs down or not, who's to worry? But if her capital runs down, once it gets to about \$90,000 then the government puts more money in to make up for the fees... (Bill)*

Bill went on to describe very complex financial arrangements regarding payment of fees. He had several public regulatory bodies to negotiate with. Unfortunately, Maria died three months after her admission to residential care and this increased his feelings of ambivalence and guilt about his role in the process of decision-making.

The central research case study demonstrates how Graham and his wife, Gillian, shared a common need to protect their lifestyle. They were consistent in their wish to remain

together at home. The only way they could maintain some power and signal their joint decision to professionals was to physically act in a way to try and maintain their shared lifestyle. They did this by being "noncompliant" with medical authority. Prior to the critical event and subsequent guardianship proceedings, Graham discharged himself from hospital and a nursing home against the advice of a geriatrician and other hospital team members, including Social Worker G. Social Worker G is very careful in her discourse with Gillian during the current admission to hospital, when the application for guardianship and financial management was made, as she expressed a fear that the couple would make the decision for Graham to return home again before the guardianship hearing, against the treating team's advice. She said:

*I was cautious in how I explained it to her because I didn't want to get her agitated to the point where she'll jump in a taxi and come and take him from hospital, which is what's happened in the past. (Social Worker G)*

This action is interpreted negatively by the hospital treating team as lack of insight but to Graham and Gillian it was perceived as the strength of their relationship and a joint decision. In this central research case study Graham and Gillian's strategies were a form of resistance to the dominant power of professionals, particularly medical authority vested in a geriatrician, but eventually the power dynamics show that the voice of professional power was too strong, particularly when combined with the legal system of guardianship.

In the other research case studies the strength of relationships and the wish to maintain valued lifestyles perceived as normal for the individual were shown in the discourse surrounding the decision-making. Edward's sister, who was able to assist him in making decisions about his finances, was not involved in the process at the start where initially Social Worker E assessed the situation as:

*Services would not go there. They just wouldn't go into that house, so I was faced with a man who was going to be left on his own without resources, nowhere to go and no one to care for him. That was the first interview. (Social Worker E)*

As stated earlier, although initially Social Worker E could not identify a family member to assist Edward and share responsibility with decision-making, family members were supportive and available and the relationships were strong. The Guardianship Tribunal

noted "that Edward's extensive support network was present to support Edward." (Order and Reasons for Decisions made by the NSW Guardianship Tribunal). Edward's children, ex-wife, neighbours, sister and solicitor were listed in the Order and Reasons for Decision as being present at the hearing. In Edward's research case study neighbours also came under scrutiny in the process due to concerns about financial exploitation. They also attended the hearing and the tribunal reported: "Edward's neighbours do not have an interest in Edward's property ... Edward and the neighbours own adjoining properties which were put on the market collectively so that a bigger parcel was available for purchase." (Order and Reasons for Decision made by the NSW Guardianship Tribunal)

However, from Social Worker E's perspective this was an issue that led to her decision to continue with the application for guardianship and financial management as if she had withdrawn this would appear to endorse Edward's decision to sell his property with his neighbours while appearing uncertain of any details. She said:

*and he said, "Oh, yes, my mate, the neighbour, ... [named neighbour], he's running with it all." Well, I didn't know who [the neighbour] was. They were talking about the fact that they were holding out for something like \$4 million for the property. They were throwing all these figures around and I thought, whoa, this is getting – this is out of my league. This is not just a little pensioner man who I can help for a little while and deal with Centrelink. There's a lot of money here. He's very vulnerable to being ripped off and if he doesn't quite know some of his business dealings ... [the neighbour] might be great; but he might not ... I think it was because of the money, there was so much involved and because he was so vague that I was really concerned. (Social Worker E)*

In Edward's research case, from his perspective, trust in his relationship with his neighbour and sister was an established and a normal part of his lifestyle. However, from the perspective of professional decision-making, for Social Worker E professional responsibility is perceived and enacted. She described possible financial exploitation and professional repercussions if she was not perceived as acting to protect a perceived vulnerable person.

In Maria's research case study Bill's ambivalence about his continuing ability to care for Maria, and the decision to place her in a nursing home, was driven by his longstanding

relationship with her. In contrast, Social Worker M and Service Provider M make the assumption that residential care is the best option based on professional assumptions of what was seen as a safe physical environment. This is an assumption that is also reflected in the other research case studies by social workers and service providers. In her behaviour Maria contested this as she felt safe with Bill. From Bill's perspective as Maria's longstanding partner, the possibility of her going to a nursing home raised very conflicting emotions centred on the personal risk of losing Maria. He said of Service Provider M and Social Worker M:

*and then they wanted her in a home ... [the service providers], they kept pushing it. They sent ... [Social Worker M] ... and they wanted to talk her into going to a home. (Bill)*

In this study the consequences of a move to residential care of a partner resulted in sadness, loneliness and irreversible loss. There was a perception of a life finished and the biggest risk eventuating. In the central research case study Graham's wife remained at home. She said:

*We've been married a long time now and you get used to each other and it's very hard to have to say "Well all of a sudden you're married and you've got a wedding ring but you're still not married you can't live together," and I don't know if I'll get back again, this life that we're leading at the moment. I don't like to think that he's in one building and I'm in the other. (Gillian)*

Similarly, Maria's partner Bill said:

*still if I turn the radio too much, I think... "Oh, I'm still thinking about Maria," and think, "Oh, I might wake her up on the morning." I still think I have to look for her if she's not there, so not used to it..." (Bill)*

From the social work perspective, this basic theme encompasses the ultimate challenge in understanding the formation of alliances within and across the private and professional contexts, as it raises the issue of the rights of the person who was the focus of the research case study. In the Introduction to Chapter Three the primary research question regarding social work challenges in socio-legal encounters is consequential to the question of what it means to be a person with dementia in the Australian context if

decision-making is challenged. Recent literature suggests that the perception of personhood or identity of a person remains despite changing abilities. Evident in each case study, the sense of the person making efforts to sustain their sense of self can be seen. In the central research case study Graham actively tried to sustain his personal identity despite disempowerment. He and his wife hired a solicitor to represent them at the hearing of the NSW Guardianship Tribunal. He said:

*...far as I understand it's all lies, I don't need a guardian to look after me and I don't need one to look after my money, I'm very capable of it ... They want to [mumbles] about making decisions see, I can't ... that. So I am going to defend myself. (Graham)*

Attempts to sustain a sense of self were also evident in the other research case studies. For example, Maria's husband described how she has always "picked away at people," meaning being very critical, and this pattern continued at the nursing home, where she made critical remarks about other residents. Jane rejected that her second son and daughter-in-law were in a position to provide her assistance due to a long-term pattern of conflict in the family where she has been closest to the son who still lives with her. Albert's sense of self can be interpreted as relating to his country of origin. Social Worker A said:

*He has no family in Australia, but he does have nieces and nephews—actually his wife's—back in his country of origin, and he wrote to them after his wife died and started sending them money. So they wrote back saying, "You're very welcome over here, come over here." So he's like one minute saying "I want to go back," and the next thing he'll say "I'm going to stay here but send them over things of my wife's and all I need to do is to pack it up and send it to them, or maybe they could come here and look after me." (Social Worker A)*

However, Social Worker A constructed this as Albert being vulnerable to possible financial exploitation, as he was sending possessions and money to his wife's family members.

The overall finding of this section, that decisions were commonly made through personal knowledge and shared needs, supports recent studies discussed in Chapter Three where, for example, Purves and Perry (2009) found that attention should be given to the way in

which family itself is understood and represented. D. O'Connor and Kelson (2009) found that decision-making was a dynamic process taking place within a relational context, and Clarke (1999b) found that 'family' emphasised the continuance of their relationship with the person with dementia. A theory of normalisation was identified where families engaged in a process of continually defining and redefining their lives together as normal for them. In this study Graham and his wife Gillian continued to define their lives together as normal, and acted on shared needs, despite the impact of the health, welfare and legal institutional systems.

Bill's account of acknowledging the benefits of services, while weighing up the disadvantages, supports the findings of Lloyd and Stirling referred to in Chapter Three, that there can be "ambiguous gain" in that unexpected outcomes of service delivery can result in increased uncertainty and a reduction of wellbeing of the individual and family. They argue the home itself confirms identity as a symbolic resource, and with the increased activity some mastery of the home is lost (Lloyd & Stirling, 2011, p. 899). Bill's experience is also congruent with the observations by Clarke (1999b) that tied up in family relationships are risks associated with the biography of the individual and the interpersonal aspects of the relationship. These perceived risks can include services inside and outside of the home that may be seen as a substantial threat and this perspective may not be congruent with the needs identified by practitioners (Clarke, 2000, pp. 91-92). For the spouses, Gillian and Bill, a major identified risk was the loss of a lifelong partner. Similarly, Bill's experience in managing Maria's finances was consistent with the research of Tilse, J. Wilson and Setterlund (2009), who found that older people commonly identified the importance of managing their finances within the context of family relationships where the maintenance of relationships had priority over the quality of asset management.

The assumption made by social workers and service providers that residential care is a safe environment, is a significant finding as the assumption can be challenged. A recent study found that meal sizes for men in fourteen hostels, or low level care facilities, in metropolitan Melbourne were not large enough. For both men and women meals did not include enough vegetables. Sixty-five percent of residents showed signs of malnutrition and were not being given enough protein. Only eleven of 103 residents showed no signs of malnutrition (J. L. Woods, Walker, Juliano-Burns, & Strauss, 2009). A Report on the

Operation of the Aged Care Act found that in 2008-2009 the Australian Department of Health and Ageing was notified of 1141 alleged assaults in nursing homes, including unreasonable force and sexual assault. Additionally, 367 police reports were made over missing residents and twenty-seven residential care facilities were sanctioned for serious breaches of the aged-care regulations which ranged from assault to malnourishment and poor hygiene (Commonwealth of Australia, 2009). While there are explanations for increases in these figures over the previous year, such as increased numbers of spot checks and reports being allegations rather than substantiated abuse, the figures show that not everyone is safe in residential care. There are many high quality residential care facilities in Australia, however the figures do challenge the blanket assumption made by the professionals in this study that residential care is safer than the home environment. This adds new knowledge that may be identified as a challenge in social work practice.

That Graham's sense of identity was not congruent with the dominant professional discourse fits with the observations made by J. C. Hughes and Baldwin (2006) discussed in Chapter Three. They argue that decision-making is linked to ethical issues and it should not be accepted that a person with dementia is not the person they used to be, despite the prevalent public paradigm of dementia being a "living death". J. C. Hughes also argues that while a person's agency may be whittled away, the life-history and notion of a situated self emphasises the context and the external factors that go to make up a person (J. C. Hughes, 2001). If applied to this scenario, Graham's coping strategies may reflect long-standing patterns of responses which make up his sense of self. Graham's various different social personae, attributes and beliefs about these attributes of himself can be viewed as being compromised by the actions of professionals. His sense of self, Sabat (2002a) would argue, needs to be constructed with the cooperation of others. In the research case study Graham tried to maintain his sense of self but this was not maintained by others which placed him in a negative social position in the decision-making process.

What is significant regarding the influence family relationships have in the decision-making process is that from the social work perspective, taking into account identifying the challenges involved in socio-legal encounters, there is a need to understand and interpret to other professionals the interconnectivity of personal and family decision-making, the loss and grief involved in separation and the meaning of unexpected

consequences for family members. Challenging underlying professional assumptions, such as residential care being a physically safer option, may also be viewed as relevant to the values and tensions in the processes involved. As raised in Chapter Two, Philp (1979) argues that social work can present a picture that is not immediately visible to others and this is a role that differentiates social work from other professions. This may be viewed as crucial in relation to the challenge for social work practice, raised in the Introduction to this chapter and Chapter One, that it is paramount to ensure that all the participants views are taken into consideration in decision-making.

### **5.3 Summary**

This chapter has predominantly explored the process of decision-making and associated interactions and negotiations surrounding issues that are viewed as relevant by the participants in the five socio-legal encounters. There has been a focus on the values and tensions that underpin the decision-making processes that brings to the fore different assumptions made by the participants in the professional and private contexts. The findings reveal dynamics of power reflected in the relationships and the alliances formed in the five research case studies. The significance of the impact of current neoliberal policies in the Australian context and the professional participants' roles, backgrounds and agency contexts which influence the individual professional's decision-making process have been explored. The influence on decision-making of important personal relationships and the connectivity of people in the private decision-making context has been shown as significant, as has the sense of the person to sustain their identity. The following chapter presents the second organising theme which extends the analysis of the process of decision-making in that the focus is on the different knowledge bases that underpin the processes outlined in this chapter.



## Chapter Six

### **6.1 Constructions and reconstructions – how knowledge bases differ and change**

This is the second chapter of the integrated presentation of the findings in the context of the literature review. This chapter relates to the organising theme which encapsulates the meaning, constructed by the participants, about dementia and capacity. These individual knowledge bases support the process of decision-making and shifted and changed, the impact of critical events and constructions of risk and capacity being crucial in this process. This organising theme therefore relates to the different knowledge bases in the private and professional contexts that drove the processes explored in the previous chapter. This organising theme can be seen as relating primarily to the third and fourth research questions the study was designed to explore, these being the impact of how dementia and incapacity were understood and the assumptions made in these understandings. However, there are key links to the other organising themes in that different knowledge bases affected the formation of alliances and reflected underlying power dynamics, which were evident in the processes of decision-making explored in the previous chapter. Values and tensions behind decision-making were embedded in the alliances formed and perceptions of critical events and capacity. Similarly the ethical issues raised by participants when negotiating action was linked to how dementia and capacity were understood.

This chapter is again structured through the basic themes that support this distinct organising theme. These basic themes are:

- Knowledge about the person and dementia are different.
- Critical events impact on how knowledge is constructed.
- Knowledge about risk and capacity is fluid and situational.

As with the previous organising theme, there is some crossover in the analysis to provide an integrated presentation and within each basic theme the findings of the study are presented before moving to discuss these in relation to the relevant literature.

### **6.1.1 Knowledge about the person and dementia are different**

This basic theme explores participants' knowledge bases regarding dementia in the research case studies. Whilst the previous chapter focused on the formation of alliances, this basic theme takes this further by deconstructing the status of the different knowledge bases in the socio-legal encounters and the consequences for the participants in terms of their ability to affect action. The research case studies show that professional expert knowledge is more highly valued, and therefore dominant, over the less valued personal or family perspectives in the private context. Consistent with the findings and analysis of the previous organising theme, the most legitimate voice heard is that of medical authority. Of significance is the dominance given to the modernist message that dementia is a disease which results in individual pathology, where the individual has to adapt, and where decline can be measured. The findings show that complexity of decision-making for social workers in the research case studies is affected by the relationships that need to develop across the different knowledge bases. This is one of the challenges the primary research question was designed to address.

The word dementia was used by social workers and service providers as a general term to refer to a perceived number of pathological disorders, including Alzheimer's disease in Maria's research case study, alcoholic brain damage and cognitive difficulties as result of a stroke in Edward's research case study, and a mixture of Alzheimer's Disease and vascular dementia in Jane's research case study. In Albert's research case study it was used as a general term which was not defined further by the social worker or geriatrician she refers to. What is interesting is that in the central research case study Graham's health condition was specifically not identified as a dementia by the social worker. Her discourse referred to Graham as having cognitive problems associated with Parkinson's Disease and not dementia.

These participants did not place any emphasis on a diagnosis of a particular type of dementia and a particular diagnosis was not given any depth in their discourse, nor was it perceived as important as the physical behaviour of the person who was the focus of the case study. What was important to these participants was the expert knowledge of the geriatrician, which was crucial in supporting an application to the Guardianship Tribunal and the presence of a disability noted by the geriatrician. This is because, as highlighted

in the discussion in Chapter Three regarding assessment of decision-making capacity in practice in Australia, at least one doctor's report is needed by the NSW Guardianship Tribunal to provide evidence of the presence of a disability and that, due to this disability the person is unable to make their own decisions.

In Graham's research case study the neuropsychologist's assessment was given dominance in the document produced by the Guardianship Tribunal giving its Reasons for Decisions. The quote from this document outlined below shows that the neuropsychologist constructed an account, from a scientific perspective, of the "truth" of what is going on inside a person. This may be viewed as incorporating the dominant modernist messages of reason and certainty. The document quoted the neuropsychologist's report:

Graham failed to demonstrate an adequate awareness of his health problems, personal care needs and level of dependency on others for most aspects of his daily activities. He did not exhibit a sound appreciation of the risks he faces in returning home without access to support services, nor did he appreciate the full advantages of nursing home care. ... Graham's documented cognitive difficulties and poor grasp of his situation suggested that he is not currently capable of sufficiently taking in, reasoning through or recalling the facts relevant to his situation ... the results of this assessment strongly suggest that he currently lacks capacity to make a fully informed and reasonable decision about his place of residence upon discharge from hospital.

#### Order and Reasons for Decisions made by the Guardianship Tribunal of NSW

For Graham, this presented a dilemma because to demonstrate "adequate awareness" he must accept the perception that a nursing home was the best option for him and make this decision. However, as he wished to remain at home with his wife he did not want to do this. Graham's capacity to make a decision to remain at home was made into a quasi-legal issue which the hospital treating team referred to the Guardianship Tribunal of NSW. The Tribunal was asked to make a decision regarding whether Graham could decide where he would live. If not they were able to appoint an alternative decision-maker to make this decision for him. This legal decision can be enforced by authorities such as the police and ambulance workers. As discussed in Chapter Three, there is no objective test that can conclusively establish capacity, so the Guardianship Tribunal relied on expert medical

and health professionals' opinions to decide that Graham lacked capacity in certain areas. In this situation, the power of expert health professional knowledge informed the decisions of the Guardianship Tribunal of NSW.

In contrast, in the private context, knowledge about a particular person was given priority in the decision-making process. Further, decisions were not dependent on the perceived rational ability of one individual in isolation of others. Knowledge about shared personal histories, social contexts and pre-existing relationships showed that the two spouses who participated in the study did not perceive changes in the person that were always constructed as a problem.

In the central research case study, Graham and Gillian have a shared history since young adulthood and shared concepts and values that are perceived as normal for them. Graham reminisced about how he met Gillian at a bus stop when he was twenty-two, after arriving in Australia with his family, aged eighteen. He saw her as "a shy little thing" which reflected his knowledge of Gillian over the years, not the knowledge of Gillian put forward by professionals at the stage of life she had arrived at in the current time.

Gillian predominantly saw Graham as the person he was in their relationship. This was based on their mutual needs and understandings and what was constructed by them as their normal lifestyle built up over more than fifty years of marriage. Graham was perceived as the knowledgeable person in the relationship. Gillian saw no incapacity. She said:

*I find that I can keep a conversation with him very well and he doesn't fault anything, he still quite wonderful with his brain power. I don't know when the Parkinson's may start to work in on him, I noticed just a wee tremble in his hands but his head is still very head strong, very good. (Gillian)*

When explored further, for Gillian the concepts of dementia and capacity were interlinked. She said:

*I think that the last time I spoke to him he might be leading to one [meaning dementia]. I noticed a stutter when he speaks and he never had that before and I think that the next time, you know the forms that they give you to fill in, a dementia*

*wasn't spoken about on it. They spoke about all the other things he has but I think next time they might somehow have that [i.e. dementia on the form]. (Gillian)*

However, in saying this Gillian was also implying that her personal experience of Graham, and the diagnosis of Parkinson's Disease, had been mediated by bio-medical knowledge and this had shaped and contributed to how she recognised Graham's health. Her knowledge of Graham was shifting to incorporate a deteriorating illness. In this regard, to some extent, it may be viewed that her knowledge had become subject to the dominant bio-medical discourse surrounding dementia.

In Maria's research case study Bill's knowledge of Maria was also mediated by expert knowledge. He related a five year history of Maria becoming more dependent on him where he got angry with her because he felt she was not listening to him. He said:

*Well, I ... you know, let's have a look here at what was happening. Well, she was incontinent both ways, sort of. And I couldn't cope with that too much, she was sitting on ... you know we were using pads and she was sitting on towels and all that. I had the washing line full of towels every second day, it was full of towels. And ... but she wouldn't listen to me anymore either ... (Bill)*

Social Worker M described herself as having an educative role, so Bill could come to understand what was happening with Maria from the viewpoint of the professional knowledge base. She said:

*And then a lot of work went into it Margaret, by the dementia adviser and myself, and then also the geriatrician to explain that this was actually a health issue ... and because he thought she was just being herself and being difficult, he said: "I don't want to make decisions for her because she's going to get back at me." But now that he's understood that no, it's called dementia. (Social Worker M)*

What was also relevant for Bill in decision-making within the personal context was a struggle in trying to meet his own needs, as well as Maria's. He described Maria as "like a Siamese twin" as she was most comfortable in his presence and often rejected the paid care workers. However, Bill's failing health resulted in very conflicting loyalties where his shared history and loyalty to Maria was paramount but he also knew that he could not continue to provide personal physical care. This personal knowledge drove him in

making alliances with Social Worker M and Service Provider M and to the decision regarding Maria's admission to residential care. However, the underlying issues for Bill related to seeing Maria as a person, not definitions of dementia or the cognitive capacity. Also, he did not perceive Maria as an autonomous person in a quasi-legal sense as his needs were bound up with hers. What is also significant to remember is that in terms of personal power in the underlying power dynamics he is in a more powerful position than Graham's wife, Gillian, as he is perceived as a responsible carer by professionals.

In the five research case studies, while private decision-making was based on knowledge within the context of family relationships and shared personal histories, it did not follow that there was an overarching code of societal values used. The values in the private context, particularly lifestyle choices, did not necessarily reflect those of societal and/or professional values because, as demonstrated, the knowledge base used can be different. This is not to dispute that there can be common private and societal values but that there is an emphasis on professionals using expert knowledge as a form of social control where values clash.

To turn to the literature, Clarke's argument that power, achieved through the status of knowledge, underpins the dynamics that are inherent in health care relationships is pertinent here (Clarke, 1999a, p. 23). Clarke argues there can be a continuum ranging from a single highly prized knowledge base which demands compliance, to multiple equally prized knowledge bases which can provide the foundation for working together (Clarke, 1999a). In this study the juxtaposition of the health and legal systems, particularly in Graham's socio-legal encounter, demonstrates that the dominant influence of professional expert knowledge is one that demands compliance in a legal setting. To refer to Hall's argument raised initially in Chapter Three, capacity can be constructed as a legal concept that can involve a determination made by legal means, but after referring to medical evidence among other kinds of evidence (Hall, 2009, p. 121).

The issues discussed in Chapter Three regarding the lack of consensus, even within the medical profession of the use of consistent labels about what causes dementia and its classifications (Forstl, 2005; Krishnan, 2007; Lautenschlager & Martins, 2005) highlight the difficulties played out in the research case studies by the social workers and service providers in their discourse on dementia. In this study these professionals placed little emphasis on the classification of dementia, to the point that classification appeared

irrelevant to them. Conversely, the impact of the biomedical understanding of dementia was paramount. As argued by Clarke, professionals can act as agents for imposing social values where a diagnosis of dementia legitimates their role (Clarke, 1999a, p. 24). This is because the professional expert knowledge was more highly valued, and needed to support an application for guardianship or financial management. Similarly, the quote from the neuropsychologist's assessment of Graham, presented as evidence of a disability, is congruent with Foucault's discourse on the "gaze" of medical power discussed in Chapter Three.

If applied to Graham and Gillian's scenario, Foucault's notion of "technologies of self" provides an interesting insight to the central socio-legal encounter. In order to function as individuals, Graham and Gillian must work on themselves to turn themselves into subjects. As Biggs and Powell (2001) outline, Foucault puts forward that the effects of the relationship between power and knowledge include the tendency for professional power to be reinforced by the sorts of questions professionals ask and the information collected. This knowledge then progresses to definition of problems. As part of this process certain voices become more powerful and increase their legitimacy while other voices become de-legitimised. Out of this relationship between professional power and knowledge comes a construct of individuals simultaneously as subjects and as objects. Graham and Gillian can be seen as subjects and objects of control. This control is played out through the decision-making process, culminating in the guardianship process.

In the literature referred to in Chapter Three, regarding plurality of knowledge surrounding dementia, Nolan and others draw attention to the transformation in thinking of person-centred care but argue that it does not fully capture the interdependencies and reciprocities that underpin relationships (Nolan, et al., 2002, p. 203). The findings of this study, in the private context, demonstrate these interdependencies and reciprocities and also support the argument discussed in Chapter Three that there are new ways of thinking about autonomy in decision-making. This is particularly argued by D. O'Connor, Purves and Downs that "health professionals must be careful about imposing a value system for understanding and evaluating decision-making that is implicitly premised on assumptions that everyone is motivated to be primarily dependent autonomous beings." (D. O'Connor, et al., 2009, p. 206)

What is interesting regarding Bill's description of Maria's interdependent behaviour is that it may be interpreted as what is described by Sabat, and referred to in Chapter Three, as "meaning making" in that although she did not perform well on cognitive tests, the meaning behind Maria's behaviour was consistent with the values held during the decades of her life. She still had capacity for experiencing feeling for her own wellbeing and maintaining dignity and could do this best being close to the person she trusts (Sabat, 2005, p. 1032).

Before moving on to the next basic theme what is important from the social work perspective, and relates to both the primary research question and the third and fourth research questions regarding the impact of how dementia and capacity is understood in these socio-legal encounters, is that the different knowledge bases are acknowledged and interpreted. Assumptions regarding dementia and capacity are made by the spouses which are informed by interpersonal knowledge, where interdependences and reciprocities mean the individual can be placed in situations where they are faced with dilemmas they cannot resolve. For example, Graham's dilemma in demonstrating "adequate awareness" by accepting the best options laid out for him by professionals and Bill's dilemma, in Maria's research case study, of trying to meet both his own needs and the needs of Maria. Similarly, the findings show underlying professional assumptions regarding the prioritisation of the voice of medical authority and orientation to future possible events rather than the person.

### **6.1.2 Critical events impact on how knowledge is constructed**

That "trigger" events can provide some insight into what prompts the decision to plan for a legal decision-maker was raised in Chapter Three. The term "critical" events is seen as more appropriate here as the findings include the perceptions of the person who is the focus of the socio-legal encounter, for whom these events are critical and life changing, as well as those people in their personal context. The findings of this theme show that critical events impacted on how knowledge was constructed, particularly by the professional participants, in terms of action that could be taken. The theme also demonstrates that a critical event can change the alliances within and across the professional and private contexts.



In the dynamics of interaction the language of expert knowledge was used by professionals to force a decision to apply for guardianship and/or financial management. For example, in Maria's research case study, as the point came when the risk to Bill's health could result in Maria being in the home by herself, this risk was perceived as too high and expert knowledge was used to justify the health professional argument. Social Worker M said:

*So then I went back to ...[(named supervisor)] and I said "What do you think?" So ... [(named supervisor)] said "Go back to him and tell him we are the specialists, we are deciding, we think it's time to do it and we shall do it." So when I have that tone with him it changed everything. (Social Worker M)*

This is a clear statement about the application of professional expert knowledge where action is effected by the professionals in the context of a critical event.

As well as being used to force decisions, critical events were used in the narratives of the social workers and service providers to justify the decisions made as, for them, these events consolidated their perceptions of incapacity in the individual who was the focus of the research case study. For these participants, what changed after a critical event was the construction of capacity, not dementia or disability. For example, in the central research case study where Graham burnt himself in the bath, Social Worker G said:

*The problem has been, why we haven't done, that is, because he presents very well cognitively. He performs very well on his mini-mental. Quite often when he initially comes in he's confused because he hasn't been taking his medication ... but he's then still quite unrealistic about how he's actually going to manage ... and the doctors have felt that he's been able to make those decisions so we've let him go each time. (Social Worker G)*

The use of language in the phrase "so we've let him go" reflects the social worker's assumption that the knowledge base of professionals would dominate and guide the action taken after a critical event such as Graham's burn.

In the research case studies social workers and service providers demonstrated that they struggled to try and manage what are perceived by them as "risky situations". There was a perception by these professional participants that a crisis, or critical event, would force

decision-making. In this respect complexity and uncertainty is inherent in the socio-legal encounters but some participants were more comfortable dealing with these aspects than others. In the central research case study, as discussed earlier, the service provider struggled to provide a service she felt ill equipped to maintain for some months and felt extremely uncomfortable about her role. For Social Worker G and the hospital health professionals, the critical event, Graham getting a severe burn in the bath, both forced and justified the need for an application for an alternative decision-maker. This forged new alliances in the socio-legal encounter between Social Worker G and Service Provider G. In Jane's research case study two weekends where Jane left home to look for her son and became lost and could not find her way home was considered the critical event which justified the application for guardianship by Service Provider J. Service Provider J said:

*The client was leaving the home and the person she was living with was not capable of understanding that she needed twenty-four hour care. We had two weekends where police were actually involved ... we tried lots of prompts. We tried to organise the son to leave notes saying what time he would be home, because she was quite capable of looking at her watch and telling what time it was. There were some evenings, some late afternoons, when he went out that we would get ten, twenty phone calls just one after another asking where he was ... when I first started in she was actually calling the police all the time, so I got rid of the police numbers and I put a big note with my number on it so it was me that she phoned all the time. (Service Provider J)*

However, for Service Provider J her discourse shows she felt comfortable with the uncertainty and complexity of the socio-legal encounter. The issue for her was the events described above, which made her course of action clear to her and she lodged an application for guardianship.

Other critical events can be pinpointed in the research case studies. Edward's son went into a rehabilitation program and this forced Edward's decision to go into residential respite care as he did not wish to be alone at home, which had consequences regarding finances and inheritance issues. Social Worker E demonstrated she is comfortable with complexity and uncertainty in that her action to pursue a guardianship application contributed to the complexity of the socio-legal encounter, whereas she may have withdrawn her application when Edward's sister became involved and started managing

his finances. Social Worker A also demonstrated that she is comfortable with uncertainty but in a contrasting way. For Albert, the critical event was an admission to hospital where, Social Worker A argued after the event, he made his own decision to move to residential care. Social Worker A explained how, when she heard Albert was in hospital, she felt justified in advocating to the inpatient health professionals that he did not return home. Her assumption is that the hospital provides a neutral environment for decision-making. She said:

*...as soon as I heard the word 'hospital' I was like, into gear.... I tracked him down and he was actually at Westmead Hospital, which was very fortuitous, because he's on the border and he could have gone to one of two hospitals. I then tracked down the inpatient social worker and I told the story and I said "you must not let him go home. I will write a report, anything you want but do not let him go home." (Social Worker A)*

However, it may be argued that the hospital environment is not neutral; but, rather, expert professional knowledge dominates. For Social Worker A, paradoxically, this admission to hospital provided some certainty regarding action whereas previously she had advocated for not disrupting Albert's lifestyle.

Chapter Three referred to literature which drew attention to the differences in the level of concern expressed by professionals and family members surrounding critical events. The studies by Kjervik and others (Kjervik, et al., 1999; Kjervik, Miller, Jezek, & Weisensee, 1994; Kjervik, et al., 1998; Kjervik, et al., 1993) highlight what they refer to as trigger events as being significant and that there were differences between health professionals and families, or people they identify as informal caregivers, in the criteria used to make decisions. These studies defined a trigger event as a situation where a person, usually a family member, was providing care and surviving on the brink and experienced a breaking point or an event which was "the last straw." This is the point where an application for guardianship was made. The findings here support these studies in regard to the issue that professionals expressed significantly more concern than the person with dementia or family members about these critical events. This previous research is taken further by this study as a critical event can be seen to change the alliances within and across the professional and private contexts and the views of the person who is the focus of the socio-legal encounter were included.

What is important about a critical event is that underlying values are brought to the fore, such as the value placed on inheritance in the family context of Edward, or the values held in the professional context of physical safety. This demonstrates a link to the second research question regarding the values and tensions behind the negotiations and subsequent decision-making. These events create an environment where there is a willingness by social workers to disrupt lifestyles, if by doing this they think it will afford some protection to the person. Critical events also highlight how knowledge is constructed and is pertinent to the third and fourth research questions regarding the impact of how dementia and capacity are understood. Significantly, critical events highlight how the concepts of risk and capacity are interrelated and when risks are defined as high capacity becomes an issue. This is analysed in the next and last basic theme of this chapter.

### **6.1.3 Knowledge about risk and capacity is fluid and situational**

The question of risk, and assessing risk, is significant to this thesis, as it is germane to the primary research question regarding the challenges faced by social workers. Webb defines risk assessment as a "process that assesses the likelihood of harm occurring in the future and tries to predict its eventuality." (Webb, 2006, p. 206) The five socio-legal encounters showed that assessing risk and capacity was interlinked and could be very problematic. Constructions of capacity were mostly based on constructions of risk. It was found that the participants demonstrated different and subjective constructions of risk, and these constructions were fluid and continually redefined. The constructions of both risk and capacity were seen as situational and as capacity became a legal issue in the individual socio-legal encounters once risks were defined as high.

The application of expert health professional knowledge regarding capacity, in Graham's central research case, was based on an assessment of the risk of predicted physical harm. Multiple hospital admissions, due to what are described by Social Worker G and Service Provider G, and the treating hospital team, as falls, not taking medication, inadequate nutrition, and hygiene issues, as well as the critical event of a severe burn, were used as evidence that future physical harm would occur should Graham remain in his own home. These perceived risks could be reduced by services to provide personal support, for example, to reduce Graham's need to mobilise, provide assistance with medications and

personal care. However, Graham was excluded from these services due to perceived high occupation health and safety issues. This is a second "catch 22" for Graham and it questions the modernist interpretations of risk and its scientific underpinning in complex social situations.

Overall, in making physical risk assessments, interlinked with decision-making surrounding capacity, about the predictability of future events the social workers and service providers described dementia in terms of deficits and loss of skills. For example, exhibiting cognitive deficits, such as short-term memory problems, confusion and consequent lack of money management skills or ability to remember to take medications at precise times. They focused on physical behaviours and how they perceived the consequences of these physical behaviours were understood by the person who was the focus of the socio-legal encounter. These physical behaviours, such as loss of money, falls, wandering, lack of adequate diet, were defined in terms of predictive risk in their narratives if they were arguing about the necessity of a legally appointed guardian and/or financial manager. When the perceived predictive risks were high, the capacity of the person who was the focus of the research case study to make decisions became an issue and lack of capacity is constructed around the ability to understand the consequences of physical risks.

What is significant in the socio-legal encounters is that the narratives surrounding risk and capacity were not static but changed and shifted. For example, the data in both Graham's and Maria's socio-legal encounters show that Service Providers G and M refer to the processes associated with providing services. The paid care workers employed by their agencies reported to them their perspective of how the service was meeting the needs of the service users and the perceptions of difficulties they encountered. This added another layer of complexity as more narratives were constructed around the service users as they become open to the scrutiny of others and to the measurement of physical risk. The service provider would then refer to the social worker and this discourse may be accepted as the "truth" or could be contested by offering different interpretations of behaviour or assessment of risk. This could create tensions and changing dynamics and assessments of risk. Similarly, a critical event, as outlined in the previous theme, changed how risk, and subsequently capacity was defined.

In the processes described above social workers and service providers were making risk assessments which established whether or not an intervention or needed resource could be allocated. The central research case study highlights this in that the decision by an alternative service provider, who refused to provide an extended aged care at home package to Graham, was making a powerful decision about resource entitlement with long term consequences. Contrastingly, Social Worker M and Service Provider M agreed on physical risk factors for Maria and were able to work cooperatively. In Albert's encounter Social Worker A made the decision not to act on the physical risk factors raised by the service provider of a CACP until a critical event. However, she had to argue her case for the service provider to continue to provide assistance to Albert as withdrawal was threatened.

This priority of risk over need is a dilemma for service users because to have needs met it seems they must, in some instances, comply with professional expert knowledge regarding minimising physical risk. However, it was found in this study that risk can be a subjective and value-based concept in relation to what is considered an "acceptable" risk. For example, for Social Worker A the risk factors encountered by Albert are acceptable and she made the decision not to lodge an application for guardianship. However, she relates that the same social context is constructed as an "unacceptable risk" by both a neighbour and the service provider of a CACP who lobbied her to "do something" and threatened to withdraw the service.

To support their narratives regarding perceived risks and the linked constructions of capacity, in four of the five research case studies, social workers used the Mini-Mental State Examination (MMSE) score, a well-known thirty-item test intended to screen for cognitive impairment, in their narrative surrounding the individual's ability to make decisions and their claims of a lack of capacity. This test is presented as "true" knowledge about capacity and could be interpreted as reflecting the modernist aim for certainty. For example in Maria's research case study Social Worker M reported the geriatrician's opinion was that Maria's abilities:

*... most likely represented a dementing process with Alzheimer's disease being the probable diagnosis. She scored 14 out of 30 on the mini-mental.* (Social Worker M)

In Albert's research case study Social Worker A quoted the geriatrician:

*...he had an MMSE of 25/30 ... losing two points for the date and day and one for registration, and one for not getting interlocking pentagons correct. He was able to draw a reasonable clock face. (Social Worker A)*

However, the application of the MMSE test is another contested issue. It is often administered in unfamiliar circumstances where familiar routines do not apply and the results show only how an individual responds to a set of questions at a specific time. It is interesting that the MMSE score is so readily referred to as evidence of abilities by the social worker participants. As argued previously, it may be concluded from the issues raised in Chapter Three that there is no standard agreed upon for assessing capacity in Australia.

The grey areas surrounding assessment of capacity are further illustrated in Maria's encounter. Since Bill was perceived as a responsible carer by Social Worker M and Service Provider M they looked firstly to him to make the decision to place Maria in a nursing home, if necessary by legal means through initiating a guardianship hearing as Maria would not go willingly outside the house. However, for Bill this personal responsibility is too large and Social Worker M describes a situation where he agreed one day and then disagreed the next. She said she asked Bill to let her know his decision:

*"Fine, let me know if you change your mind", then he thought about it again and he said "Oh maybe I need it." I said, "Okay, do you want to do it? Do you want me to do it?" He said "Alright, let me think about it." Called him back. "Oh no, I don't want to do it," so just backwards and forwards so often between does he want it, does he not want it? And I thought, I can't be the one telling him you need it or you don't need it because he wasn't doing anything objectionable by her, he was a very conscientious carer, he had the services involved.... (Social Worker M)*

This reflects that for Bill making a decision placed him in a bind as the personal consequences of this decision were too difficult and deeply disturbing. He looked to professionals to make this decision and relieve him of the burden. For Bill it was a comfort that eventually he has certainty in that the responsibility was taken from him by the professionals. The difficult concepts surrounding the weighting process of a combination of variables to make a decision on capacity, and the need for state intervention in this unique situation may be seen as difficult concepts for Bill to grasp at

this stage in his life. As demonstrated in Maria's research case study, in the decision-making process where there was an alliance between professionals and a family member, these grey areas surrounding capacity issues meant that the concept of responsibility, or who should act, became very complicated and stressful and involved lengthy negotiations.

To return to the relevant literature, that risk was a central issue for participants is consistent with discussions in Chapter Two where it was highlighted that risk may be viewed as a major facet of modernity: the development of risk issues is associated with expert knowledge and seen as both measureable and controllable. However, alternatively, risk may also be viewed as subjective. The finding here that professional participants' constructions of capacity were linked to, and supported by, constructions of predictive risk matches the assertion by Hall (2009) that within a legal framework predictive lack of capacity is linked to risk assessments. The participants' experiences are also congruent with the issues raised in Chapter Three regarding the lack of agreement in the Australian context on capacity assessments.

It is noteworthy that the findings in Graham's socio-legal encounter, regarding the nature of assessment of predicted physical harm, can be related to Webb's argument that risk assessments, in general practice, are based on strong notions of predictability and calculation that a future event is likely to occur. These can rely on existing scientific knowledge which is provided by experts. However, he further argues that in social work the assessment of risk lacks scientific rigour, and although some uncertainties can be reduced risk assessment is often based on value-laden assumptions (Webb, 2006, p. 19). The findings here support that in the socio-legal encounters risk is based on variable value positions.

The data shows that when the perceived predictive risks were considered high the capacity of the person to make decisions became an issue for professional participants. However, judging decision-making capacity in accordance with the seriousness of consequent risks is a contested issue. In Chapter Three, the more global nature of predictive risk assessments was raised, in that the consequences flowing from a finding that a person is not competent to make a certain decision in a particular area can result in appointing a substitute decision-maker for all future decisions (Hall, 2009, p. 123). In the Australian context, this is for a time specified by the Guardianship Tribunal if lifestyle



choice is involved. However, if a financial manager is appointed there is no time limit and the order for an alternative decision-maker will be in force, most likely, throughout the rest of the person's life. Within a legal framework Parker (2003) argues that there are concerns that where decision-making ability is judged in accordance with the seriousness of consequent risks to prove incapacity this can result in paternalistic medical interventions (Parker, 2003, p. 492). In the socio-legal encounters studied here there is a strong link between professional expert knowledge and opinions regarding capacity based on predictive risks regarding physical harm.

Webb asserts that decisions resulting from risk assessments have the effect of sealing the destiny of service users by determining whether or not an intervention is required or if resources can be allocated (Webb, 2006, p. 74). This is most clearly demonstrated in data presented in Graham's socio-legal encounter. Similarly, the findings in this study also support Webb's argument that risk claims are not simply propositions but a narrative that supports an argument for or against a particular decision. He claims that throughout a process social workers are responding to a situation, taking up a particular perspective, eliciting value positions and weighing up pros and cons (Webb, 2006, pp.154-155).

How the social work and service provider participants focus on measurement of risk supports Green's (2007) thesis, put forward in Chapter Two, where he addresses contemporary explanations for the rise of risk in the day-to-day practice of many social workers in community based services: in particular, the priority of risk over need. Green's other points regarding the rise of risk in daily practice of social workers include the relocation of responsibility to individuals and the culture of blame (Green, 2007, p. 395). These points are taken up in the next chapter as there are key links between constructions of risk and balancing responsibilities and rights. Clarke makes the point, in relation to priority of risk over need, that there can be structural constraints on the ability of service users to influence the development of services as they are a dispersed group who lack a "critical mass" in identifying and responding to common problems (Clarke, 1999a, p. 23). This demonstrates the key link in this study that can be forged between the three organising themes in that power dynamics are inherent in the process of decision-making.

The findings of this study regarding the variable notions of acceptable risk, particularly evident in the alliances and the tensions that arose between social workers and service

providers supports the findings of Green and Sawyer (2010), raised in Chapter Two, that responsibility for risk - who carries what risk and what the liabilities are - is complex in the context of working relationships. However, the participants in Green and Sawyer's study described the client's wish to remain at home as the defining rationale for the service, and in this context both service user and service provider embarked on a process of identifying risks, eliminating some and modifying others. This played out differently in the research case studies in this research. This could be seen as the starting point in the five research case studies but as the process evolved changing perceptions of risk and capacity resulted in alliances being formed to achieve a different goal by the professional participants; that of entry to residential care for the person who was the focus of the research case study. All five individuals who were the focus of these research case studies were admitted to residential aged care either during the process or very soon after a Guardianship Tribunal hearing.

That the social workers consistently supported their narratives regarding perceived risks with a discourse on the Mini-Mental State Examination score of the person with dementia is an assumption that can be challenged. As discussed in Chapter Three, K. Sullivan argues that the MMSE lacks sensitivity to all but gross cognitive impairment and states that initially the test itself was not developed to assess capacity but was intended to be used to direct further investigations. For example, if memory is found to be a problem on the MMSE test then further investigation of memory function should be followed up. The use of the MMSE is the subject of on-going debate, the arguments for its use being that it is cost effective and some researchers claim that it is a better predictor of decisional capacity than variables such as education, verbal abilities and the ability to perform activities of daily living (K. Sullivan, 2005, p. 112). However, against this it is argued that the scores on this test are poorly correlated with other measures of capacity and insufficient to determine whether a person has the ability to make specific health care decisions (K. Sullivan, 2005, pp. 116-118).

What is significant here, in the analysis of this basic theme, is the powerful nature of the quasi-legal discourse surrounding alternative decision-making and the perceived roles of professionals by individuals. Due to what may be viewed as dominant modernist societal values surrounding expert professional knowledge, and the grey areas inherent in issues of capacity/incapacity, family members can turn to professionals to provide information

and make decisions. The implication for social work practice, in relation to the primary research question, is that the challenges presented by these socio-legal encounters are that when weighing up alternatives in the decision-making process attention is given to reflect on assumptions made, such as the MMSE score, and predictions of risk, especially physical risk, which can be measured and recorded, as opposed to emotional risk. These issues are all linked to the second and third research questions regarding the impact in these situations of how dementia and capacity are understood and what assumptions are made. In turn these issues link to the first two research questions as they reflect how individuals participate in the research case studies during the process of interaction and negotiation and the underlying values and tensions.

## **6.2 Summary**

To conclude this chapter, the different knowledge bases that underpin decisions in professional and private contexts have been explored. These different knowledge bases raise the importance of the contested and related concepts of risk and capacity, understandings of which are fluid and specific to each social situation. The role of critical events is central in forcing and justifying the decisions of professionals and can change alliances. This is relevant to the primary research question of this study, in that it is the social work challenge to appreciate the worth of each knowledge base and reflect on differences. To this point ethical dilemmas that underpin the process of decision-making have been touched upon in the analysis of the findings. These ethical dilemmas are focused on in the next chapter, which is the final chapter presenting the integration of the findings of the study in the context of the literature review.

## Chapter Seven

### **7.1 Ethics and messy morals: how ethical dilemmas involve balancing responsibilities and rights**

J. C. Hughes and Baldwin argue that "morals are messy: ethics is everywhere: the major theories and principles of ethics can conflict and there are no easy solutions to the moral dilemmas involved in making difficult decisions" (J. C. Hughes & Baldwin, 2006, p. 15). The organising theme of this chapter relates to the findings regarding the ethical dimensions of decision-making in the five research case studies. In the two preceding organising themes the ethical dimensions are, in the terms of J. C. Hughes and Baldwin (2006), "everywhere" in the process of decision-making and in how different ways of knowing impact on how risk and capacity are constructed in and across the professional and private contexts. Consequently, this organising theme relates to all four research questions the study is designed to explore. Banks' definition of ethical dilemmas is useful here in that she states they are present when the individual is faced with a choice between two equally unwelcome alternatives, which can involve a conflict of moral values, and it is not clear which choice will be the right one (Banks, 2006, pp. 13-15). As raised in Chapter Two, this definition is also used in the Australian Association of Social Workers Code of Ethics, which acknowledges the complex nature of decision-making in practice within the context of managing power relationships where individual social workers bring their own lived experiences and knowledge (Australian Association of Social Workers, 2010, p. 14).

In this chapter, the organising theme is supported by three basic themes. Again there is some cross over in the analysis to provide an integrated presentation of the organising theme and within each basic theme the findings of the study are presented before moving to discuss these in relation to the relevant literature. The basic themes are:

- Negotiating responsibility for action which limits rights.
- Multilayered nature of protection is diffuse in balancing rights and responsibilities.
- Personal context intensifies need to balance responsibilities and rights.

This chapter has a focus on the way ethical choices were made by the professional participants, especially the social workers. In the analysis of this third organising theme it is useful to refer back to some significant points regarding ethical issues raised in the literature review. Particularly helpful in structuring this chapter is Ife's discourse on ethics and rights, noted in Chapter Two, where he observes that while ethics and rights may be involved in the same issue, ethical decisions can be seen as attached to the worker whereas rights can be seen as attached to the person with whom they are interacting (Ife, 2008, p. 122). However, as Ife argues further, while ethics and rights may be involved in the same issue the different discourses mean they are constructed in different ways. The human rights discourse shifts the focus from the worker to the person with whom they are interacting. This rights discourse allows for the client to be seen as an active participant in the decision-making process and this study is designed to be inclusive in this regard (Ife, 2008, p. 122).

In the five research case studies the participants balanced diverse professional and private responsibilities and the rights of the individual who was the focus of the research study. This is consistent with one of the central features of ethical tensions often faced by social workers, that of the tensions between autonomy or self-determination in decision-making and beneficence or the obligation to care for and benefit others (T. C. Healy, 2003). This is evidently a challenge in social work practice and relates to the primary research question of this thesis. As initially raised in Chapter Two, Ife argues that codes of ethics cannot provide clear answers and the real world of practice is much more complicated and messy. It is the underlying morality of social work and social workers' actions that is the issue (Ife, 2008, pp. 124,128). This organising theme shows that the balancing of responsibilities and rights ranges from what Titterton (2005) describes as a dominant safety-first approach, to one that supports the rights of individuals to take risks.

### **7.1.1 Negotiating responsibility for action which limits rights**

The key point about negotiating responsibility for action which can limit rights is that, as the guardianship legislation in Australia is intended to be inclusive and easily accessible anyone, professional, family member or other interested party such as a neighbour, may make an application for guardianship or financial management with supporting community worker and medical reports. The findings of this study show that this meant

that responsibility to take the action to submit an application had to be negotiated between the participants. There were no rules or guidelines for this process, which threw up conflicting tensions, was stressful, lonely and a painful process for some of those involved. Denying the right of a person to make their own decisions was a burden that was not taken lightly. What is demonstrated in the socio-legal encounters is that responsibility for action is "passed around". Banks states that the term "responsibility" is rooted in the notion of responding to the perceived needs of other people, to demands or calls from others and "encapsulates the sense of engagement by moral agents." (Banks, 2006, p. 126) Due to the complexity involved in delivering services, as demonstrated in the analysis of the previous themes, social workers, service providers and family members participated in negotiations regarding who should be responsible for taking action based on what judgements were made about perceived future risks. That this is stressful is expressed by the Service Provider G:

*I didn't feel the social workers [community and hospital] were supportive. Well, it was always down to me, being the one that's carrying on writing reports, putting Graham constantly back into hospital because he couldn't move. Sometimes the ambulance won't take him. I had him on VitalCall, and he actually pushed the VitalCall himself and they turned up and won't take him because Gillian was standing there in her dressing down saying "I'm the carer and I look after him and I do everything and I can't see why you have to take him to hospital." It's this co-dependence, she hated him being away. (Service Provider G)*

While expressing responsibility for Graham as a service user this was experienced as a burden to be passed to the hospital staff to take action. This action could be seen as a responsibility to society to maintain social order and was consequently perceived by Service Provider G as being the role of those vested with medical authority or power, being the social workers in either community or hospital contexts. The complexity of the situation was found to be overwhelming by Service Provider G. However, when the burden of responsibility to act was picked up by the hospital treating team after the critical event, Social Worker G and the hospital treating team adopted a safety-first approach to protect Graham as a vulnerable person, which is problematic as it ignored Graham's other needs and denied him the right to choice and self-determination. What is significant for Social Worker G was that she was also acting on perceived responsibility

to her agency, the hospital and use of its resources, which can also be seen as a responsibility to society as use of tax payers funds since Graham has had eleven admissions over the preceding twelve months. She said:

*So the main reason is we're protecting Graham's physical safety. I guess another reason why we felt we needed to put the application in, because the services were pulling out not only for him, but for her, which means they would be getting no cleaning, no medication, no food, no shopping. They both declined personal care, so ... I don't always like putting in guardianship applications because you do feel like you're basically applying to have someone appointed to make decisions for someone, particularly when Graham's able to clearly express that he's not happy with that and he wants to go home. So that's always difficult. (Social Worker G)*

Social Worker G's moral reasoning affirms she thinks she has chosen the right course of action and she can live with this decision, reflecting that in ethical decision-making choices have to be made and justified. What was problematic was that Graham's competence to make his own decision about remaining at home was, as presented in the previous organising themes, dependent on the power vested in medical authority. In this scenario, at the point in time when the application for guardianship was lodged, the alliance between Social Worker G, the treating hospital team and Service Provider G and her agency presented the same narrative to the Guardianship Tribunal. This narrative could be seen as one-dimensional, in that Graham was at physical risk in his current living situation and lacked the decision-making capacity to determine where he will live. He therefore needed an alternative decision-maker, i.e. the Public Guardian, to make this decision for him. This is a clear statement that safety issues outweigh Graham's right to choose, where beneficence takes precedence over autonomy, and as discussed in the two previous chapters, physical risks override emotional wellbeing.

This central research case study can also be presented as a wicked problem which is multidimensional and where there may have been opportunities for alternative solutions or choices in the process before the critical event. It could be described as a failure, or systems block, in the inter-related components of the welfare system in the delivery of services to Graham. In the process leading up to the critical event for Graham, which created a cohesive alliance between the professionals and a shared narrative presented to the Guardianship Tribunal, risk and responsibility were transferred between many players

in the delivery of services. These comprised firstly, the community based team which included a geriatrician and social workers. Secondly hospital based social workers, including the Social Worker G, and two other social workers, the geriatrician and other members of the hospital treating team and thirdly, Service Provider G and her agency. For Graham and his wife this created uncertainty in establishing trust and prevented the formation of working relationships and alliances.

Ironically, Graham and his wife expressed trust in Service Provider G and her staff providing direct care, yet it is Service Provider G who expressed the most emotion in describing her burden of responsibility. Building relationships and trust has been a key concept in social work practice, as observed in both chapters of the literature review, and social work is a profession that is highly relationship based. However, there appears to be a lack of trust in the relationships between Graham and his wife, Social Worker G, and the hospital team. Predictions of future risk regarding Graham's physical safety meant that, due to the critical event of a burn, duty of care issues arose for Social Worker G and the hospital team. In being responsible to society the adopted approach resulted in a perception of Graham being in need of protection. These issues will be explored later when analysing the conceptual notion of protection which, in this study, is multi-layered.

As the context of this central research case study is hospital based, Social Worker G and the hospital team perceive Graham's social situation as a problem presented that needed to be solved in a short period of time. There were contrasting responses in the other research case studies in community settings where choices could be made in sequence as more information became available to the social workers and the time frame was not so constricting. In the research case study of Maria different ethical dilemmas were presented to Social Worker M as Maria had a partner who was perceived by Social Worker M and Service Provider M as a "responsible carer." In terms of the legal context, as discussed in Chapter Two, Bill is the "person responsible" to make decisions for Maria. He can be identified through the guidelines of the Guardianship Tribunal of NSW as a person who can made decisions on an informal basis without resort to the appointment of a legal decision-maker (Guardianship Tribunal of NSW, 2003). Although in the central research case study Graham's wife could also be perceived in this way, there is a difference in values placed by the professionals on what was perceived as responsible caring. Bill was perceived as making responsible decisions for Maria whereas



the values underlying Gillian's decisions are questioned. Initially, for Social Worker M this meant the burden of making choices and decisions rested with Bill:

*...so we've given him all that information on guardianship. He considered it, he said "I need a guardian for Maria." Okay, so we'll put in the application. I was going to put in the application for him initially, drafted it out, took it to his place. He went through the whole thing; he finally understood guardianship and then he said "I don't need it, I'm the person responsible." (Social Worker M)*

However, Bill's ambivalence about carrying the burden for submission of an application resulted in passing the burden to Social Worker M and Service Provider M who picked up the burden and responsibility for action in a collaborative alliance. The ethical dilemma for Social Worker M then became one of legal consent as Maria's right to make her own decision to remain at home became a legal issue because she refused to leave the house and Bill could not take her to residential care. Courage and professional integrity to stand by a decision is shown by Social Worker M when she followed through on her professional responsibility to Bill, who was also a service user, and to society, by controlling Maria in the interests of social order. Bill commended on this:

*...they did a fairly good job to get her out of the house and into the ambulance. That ... [Social Worker M], she was marvellous, really, that way. I would have put money on it to say "You'll never get her out of the house," because I tried and tried. (Bill)*

The moral reasoning shown by Social Worker A and Social Worker E in balancing rights and responsibilities in the decision-making process provided further examples of different types of complexity, moral reasoning and competing value tensions. Social Worker A resisted the pressure from a service provider, friends and neighbours to take action to limit Albert's decision to remain living at home alone after his wife died. She said:

*It's very hard because you've got the neighbour, who is an aged care physio, and you've got service providers, you've got the friends and they are all pressuring. The pressure was enormous and you think, well, am I doing the right thing? I just question myself constantly. (Social Worker A)*

The burden of responsibility was clearly in Social Worker A's "court" and passed to her by those involved and the decision to take no action weighed on her. She encouraged the service provider not to withdraw, and to work on building trust with Albert. She said:

*They're like: "Oh he won't let us do anything, what's the point in going in?" and I'm like: "Please hang in there, please hang in, just start slow, build up, build up your involvement, get his trust." (Social Worker A)*

This highlights the need of service providers to provide set practical assistance in certain physical areas such as personal care, shopping, domestic chores, transport. To be eligible to continue receiving the community aged care package Albert needed to accept assistance in at least three areas to demonstrate that he had complex needs and required a coordinated package of care. This contractual arrangement and the threatened service withdrawal had the potential to isolate Albert, as he would only accept assistance with shopping and banking. This was congruent with the shift of responsibility to Albert, as a consumer, to enter into a contract to accept certain assistance through the purchase of a care package. If he did not agree to the terms set down in guidelines framed by legislature the package could be withdrawn. There was no responsibility on the service provider to continue providing assistance and this could, in effect, isolate him. In this research case study, as with Graham's research case study, the mode of service delivery is difficult to reconcile with the development of trust.

In common with the other social workers, Social Worker A did not refer to systematic guidelines, although very conscious of the competing social work ethical dilemmas, but was confident in her discretionary judgement in her choice to take no action. She was an experienced professional who had an ability to work in a complex situation of competing interests and prioritize her decisions. In her moral reasoning she could see no benefit for Albert in submitting an application for guardianship despite perceptions of high physical risk factors and possible financial abuse. Albert's right to take risks was upheld. She argued against a Guardianship Order as coercive powers would be needed and the enforcement of an order could be left to service providers and their direct care staff. She said:

*...this gentleman is a force to himself. Who's going to be coercive? You couldn't get him out of the house. That means then if you get a coercive order [to accept*

services], for the Office of the Protective Commission, it's down to a little old lowly paid care worker to enforce that. I'm not prepared to allow that to happen because that's terrible for that worker. She's got a bully who says, "Take me to the bank, now!" and she's got to say "Well no, you're not allowed." (Social Worker A)

Similar to Social Worker A, Social Worker E was an experienced social worker. While taking a different course of action to Social Worker A, Social Worker E also displayed attention to weighing the potential consequences of a proposed action. Social Worker E took responsibility for her action to submit an application for financial management to the Guardianship Tribunal, although this was a lonely position, a burden of responsibility, and a difficult position to defend. She said of the Guardianship Tribunal hearing:

*I'd rather have the cast of thousands and go through the motions of the tribunal because at least then everyone has their say and it's not that they're telling me and then I'm the arbiter. I did not see it as a social worker's role ... It's the social worker's role to have everything out there, cards on the table, transparent, someone else makes the decision ... In the end they [Edward's children] all said "Aunty so-and-so, she's fine, that's fine, that's fine." Even though I had expressed in the tribunal – I said why I was coming because of course as the applicant they ask you why are you bringing this and then I had to say, "Well, of course, as you can see, we now have the sister here who has the power of attorney and so on. I basically said to them what I've said to you, in some senses, everything's done and dusted. I think that was interesting because the solicitor, he sort of looked at me like – he thought, "You've gone to all this fuss for nothing, haven't you? It's a bit over the top." He really wasn't – well, maybe that was just the solicitor feeling – if he's done the power of attorney then he knows best and why was I bothering.* (Social Worker E)

Here Social Worker E's action may be viewed as fundamental to postmodernist questioning of expert professional knowledge. It was her view that in the negotiations and decision-making process all those who had an interest were involved and all perceptions were weighed. Concern about the financial consequences and repercussions regarding hereditary issues was a driving force in her submitting an application for financial management. Significantly too, this action was also to protect herself from future consequences and this will be taken up in the analysis of the next basic theme.

To refer to the literature, the discussion in Chapter Two regarding the neoliberal dominance in social policy is significant here as these policies provided the context within which the participants were situated and the practical outcome of these policies critically impinged on the professional and private lives of the participants. What Powell describes as the neoliberal identification of concepts such as self-responsibility, means that it may be argued that the regulation of personal conduct for older people has shifted from the discourse on structured dependency by the state to one on the responsibility of older people as consumers (Powell, 2006, pp. 52-53). It can be seen how the transfer of responsibility to older people and their families and the movement away from the helping relationship to managed care, alongside the negative effects of fragmentation of services and isolation, is played out in the research case studies in that responsibility for action is "passed around."

A key link can be forged between the ethical dilemmas faced by Social Worker G and the constructions of risk encompassed in the previous organising theme. If Titterton's argument, that at the heart of many of the issues in relation to risk taking lies the issue of rights, is applied to this central research case study the recognition of the importance of responsibilities is significant. Titterton argues that rights need to be balanced by responsibilities as many rights, if guaranteed unconditionally, would infringe the rights of others. Any risk should be conditional on the competence of the individual taking that risk as well as responsibilities of those providing care (Titterton, 2005, pp. 46-47). However, it has been demonstrated in this study that the competence of the individual can be a contested issue when related to risks. Ife also identifies a specific responsibility of social workers to ensure the rights of older persons are respected both formally and through legal mechanisms and highlights that, although old age should not be pathologised, some older people can become increasingly exposed to the possibility of abuse in whatever form (Ife, 2008, pp. 61-62).

Conversely, the one dimensional argument presented by the allied professionals to the Guardianship Tribunal regarding Graham's need for protection, may be seen to be based on Beauchamp and Childress's (2001) four principles of biomedical ethics discussed in Chapter Two. The difficulty with this approach is that, as J. C. Hughes and Baldwin (2006) point out, the four principles can conflict. For example, Social Worker G sees "doing good" or the best decision was protecting Graham and made the choice that

Graham needed an alternative decision-maker, but this conflicted with the principle of autonomy. If Graham's socio-legal encounter is considered a wicked problem a different choice may have been made. Webb argues that wicked problems have silo effects where there is a transfer of risks, or risk is a cross-cutting issue that can be transferred around from one unit of an organisation to another or to another partnership agency (Webb, 2006, p.199). The passing of the burden of responsibility and therefore risks across agencies and professional participants and family is demonstrated in this study.

The lack of trust displayed by private participants, particularly in Graham's socio-legal encounter, is congruent with what is highlighted in Chapter Two, in that Powell argues there has been a move in western societies from trust to risk. He argues that social forces that create risk associated with ageing imply a breakdown in trust as a key modernist principle in contemporary society. Trust is based on expectations about future events whereas risk is based on future events that are unpredictable. Trust is hard to build and easy to destroy and familiarity with a situation, person or place produces trust (Powell, 2006, p. 120). Equally, Bill's ambivalence about carrying the burden for submission of an application for guardianship for Maria is consistent with the findings of J. C. Hughes and others (2002) who identify duty and responsibility to the person with dementia and guilt as being ethical issues that are the most troublesome to arise from a personal perspective and are shaped by long-term relationships. Nonetheless, Bill's appreciation of Social Worker M's ability to follow through on her decision and physically assist in Maria's journey to a nursing home demonstrated that for a successful alliance across the professional and private contexts perceptions of unacceptable risk are matched. This match is an achievement for Social Worker M as it has shifted and changed throughout the encounter.

A scoping review by Mitchell and Glendinning on how groups of people perceive and understand risk referred to in Chapter Two raises concerns regarding practitioners' need to feel their role is useful and relevant and that clients respect their professional competence. Families also need to feel that practitioners are competent and able to provide a service that is relevant to them and this can conflict or coincide with practitioners' need for respect for their professional competence. They argue that agreeing on risks is a vital link (Mitchell & Glendinning, 2008, p. 312).

In Chapter Two, Mattison (2000) identified two major groups of ethical theories that have relevance to social workers in helping understand the principles on which ethical decisions are based. These are the deontological and teleological approaches. The findings here show that the experienced social workers, namely Social Workers A and E, believed that decisions were made in relation to the consequences that may result and their actions could be justified on the basis of the consequences and not on fixed moral roles or the deontological approach (Mattison, 2000, p. 204).

What is argued here is that in these "messy" situations it is the moral reasoning used by the social workers that is important in justifying actions, as opposed to taking a narrow focus on one issue or principle. In response to the primary research question this moral reasoning is clearly a challenge in social work practice and incorporates weighing up issues that are pertinent to the four research questions. Reflection on the process of interaction and negotiation surrounding the unique issues in the socio-legal encounter, and unravelling the underpinning values and tensions, as well as reflecting on understandings of dementia and capacity may be viewed as being integrated into the reasoning. Ethical judgements entail action and as Banks argues a social worker should be prepared to act on decisions and argue the case (Banks, 2006, p. 155). The experienced social workers demonstrate responses and strategies in making the choices between undesirable outcomes based on the consequences of their actions. In the context of current social policy, which transfers the responsibility to older people and their families, social workers have to work extra hard to build trust, which is difficult as opportunities are limited by the complexity of service delivery and this presents a significant challenge in social work practice.

### **7.1.2 Multilayered nature of protection is diffuse in balancing rights and responsibilities**

The discussion in the first section of this chapter on the concept of taking responsibility for an action that can limit the rights of a person leads to the concept of protection, as the action taken is linked to the notion of protection of a vulnerable person by participants. This section explores the concept of protection in the five research case studies and the finding that protection is multi-layered.

At the surface level was the legal discourse on the need for protection: that the person who was the focus of the socio-legal encounter was at high physical risk and lacked the ability to understand the consequences of these risks and so lacked the ability to make his/her own choices and needed an alternative decision-maker. As discussed in the analysis in Chapter Three, this is a powerful discourse. Behind this legal discourse is the discourse arising from what Webb describes as the "blame culture" where people are increasingly pointing the finger of blame at each other and are no longer prepared to accept risks (Webb, 2006, p. 12). There is an element of "watching your back." This discourse was one where, regarding decisions made, weight was given to possible legal and personal repercussions for those in the professional context that could be related to what are perceived as duty of care issues. Here others' reaction to decisions made are significant in that the choices were not necessarily focused on the person who was the centre of the socio-legal encounter and their best interests. Alongside this layer of protection, professionals also wanted to act to protect the rights and interests of others, such as a spouse or other relatives, neighbours and shopkeepers, and there were conflicting responsibilities to the person who was the focus of the research case study and the people who surrounded them in the private context. Another layer of protection involved occupational health and safety issues described by service providers that gave rise to the need expressed by these participants to protect direct care staff as well as provide safe physical conditions in the homes of service users. Lastly, at the personal level there was a need for family members to protect both themselves and the person who was the focus of the research case study in areas such as lifestyle change and being confronted by changing abilities. These layers of protection add to the complexity of moral reasoning in decision-making and the conflicting tensions and choices for professional participants involved in balancing rights and responsibilities.

To turn to the surface layer of the notion of protection, that of the legal discourse that a person who is perceived as vulnerable is in need of protection. Mitterton, in the context of the legislation in the United Kingdom, states a widely used definition of vulnerability is one used in a report issued by the Lord Chancellors Department in 1977. A vulnerable person is one who:

is or may be in need of community care services by reason of mental or other disability, age or illness; and who is or may be unable to take care of him or herself,

or unable to protect him or herself against significant harm or exploitation.  
(Titterton, 2005, p. 31)

In the central research case study Graham met this definition of vulnerability, and was therefore in need of protection, from the perspective of those in the professional context. This view of Graham as a dependent person reduced his right to take risks as Service Provider G, Social Worker G and the hospital team needed to control the risks Graham was perceived as taking.

In the Australian context, the word "vulnerable" is not used in guardianship legislation although it is used in public and private discourse. As discussed in Chapter Three, for a guardian or financial manager to be appointed for a person who is perceived as needing protection in NSW the presence of some form of disability must be established. This is not enough in itself, it must also be established that due to the presence of this disability the person is incapable of making his or her own personal or financial decisions. The third criterion is significant in applications being heard and the making of an order by the tribunal. This concerns whether it is in the best interests of the person concerned and the tribunal is satisfied that there is no appropriate informal solution to the problem that has arisen. "Best interests" infers a principle based ethic, that of beneficence.

What is significant is that once this principle based ethical argument was used by professionals in positions of power in a legal context it was difficult to refute by those who contested it. This was particularly so when linked by professionals to the discourse of unacceptable risk. However, in the research case studies the decision to use this argument was based on more complex and diverse reasoning than the one-dimensional argument that a vulnerable person needs protection. There were other factors at play that were not directed at the "best interests" of the person concerned.

Firstly, there was the need of the professional to protect themselves from the blame of others as they perceived they had an obligation to act in certain ways, otherwise they may be challenged. In the central research case study the critical event of a burn changed the assessments of Social Worker G, the geriatrician and other members of this team, of Graham regarding Graham's capacity to make the decision to remain at home. Social Worker G said:



*...he's come in now with a serious injury needing surgery. And he was in a lot of pain because of it, and if he went back home it's just going to cause further injury to him. And I guess every other time he'd come in he wasn't in a good situation, but this was, I guess this was just the straw that broke the camel's back because it was a lot more severe injury. And I guess we'd also proved that he'd gone into a nursing home and he managed quite well there. He said he was happy there, he didn't come to hospital with not coping. So we'd sort of felt like we'd tried both options and one worked and one didn't. And then he went back home, hurt himself, and so we just felt like we didn't really have a choice. But yeah I mean we've let him discharge himself many, many times before and each time we're like, oh do we put an application in. (Social Worker G)*

The emphasis by Social Worker G on the predicted risk of harm to Graham reflected the possibility of blame directed at the team should Graham again return home. That a hospital discharged a patient to an unsafe environment may be interpreted as a breach of duty of care. In the central research case study it can be interpreted that it was reasonably foreseeable that Graham would hurt himself again and the hospital could be seen as negligent and open to blame and possible litigation, internal and external complaints or exposure in the media. This was a major factor for Social Worker G in balancing Graham's rights and the hospital team's responsibilities and created a turning point in the decision-making.

Similarly, as was raised in the analysis of the previous basic theme, for Social Worker E her concern about the financial consequences was a driving force in submitting an application for Guardianship. She said:

*I guess my concern is that if some time later the children end up saying, "Look, we have been gypped" because I think the wife could have been very objecting. She was saying "I am concerned about the children, that if she [the sister] takes control and has power of attorney will the children get their fair inheritance. The sister could be very influential in a will, if she decided that she wanted the Cat Preservation Society or something she could have persuaded him. And the kids could come back and said "we want this." (Social Worker E)*

This is a common thread in the five research case studies, where perceived professional accountability surrounding risk factors took the decision-making focus away from the person whose best interests needed to be served and where the argument was used that they were vulnerable and in need of protection.

The consideration of the rights and interests of others in decision-making and arriving at an option for action was also relevant for Social Worker A and Social Worker M in their moral reasoning. For Social Worker A the rights and interests of neighbours and friends were considered but the choice made reflected the balance of Albert's right to take risks. Social Worker M considered Bill's interests, as a carer and spouse with health problems of his own, and her action was to support him. Lastly, Service Provider J had to consider the rights and interests of neighbours and shopkeepers who became distressed at seeing Jane "wandering" and looking for her son and this scrutiny from others also placed her agency in a perceived position of possible blame. The utilitarian ethical principle of promoting the greatest good for the greatest number is relevant here.

Another layer of protection, which took the focus of decision-making away from the person who was perceived as vulnerable and their best interests, involved occupational health and safety issues. Here they were linked to the prioritisation of the wellbeing of the workforce over the wellbeing of the service user in the central research case study. Service Provider G says of the home environment:

*And I said really, expecting my carers to go in with the dog urinating on the floor and Graham wasn't wetting himself then but the whole house, it was just an OH&S nightmare and I said you know really we could refuse to go in. (Service Provider G)*

As has been raised previously in this thesis, the refusal of services can have the potential to seal the fate of the individual service user. The threat to withdraw services, to people who were considered vulnerable was significant in all but one of the research case studies. The exception was Maria's socio-legal encounter, where Bill was considered a responsible carer and so partnerships could be formed and, consequently, responsibility may be shared and an alliance created. For Jane, Service Provider J was the applicant to the Guardianship Tribunal and the application was made on the premise that because of safety factors relating to Jane's behaviour, as well as safety issues in the home, the

agency could no longer continue to provide a service. Albert's research case study was referred to in the analysis of the previous basic theme where possible refusal of services was relevant. However, for Social Worker E the decision was made early that services would not consider entering Edward's home as she said:

*The house, because it was in such a squalid, dilapidated state with no plumbing and I think even condemned condition it wasn't going to be that I could get services in. (Social Worker E)*

Service Provider G related occupational health and safety issues and duty of care from the perspective that these issues could be used to refuse to provide services and a way to force decisions regarding accommodation. She said of work completed on the home to ensure the safety of Graham and Gillian:

*...when they turned up with that railing for the front door ... Gillian came out, they are very cunning, and said "our toilet seems to be blocked, could you have a look?" So this is the maintenance from [named service], I don't know why they were there but anyway, \$5000 later they fixed up the blocked toilet. And while they were there, fixing the toilet ... and of course all the gutters leaked and the inside of the house leaked. Water was coming down the walls. Now because they had a duty of care, because they were putting the railing in and then they had to fix the toilet, another \$5000 later they had to put new guttering in around the house. Although in hindsight, if they hadn't done that they would have had to make that house not, you couldn't live in it, and perhaps that would have been a catalyst to get them out. But because they came in and fixed the toilet, then did the guttering, they got to stay in the house. (Service Provider G)*

This was another "catch 22" for Graham and Gillian reflecting the imbalance in power in the relationships and the way various factors shaped delivery of services which come from policies such as the *Aged Care Act (1997)* and *OHS Act 2000*. They accepted home modifications offered by home services as their right enshrined in the *Aged Care Act 1997*, which is designed to ensure the recipients of services enjoy the same rights as other people. These home modifications also met their needs but this was used in argument against them by Service Provider G in her construction of the couple as "very cunning" and not fitting the system of care offered.

The last layer of protection was at the personal level where there was a need for family members to protect both themselves and the person who was the focus of the research case study. These responsibilities could conflict. In the central research case study, Graham and Gillian demonstrated their need to protect themselves from professionals when Graham discharged himself from hospital several times, and a nursing home, against professional advice. Gillian's interpretation of Graham was that he was an independently functioning person and not a vulnerable person in need of protection. However, in Maria's research case study Bill protected Maria's rights in some instances by allowing self-determination, yet continued to try and protect her by denying other rights such as a choice in living arrangements. For example, Bill said of personal care assistants:

*...but they're sending young girls and Maria wouldn't have it sort of, you know, I don't know. So we cancelled it, and we carried on for a long time, years actually. And then I actually wanted to get some help again for ... because Maria wasn't showering anymore and objecting to me sort of, you know. (Bill)*

Yet the point came when to continue to protect Maria, if he was no longer able to care for her, the only option was residential care. In this respect their best interests are intertwined:

*...and then at the end I actually was in terrible pain, I had to ... I was passing a kidney stone but I didn't know, you know, it was very sore, very sore. And I didn't know, I was walking up and down in the backyard in the middle of the night, because the only ... I couldn't sit, I couldn't lay down, I could only stand up, so I did that. And then in the morning I still had to look after Maria as well, and then I thought to myself "something has to be done now. I ... something is going to happen to me and then we're all stuck," you know? And that's when she went in a home. (Bill)*

As well as the personal physical risk factors which could pose threats that gave rise to the perceived need for protection, to be protected from other family members was also relevant in this study. Social Worker A described how she saw Albert being at risk financially and in need of protection against financial exploitation by his wife's relatives. Social Worker E described how Edward's sister and ex-wife had different perceptions of

Edward in regard to his drinking habits and his sister protected Edward. Social Worker E said:

*... ex-wife and she always – she still thumped on all the time about his being an alcoholic. She would not let that go, would not let that go at all. That was a red rag to the bull, as far as the sister was concerned, so the sister was at great pains to say that he is not an alcoholic. He had a stroke and that's what's contributed to all of this ... She saw the house, she came back to me and she was quite shocked. She had no sense of the way he was living. Because I guess the thing with Edward was he still presented as a very gentle, sweet, nice, cooperative man, always.... I think there was a sense in which the sister probably could see him as big brother, a bit of a dole duffer now, but basically still okay. (Social Worker E)*

To turn to the relevant literature, the findings raise the issue of interpretation of common terminology such as vulnerability. The findings are congruent with Fawcett's argument that although the concept of vulnerability is increasingly being written into legislation as being objective and having a fixed meaning, this meaning can be contested because vulnerability can be interpreted in a number of ways (Fawcett, 2009b, p. 473). Further, judgments about incapacity are generally made within a context in which professionals prioritise physical safety and reduction of risk over emotional aspects and the promotion of personhood (Fawcett, 2012 p.7). Correspondingly, Mitterton argues, there is no statutory framework for risk taking as such (Titterton, 2005, p. 34).

Likewise, use of terminology such as duty of care, is open to interpretation. Generally it means different things to different people but what is relevant to social work practice and other health professionals in Australia is that under common law, negligence is conduct that falls below the required standard for protecting people against unreasonable risk or harm (Thompson, 1989). There are key factors that are referred to when assessing possible negligent conduct; these being a duty of care, standard of care and breach of duty of care that causes harm or loss. The emphasis is on what can reasonably be expected in practice in regard to competency and skills for a person in a particular position, not that decisions or care must be perfect. What is important is that adequate professional standards can be demonstrated and a reasonable social worker (or other professional) would do things according to law, relevant policies, professional responsibilities and their own skills and training (van de Zandt, 2000). If there are two possible practice decisions

that are both acceptable then a social worker would not be considered negligent for doing x rather than y (Thompson, 1989, p. 10). Also, what may be expected from an experienced social worker would differ from a first year graduate. The research case studies show that the fear of blame and possible consequences is a factor in decision-making and in balancing rights and responsibilities.

The findings regarding the layer of protection relating to occupational health and safety issues reflect many potential dilemmas. The legislation relevant to providing services in the homes of older people in the state of New South Wales, Australia, includes the *NSW Occupational Health and Safety Act 2000*, the *NSW Occupational Health and Safety Regulation 2001* and the *Aged Care Act 1997* (Commonwealth Act). As the workplace is the client's home and as it is a private dwelling clients are exempt from obligations imposed in the *Occupational Health and Safety Act* and it is the home care organisation, as employer of the home care workers, who has the statutory responsibility to ensure a safe place of work. The obligations are that there is a common law duty to take reasonable care for the health and safety of others and the duty of care is the legal obligation to avoid causing damage or loss that could have been reasonably foreseen (Ageing Disability and Home Care & Department of Human Services NSW, 2010).

This is a balancing act as home care service organisations may also be seen to have a duty of care to service users as well as workers. The *Occupational Health and Safety Act* does not require a home care organisation to sacrifice the interests of one party for the other but must, as far as is reasonably practicable, ensure the safety of both. This can be a tough deliberation, as the research case studies show, and if there are tensions it is recommended that a risk assessment is undertaken and a plan to manage risk developed (Ageing Disability and Home Care & Department of Human Services NSW, 2010). Against this the *Aged Care Act 1997* aims to ensure high quality aged care services and enshrine principles of access, equity and promote ageing in place. However, what can be seen in the research case studies is that due to the imbalance in power relationships those identified as having a need for services by the *Aged Care Act 1997*, that is the older person, can be marginalised in the decision-making process, protecting workers or the agency from blame at the sacrifice of the service user. As Green puts forward, in practice the potential risk in a service user's future becomes more important than the reality of their present needs and the focus can shift from the past to determine how the present will

unfold to a focus on the future unrealised risk (Green, 2007, p. 401). This shift of focus can also be used as a powerful argument to refuse to provide services.

As well as refusal of services in Graham's socio-legal encounter, the data regarding the last layer of protection, the personal level, is consistent with Clarke's study, referred to in both Chapter Three and Chapter Six, where she found that family carers interpret risk with a baseline of the person being able to take risks and judge the consequences (Clarke, 1999b, p. 299). Clarke also found that the rights of the person with dementia are tangled up with the rights of people she identifies as carers. If applied to this scenario, Gillian and Graham had shared rights to services and maintenance of their lifestyle but Gillian did not perceive herself as a carer who needed to protect Graham.

Before turning to the final basic theme the important aspects of this analysis of the concept of protection in the five research case studies is that a powerful legal argument can be presented, that a vulnerable person is at risk and in need of protection, and this argument is difficult to refute. However, this argument is constructed to initiate a legal action at a particular point in time based on a professional interpretation of risk and capacity. As discussed in the previous organising theme, risk and capacity are viewed in this thesis as interlinked contested issues. An analysis of the multilayered nature of protection demonstrates how the need to use this legal argument arises, when balancing rights and responsibilities, and that the decision-making process is based on other layers of protection that can take the focus away from the best interests of the concerned individual. Deconstructing these layers of protection is without doubt central to the primary research question of this study as exploring these layers of protection are important in the weighing process in decision-making regarding whether to take action and proceed with an application for guardianship or financial management.

### **7.1.3 Personal context intensifies need to balance responsibilities and rights**

The findings here reflect that when linked to the notion of responsibility, pre-existing family relationships have the potential to drive the perceived need for an alternative legal decision-maker by those situated in the professional context. To finalise the analysis in a rounded way and provide a fuller picture of the research case studies it is significant that some potentially important players were left out of the process. In the research case

studies the social worker participants' responses, and moral arguments, were unique, diverse and wide ranging in the decision-making process of balancing rights and responsibilities. As put forward in Chapters Five and Six, these responses were driven by issues within their professional context, such as resources available and relationships and alliances with service providers, but also to a significant degree by the way the person who was the focus of the research study was situated in their family relationships and private context.

What is significant here is that established family relationships came to the fore when considering the legal requirements that an application for guardianship must be a last resort and based on "need." Existing family relationships can provide a bridge to form alliances, such as in Maria's research case study. However, in the other research case studies lack of a person perceived to be making responsible decisions was a driving force in the perceived need to act and submit an application for guardianship. When analysing the established family relationships some significant family members were excluded from the process for varying reasons, while others were seen as "not responsible."

In the central research case study Graham and Gillian had two children in professional employment. Social Worker G said of their relationship with their parents:

*They've always been odd, the children say they've always been a very strange couple. And I think that's why they're, the family are a little bit... They're involved, they stay in touch with them, but they feel like there's not much they can do, they can't tell them to do anything, they've always just done their own thing. (Social Worker G)*

The Tribunal Reasons for Decisions noted that:

Graham and his wife have two children. The Tribunal was unable to contact them prior to the hearing, and they did not directly participate in the hearing. There has been some estrangement between parents and children. The Tribunal relied on information supplied by others to get their views ... [Social Worker G] has also spoken to [daughter] who told her that she thought her father was able to make his own decisions. Geriatrician had spoken with Graham's son who indicated he was unable to make decisions for his father. (Order and Reasons for Decisions made by the Guardianship Tribunal of NSW)



Graham and Gillian acknowledged that there was little family contact. Gillian said:

*We love them but we don't see anything of our children and I don't know why, I have no idea. We don't fight or argue with them but they just don't come very often.*  
(Gillian)

The resulting action of these established family patterns showed that the two children had no power in the events concerning their parents that unravelled leading up to the Guardianship hearing and in the Guardianship hearing itself. It is unknown how much this was an active choice to withdraw, or a disempowerment due to the established family patterns. However, this withdrawal and lack of family responsibility left Graham without power vested in a family member and exposed to the use of increased expert power and scrutiny by professionals. His wife's opinions had previously been marginalised as she was not seen as a "responsible person." It is perceived by Social Worker G that an alliance cannot be formed with any family member. This lack of a 'responsible' person to negotiate with placed more responsibility on those in the professional context. This in turn increased the "stakes" regarding professionals' perceptions of their responsibility to others, including society, and possible repercussions. This could be interpreted as bringing into play middle-class values.

Jane's research case study had similar characteristics to the main research case study in that she had a son who lived with her, but he was not perceived as making responsible decisions or providing care to Jane by Service Provider J. She said:

*We were cleaning up the kitchen. There were issues with old food. When we went there we weren't exactly sure what sort of food the son was actually feeding her. We don't believe he was actually feeding her at all. We were finding knives and half cut up pieces of cheese and things like that overnight, so we were trying to put in sandwiches and things that she could actually graze on. Medication was also an issue.* (Service Provider J)

However, Jane had a second son and the established family pattern of interaction was one that excluded this son and his wife. After Jane's husband died several years before the research her second son and daughter-in-law came from Queensland with the intent to provide support to Jane. Due to family conflict this did not eventuate. However, Service

Provider J stated that if Jane had a "responsible carer" she may still be at home and her second son and daughter in-law were perceived as such.

In Edward's research case study, Edward had three children who were significant in his life yet due to health related problems were unable to take up the role of "person responsible." The established family conflict between Edward's sister and ex-wife presented ethical tensions for Social Worker E regarding concerns about her being seen to endorse Edward's sister as the person responsible to make decisions. In these three socio-legal encounters it is difficult for the social worker to identify a family member as the "person responsible" and this created ethical tensions in balancing responsibilities and rights. Albert's research case study contrasted this; from his social isolation ethical tensions arose due to the lack of any person, either as "person responsible" or otherwise. For Albert, in his established relationships he had been reliant on his wife and her death, immediately prior to his referral to Social Worker A, created a void. The absence of his wife opened up his life to public scrutiny, and the scrutiny of neighbours and intensified the professional need to balance his rights and their responsibilities.

To return to the literature, overall the previous discussions on Foucault's work are relevant here as established family relationships are critical in defining the extent to which the professional gaze and interplay of power relationships were intensified in the research case studies. The findings in these socio-legal encounters strongly support Phillipson's (1994) statement that difficulties can arise as family relationships do not come with a readymade set of moral rules set out for older people. Also, as governments attempt to shift responsibility back towards the family some older people do not want to be dependent on their children and any care given by families is always negotiated within a social and biographical context (Phillipson, 1994, p. 109).

In Australia the current policy context of neoliberalism shifts responsibility back to the individual older person and their families and the discourse sees individuals as being responsible for themselves. The duality shown in this research is that when older people and their families do not respond according to dominant societal values then they are open to scrutiny by professionals and the intensified professional gaze. The findings show that conflict between the family and health and welfare systems can give rise to tensions that result in an application for guardianship. This is consistent with the findings of Peisah, Brodarty and Quadrio referred to in Chapter Three. In their study family conflict

commonly involved the person with dementia in conflict or in an alliance with one or other of the family members (Peisah, et al., 2006, p. 486). Such family conflict was considered a valid reason for a guardianship application. The perceived need to submit an application for guardianship in the research case studies was the same as the two major issues identified by Carney and Tait: accommodation and conflict. They found these issues were the hardest to resolve when presented to guardianship tribunals. Conflict could be either within the family or between the family and professionals (Carney & Tait, 1997, p. 142).

In this study, ethical tensions were increased by pre-existing family relationships and this is congruent with the findings by T.C. Healy (2003) in a study examining social workers' ethical tensions as they made decisions about the capacity of older people. Areas that contributed to ethical tensions were clinical uncertainty and pressure from other professionals. The findings of this study take this further in that clinical uncertainty also arises from tensions between established relationships within families.

Before summarising this chapter, what is important about established family relationships is that, as Banks notes, "laws do not tell us what we ought to do, just what we can do." (Banks, 2006, p. 11) The legal context in the five research case studies can provide guidance to social workers on what may be done and reflect current norms and values in Australian society. These norms and values are pertinent to the research questions regarding understandings of dementia and capacity as current social norms and values may be viewed as reflecting dominant discourses surrounding these concepts. What "ought" to be done to resolve the ethical dilemmas is still a choice by the individual social worker where responsibilities and rights need to be balanced. As raised previously, this is a core challenge in social work practice in these socio-legal encounters. Ethical tension can increase and become more messy if professional participants cannot identify a "person responsible" and feel confident that an alliance with this person will result in decisions that are seen as appropriate at the societal level. This is relevant to the research questions regarding the process of interaction and negotiation around the unique issues in the five socio-legal encounters and underpinning values and tensions, as there are variable, subjective and contrasting opinions regarding the responsibility or otherwise of family members which need to be given weight in decision-making.

## **7.2 Summary**

To conclude this chapter, and address the primary research question of this study, balancing responsibilities and rights may be seen as being at the core of how social workers endeavour to meet the challenge of working with older people, their families and other professionals these in complex situations. From an exploration of the basic themes presented in this chapter the findings show that in balancing responsibilities and rights tensions and messy morals can intervene and the concepts of responsibility and protection are divergent and multilayered. Issues arise that take the focus of decision-making away from the person whose best interests are said to be served and the argument presented that a vulnerable person is in need of protection. The issues raised in the chapter bring to the fore, once again, the pivotal importance of constructions of risk. What is significant is that the social workers are able to present moral arguments to support their choices in decision-making. However, these are not identified as moral arguments by the social workers, although there is an awareness of the ethical dilemmas and complex range of policies and legislative requirements within which they practice.

## Chapter Eight

This final chapter summarises the study and considers some of the theoretical and practical implications of the research for social work practice and the wider theoretical implications. Limitations of the study and suggested areas for further research are then discussed.

### 8.1 Summary of the study

This thesis set out to examine the engagement of social workers in the adult guardianship process where people with changing abilities attributed to dementia are identified as needing an alternative legal decision-maker. This has been done by addressing the research question: *In a contemporary Australian health and welfare context what are the challenges in social work practice with older people, their families and other professionals in disputed, complex and uncertain situations where a legal alternative decision-maker is perceived as necessary?* Five research case studies, or socio-legal encounters, were explored by analysing a variety of data collected through semi-structured interviews, document analysis, observation and reflective notes. A thematic network analysis of this wealth of rich data revealed a global theme: *power plays and contestations*. At the interface of these socio-legal encounters there are power plays and contestations where the players participate by bringing their own perspectives, and in this process alliances are formed which reflect underlying dynamics of power. It may be argued from the analysis of these research case studies that one of the major challenges for social work practice is to unravel the power plays and deconstruct the contestations, as at the interface of each individual socio-legal encounter there are many contested issues such as diverse constructions of risk, capacity, protection and responsibility.

The literature reviewed in Chapters Two and Three gave direction to investigating what may be the significant challenges faced by social workers when engaged in socio-legal encounters. To summarise, some of the main challenges raised include: the impact of neoliberal policies; different and varied understandings of dementia and capacity; the double perspectives in social work practice of care and control; the growing emphasis on

risk and the development of risk-taking approaches; developments in social workers' understanding of and approach to ethics; and deconstructing the many tensions and disparate notions regarding ageing and what it means to be a person with dementia in socio-legal encounters. Most significantly the essential mediating role of social work means that a central challenge is to ensure all participants' views on critical and contested issues are taken into account in decision-making and any resulting action is shaped by the unique context of the encounter. The findings and analysis chapters of this thesis substantiated that these are all challenges faced by social workers in socio-legal encounters and contribute to the complexity and uncertainty in social work practice.

The study also asked four subsidiary questions surrounding the process of interaction and negotiation, the values and tensions behind the negotiations and the impact of how dementia and capacity are understood in the research case studies. Separate chapters on the three central themes in the network analysis highlight the importance of negotiation at the interface of decision-making and address these four research questions. Firstly, in Chapter Five, it was found that participants' professional and private contextual influences affect decision-making and this is critical in understanding the inherent power dynamics in the negotiations. Therefore recognizing power dynamics and possible alliances that may be formed within and across the professional and private contexts may be viewed as a challenge in social work practice. Other noteworthy challenges include recognition of the role of service providers in the interactions and negotiations, the significance of how a family member is identified as "responsible" or otherwise, the organisational complexity and fractured nature of services, which influences how decisions are made, and a need for social workers to understand and interpret to other professionals the interconnectivity of personal and family decision-making.

Secondly, in Chapter Six, it was found that participants' individual knowledge bases that support the process of decision-making can be different and shift and change throughout the encounter, particularly in the areas of contestation. A major challenge identified for the social workers here is to acknowledge and interpret the differences and the underlying assumptions, such as professional assumptions regarding the predictive nature of risk or alternatively private participant' focus on emotional risk factors such as loss. Further challenges revolve around how to respond to critical events where underlying values are

brought to the fore and how understandings of dementia and capacity can shift and change at the interface of critical events.

Thirdly, in Chapter Seven, it was found that in the encounters, negotiations are embedded in ethical dilemmas that involve balancing responsibilities and rights. This study reveals that the challenge for the social work participants is to weigh up issues that are pertinent to the four research questions in each unique socio-legal encounter. Exploring and reflecting on the possible layers of protection are important in this weighing process in decision-making, as is the vexed issue of who will take responsibility for an application for guardianship or financial management.

In order to explore the adult guardianship process through the research case studies this study drew on perspectives from social constructionism and the links which can be made to modernism and postmodernism. Through an exploration of how changing health and welfare discourses impact on the experience of ageing it was argued that identity in older age is shaped by social contexts and consequently this influences the way in which social work is practised. It has been argued that over the past thirty years a succession of health and social welfare policy reforms have had an unprecedented impact on older people. The detailed investigation of the five research case studies demonstrates the micro impact of neoliberal policies in the Australian context and supports the argument regarding the implications of these policies. Deconstructions of the five socio-legal encounters raise critical issues such as gaps and lack of coordination in services due to policies of marketisation and privatisation, the rise and domination of the concept of risk, the channelling down of responsibility to individuals and families and growth of professional power.

Changing dementia and capacity discourses, within the wider context of health and welfare, and their various influence on the context of social work practice with older people were examined. This study has demonstrated the importance of the unique Australian legal framework in which these research case studies are embedded. Alongside the health and welfare policy reforms there have been parallel changes over the past thirty years in how dementia and capacity are understood and conceptualised. It has been argued that dementia and capacity discourses have been constructed and changed over time and it is important for social workers to understand these changing discourses in order to build effective working relationships. In current social work practice there is

clearly a mixture of competing and divergent beliefs played out in individual socio-legal encounters regarding knowledge about dementia and capacity.

In keeping with a multiple case study design the socio-legal encounters were of interest because they shared ideas or common characteristics about which a better understanding was being sought (Stake, 2006). The ideas may be seen to link together the two central arguments, research questions and answers in this thesis. The ideas that held the cases together were understanding the process of adult guardianship, and what it meant for an individual with dementia, and the associated social work responses. The two central arguments reflected these ideas at a macro level. The research questions anchored these claims and the answers provided knowledge regarding these claims.

The two central arguments were that, firstly, identity in older age is shaped by social contexts and for those with dementia what that means within these contexts is crucial. Secondly that dementia and capacity discourses have been constructed and changed over time and consequently dominant discourses can shape social work practice. Chapters Two and Three reviewed literature that gave direction to weighing the issues associated with these claims. Shifting notions underpinning health and welfare discourses since the Industrial Revolution were explored in order to expose contrasts and contended that contemporary policies of neoliberalism shape the meaning and construction of old age. Similarly how dementia and capacity discourses have shifted and changed over time was discussed to understand the unique impact of what it means to be a person in contemporary Australia whose decision-making abilities are challenged. The historical and contemporary influences of these shifting discourses on social workers engaged in practice with older people were considered. The literature reviewed in these Chapters gave pointers as to what may be the significant challenges faced by social workers when engaged in socio-legal encounters and gave direction to the overall research question regarding the challenges faced by social workers in a contemporary health and welfare context where a legal alternative decision-maker is perceived as necessary. In contrast to previous times for example, the growing emphasis on the concept of risk and the shift away from understanding capacity was considered a binary concept. How these issues played out was reflected in the answers to the research questions.

The overall research question was designed to provide a focal point for the two central arguments. It expressed the essence of the enquiry and linked the arguments to a specific



contemporary health and welfare context. Older people with dementia, health and welfare services and dementia and capacity discourses are embedded in socio-legal encounters. The four subsidiary research questions were designed to explore the process of interaction in socio-legal encounters: values and tensions underpinning these and understandings of dementia and capacity within this specific context. These questions provided more in depth focus to the enquiry. Terms such as "negotiation", "values" "understood", and "assumptions" indicated the social constructionist framework underpinned the research. Answers to these subsidiary questions, as outlined above produced knowledge and provided insights related to the two central arguments. Examples included recognizing power dynamics and alliances across professional and private contexts and health and welfare systems, and the impact of the role of service providers in the interactions and negotiations.

Whilst the answers to the research questions reflect the thematic analysis across all the data, the dynamics within and between the research case studies anchor the claims made in the arguments. Commonalities gave raise to issues that reflected differently in the individual socio-legal encounters. For example, a common feature across encounters was that the person who was the focus of the individual case study had a medical diagnosis of cognitive abilities compatible with those identified within the jurisdiction of the Guardianship Tribunal of NSW. However, this played out differently in the individual scenarios. Understandings of dementia by the social work participants included a specific medical diagnosis such as Alzheimer's to using dementia as a general term for behaviours with an inconclusive diagnosis. What was significant to the social workers was a medical diagnosis to support an application for guardianship or financial management. Similarly, the private contextual influences in decision-making were particularly relevant in explaining how commonalities played out in different ways in reference to the impact of both family support and support services in the individual socio-legal encounters.

## **8.2 Theoretical and practical implications for social work practice**

### **8.2.1 Theoretical implications**

The findings of this study are theoretically significant in that the perspectives from social constructionism presented here, with an emphasis on links to changing discourses

between modernist and postmodernist messages, enabled the study to focus on exploring the underlying values and tensions and how these were played out in the five socio-legal encounters studied. The purpose of this study was to provide social work knowledge that can be used for more effective practice. Drawing on modernist and postmodernist concepts has been useful in developing social work knowledge as the differences provide a comprehensive framework to interrogate what social work knowledge is. It appears that there is not a dichotomy between the ideas and concepts of modernism and postmodernism, rather the boundaries are mixed and blurred in the five research case studies.

The social constructionist framework used to analyse and interpret the five case studies did not change in answering the research questions posed, hence the research findings did not challenge the use of this approach. Rather the social constructionist lens enabled the interpretation of the findings in a particular way which allowed new knowledge to be gained. For example knowledge regarding assumptions made by social workers such as the notion that residential facilities are safe, and the best option. Similarly, knowledge has been gained on the complexities involved in social situations where there are multiple players located in different agencies. Overall the social constructionist lens facilitated a developmental approach to the study to facilitate exploration of the discursive structures surrounding social workers, and other professionals, in health and welfare contexts.

This study supports the claim of social constructionist theorists that emphasis must be given to the idea that if multiple perspectives are taken into account viable alternative explanations can be considered. As highlighted this is of crucial importance in the process of decision-making. For example, one perspective in these encounters is that the person with dementia is understood as having "no insight" into their given situation because they do not agree with the dominant professional view that a move to a nursing home is the decision to be acted upon. The alternative perspective is that the person concerned is striving to sustain their sense of self, where a decision to move to a nursing home disrupts relationships and lifestyle and is not a decision they want to make. These alternative perspectives mean that a choice or decision is between two competing interpretations instead of trying to decide whose view is closer to the truth (Witkin, 1999). This questioning of dominant knowledge bases means working across power differences for social workers to engage in a meaningful way in practice. However, as a word of caution,

highlighted previously in this thesis, this does not mean that all perspectives are given equal weight in the negotiations but it does ensure that all views are taken into account and negotiated (Fawcett, 2009a, p. 125).

From a social work practice perspective what is significant is that the underlying values placed on inclusion in decision-making is identified as important. This is in line with the AASW Code of Ethics regarding ethical decision-making when social workers are engaged in practice within power relationships (Australian Association of Social Workers, 2010). In the first three chapters of this thesis, attention has been paid to the argument that social work values and ethical stances are congruent with social constructionist perspectives (Allen, 1993; Witkin, 1999, p. 7). As Witkin argues, rather than decision-making from a position of certainty, social work values are in line with questioning dominant knowledge structures (Witkin, 1999, pp. 6-7). The findings of this study show that within the contexts of socio-legal encounters there is a mixture of social work compliance with, and questioning of, dominant expert medical knowledge. The dynamics of the power relationships mean that in these contexts questioning dominant knowledge structures is not necessarily an easy social work action to take. However, it has been argued in this thesis that social workers are in a unique professional position to interpret differences and negotiate between those who have been excluded and those who have the power to exclude (Philp, 1979). It is observed by Parton and O'Byrne that if they can be identified, through the use of social constructionist perspectives, the social processes through which people interact and assign meaning to aspects of their experience has practical implications for social work practice in that it may be easier to know what to do (Parton & O'Byrne, 2000b). This study supports this assertion in that the relevance of understanding the exercise of power and power relationships in the socio-legal encounters has been demonstrated. As K.Healy observes this is especially important in contemporary contexts when terms like user rights and enablement are used (2001).

The further significance of this research is that the theoretical perspectives allowed for assumptions to be questioned where there are competing versions and interpretations of events in the socio-legal encounters. The findings show that in decision-making there are clear assumptions being made that are open to challenge and there is an opportunity for social workers to interrogate their knowledge and case reasoning. For example, across the socio-legal encounters there is a strong professional assumption that acceptance of

services in the home is a "good" thing, whereas for private participants this can be an ambiguous gain. What is pivotal to the research findings is the weight given by professionals in decision-making to assumptions regarding physical safety being given priority over emotional health and the link to concepts of risk. Assumptions made regarding professional expert knowledge of both dementia and capacity can also be challenged as the research case studies show that these understandings shift and change within individual socio-legal encounters, particularly if associated with a critical event. A further assumption which may be challenged is the use by social workers in their discourse of the relationship of an MMSE score achieved by the person with dementia to provide evidence of dementia or capacity. The use of this score by the social workers may be interpreted as linked to the modernist notion of providing some certainty in these complex social situations.

However, in contrast to this, the research case studies showed clarity of position by experienced social workers where strategies and responses were drawn upon that are congruent with confident social work practice in situations of uncertainty. These strategies included one example where the social worker, after weighing up the alternative courses of action, decided not to take action. This could be construed by others as "doing nothing" but was a considered response. Another social worker pursued an application for guardianship because she sought transparency in decision-making and rejected making a default decision where her withdrawal from the situation would endorse a family member as the decision-maker. This brings up again the importance of the understanding of ethical issues in contemporary social work practice that this study brings to the fore. It may be argued that there is now an understanding that it may not be possible to make a rational choice between two values and, for the social worker, ethical theory provides what McAuliffe describes as an invaluable knowledge base that enlarges social workers' thinking on and understanding of moral issues (McAuliffe, 2010, p. 44). However, there is the trap that Ife identifies, as raised previously in this thesis, that a discourse of ethics is about individuals making ethical choices in specific situations. In this sense it fits readily into the dominant neoliberal ideology as the social worker is described in terms of the individual practitioner making individual choices. There is an emphasis on the worker and the decision that worker has to take. For Ife, if it is balanced by a human rights discourse this shifts the attention away from the worker to the person the worker is interacting with (Ife, 2008, p. 122). The findings of this study show that the

counter balance may also be viewed as inherent in the theoretical perspectives, in that there is an emphasis on negotiation and orientation that all perspectives are taken into account and risks and benefits for all participants weighed up.

Nevertheless, while it may be possible to illustrate how the theoretical perspectives used in this study can provide important reference points for the analysis and continuation of social work knowledge, it must be noted that there may also be some limitations or barriers to the use of some of the theoretical implications in practice. It has been put forward that many practicing social workers are reluctant to engage with theory and that some social workers question whether postmodern theories can provide a coherent framework for practice (K. Healy, 2005). Theories from social constructionism, modernism and postmodernism present many difficult concepts to grapple with. In undertaking this research, the writer has experienced the organisational culture of social work as a practising social worker in a health care setting alongside the academic context of being a student. At times it was found that it can be difficult to find a bridge between the use of language associated with the particular theoretical perspectives in this thesis with the context of practical social work practice. However, many of the ideas and concepts presented in the theoretical perspectives of this thesis are familiar to social workers in practice, such as the complexities of decision-making power, "de-skilling" of the workforce where social workers work alongside other professions in positions labelled as "case management," and the impact of lack of coordination of services on clients.

It is also important to bear in mind some of the critiques of social constructionism with its links to postmodernism, such as concern about the relativism inherent in the perspectives raised in Chapter One. In keeping with the appeal of social constructionism is the notion that any theoretical perspective should not be uncritically accepted. It has been suggested that the language used by some postmodernist authors may appear to be arcane and convoluted and therefore inaccessible to practising social workers (K. Healy, 2005). Also, there is the critique that a focus on language practices may ignore oppressions shaped by macro-social structures (Burr, 2004; K. Healy, 2001). As the emphasis of social constructionism is on processes operating at the level of the individual the argument may be raised that, as there is a focus on localised responses, there may be a loss of the ability to advocate for and action structural change. For example, a focus on individual socio-

legal encounters as presented in this study may mask a possible need for structural or political change in regard to guardianship laws and processes in the Australian context. However, this thesis has attempted to address the impact of structural changes within which the individual socio-legal encounters are embedded, such as neoliberalism, and as indicated earlier in this section the progress in an understanding of ethical issues and the context of social work practice can also provide a balance. The challenge is therefore to recognise that there may be barriers from social work practice in bridging the gap between the fit of theory and practice. It is hoped that the significance of this study is a recognition that theory can guide practice as the theoretical perspectives used here have the potential to identify and bring together complex and diverse concepts and ideas that are found in contemporary social work practice. Although arbitrary, it is possible to tease out the more practical implications for social work practice of this study and these may help to assist in reducing social work practice barriers to the theoretical perspective of this study.

### **8.2.2 Practical implications for social work practice**

The purpose of this study was to enable social workers to better understand the dynamics involved in adult guardianship proceedings for a person with dementia and provide knowledge that can be used for more effective practice. In deconstructing the five research case studies areas can be identified where the theoretical approach and findings of the study have more direct practical implications for social work practice. The conceptual skills that social workers can bring to practice in these encounters includes knowledge and understanding of the historical context and an ability to analyse the social situation and multiple perspectives. It is of significance that a key finding of this study shows that from an ethical stance, what is important in these messy situations is the clinical reasoning used by social workers in justifying actions as opposed to taking a narrow focus on one issue or principle. Going beyond modernist positivist ideas to explore the way knowledge is socially constructed provides a focus to explore what good standards of social work practice may be in the context of similar socio-legal encounters.

A practical implication of the study for social work practice is that questions are raised that may be used by social workers to critically interrogate and to provide pointers for practice in similar socio-legal contexts. The importance of constant questioning arises

from the social constructionist perspectives of this study and, it may be argued, is very congruent to social work practice in that social workers are in a position to raise questions whereas other professions may not be so easily positioned to do this. These questions can focus on understanding the changing discourses between modernism and postmodernism that may assist in getting to underlying values and understandings. For example, is the person with dementia being viewed as having a disease and therefore unable to make any decisions, which marginalises their perspective? Alternatively, is their view being taken into account and is it acknowledged that the person can make many decisions and has many abilities? Is the person with dementia being devalued due to ageism and is there emphasis on vulnerability as part of identity, or is identity seen as multifaceted? For example, is the person positioned as "good husband," a "caring partner," as well as having changing abilities due to dementia? Is cultural and economic diversity being addressed in the encounter? Is complexity and ambiguity acknowledged in the encounter and how are conflicting perspectives understood? This is particularly relevant to the findings of the study regarding the concept of protection of a "vulnerable person" where, when the multiple layers surrounding the concept of protection are peeled back, it may become more obvious who is protecting whom from what in socio-legal encounters. It may be argued that social workers have the practical skills to identify and clarify issues by raising these kinds of questions.

This study has also highlighted the dualities that may be presented in social work practice in socio-legal encounters, such as whether the older person is being identified as vulnerable and therefore positioned negatively and not viewed as able to take "risky" decisions. The older person may be simultaneously viewed as a consumer, able to make decisions about service provision, financial decisions regarding entry to residential care, or how to negotiate systems of service delivery at home. It may be argued that what may be seen as important in similar socio-legal encounters is how social workers address the paradoxical issues raised in this thesis where older age can be viewed as a time of active consumption and self-responsibility or as being a vulnerable person in need of care.

This thesis has highlighted Philp's (1979) idea that social work knowledge takes place within a framework and the historical roots of social work emerged between the private and the public, where interpersonal concerns are played out and the social is that area where the state penetrates the world of private relations. In contemporary Australian

society, socio-legal encounters clearly fall into this space. It has been shown that in this space there is the duality of social work functions of providing benevolent support and also providing control in the interests of social order. The findings of this study regarding negotiation of responsibility for an action which limits the rights of a person is especially relevant to this double perspective of social work and the function of social control. The research case studies demonstrate how who takes responsibility for action within the socio-legal encounter can be passed around between the players and can be a problematic and troublesome issue. For example, a partner looking to a social worker to make a decision about moving their spouse to residential aged care because it is assumed that this is the professional's role due to the possession of expert knowledge and power. However, this also relieves the partner of taking responsibility for a very difficult choice and this can be a comfort to that person. Alternatively, it may be seen that this decision is the responsibility of family, which is in line with neoliberal values, and not one willingly taken up by a social worker. Identifying and understanding these grey areas of practice where responsibility for action is passed around reveals that it is useful to draw on a mixture of modern and postmodern assumptions. These may assist social workers in similar socio-legal encounters to weigh up options and make decisions within the context of the requirements of the Australian legal framework.

The findings of this study have practical implications for social work practice in that the research is located within an Australian legal context where there is unique legislation in place coupled with no comprehensive approach to assessing or addressing the support needs of a person whose decision-making capacity is in question. Social workers are well placed to work in the space created by socio-legal encounters as they have practical skills to address the diverse and multi-faceted issues that arise. For example, conflict resolution in families where there are often entrenched patterns of family functioning or situations where there are very disparate underlying values reflecting different knowledge bases between service providers and the person with dementia. Social workers have the conceptual skills to work through the complexity of socio-legal encounters to find informal solutions and this is congruent with what is written into the legislation in that all informal solutions need to be tried before an application for guardianship is made.



### **8.2.3 Wider theoretical implications**

This study is significant in that it will contribute knowledge in an area where there has been very little research in the Australian context. While the focus of the study has been on the process of appointment of a legal decision-maker, the study may be considered valuable in understanding the wider context of how dementia and capacity discourses are perceived across family and professional relationships and how decisions are made in similar social situations. For example, dementia is stated as the major cause of entry to residential aged care (Access Economics, 2003) and so consequently many people are facing difficult decisions surrounding this issue. Wider theoretical issues, such as the dynamics of power and constructions of risk, may also be seen as relevant across professional boundaries and therefore many of the findings of this study may be viewed as applicable to other professions such as nursing and medicine.

This study also has wider implications in understanding the impact of neoliberal policies in an Australian context on the health and welfare sector. As explored in Chapter Two, Australia has a unique and long history of provision of services by non-government organisations through government funding but not necessarily government control on the type and quantity of the service to be delivered. Historically, non-government organisations have often been viewed as innovative and socially responsible in addressing human needs (O'Connor T. & Sacco, 1993). However, as T. O'Connor and Sacco point out, the irony of current government policies is that that they are creating an identity change in non-government organisations because in the process of cooperating with governments to become more efficient and accountable these organisations are being subjugated to a particular form of privatisation (O'Connor T. & Sacco, 1993). This study demonstrates the impact of this type of privatisation where non-government organisations operating on a not-for-profit basis provide packages of care alongside private for profit organisations under the same regulations and guidelines. While the aim may be stated as standardisation of services, from the findings of this study the outcome for older people appears to be that there is fragmentation and considerable variation in delivery of services which are hard to access.

A general wider theoretical implication of this research is also that it demonstrates the complexity of working with people who cannot easily be quantified. Many of the concepts in this thesis, such as what constitutes knowledge and a plurality of

understandings, may be applicable to other professional practice contexts in contemporary health and welfare systems. Similarly, it may be useful for other professionals to draw from modernist and postmodernist ideas. Social constructionist ideas support the notion that there may be a number of elements in any given situation but some basic processes may essentially be described so that decision-making can be better informed, such as those in assessments (Parton & O'Byrne, 2000a). How decisions are made with the person who is at the centre of the assessment can have a major impact, such as whether emotional welfare is taken into account as well as physical welfare. This is a challenge in an environment where there is an emphasis on risk assessments and the physical need for the safety of an older person is given priority. The constructionist approach has much to offer as it is the process that is viewed as important rather than searching for deficits. The research case studies clearly show that there is an on-going process, that is not linear or static, and there can be collaborative conversations and changes made as more is learnt in social situations that are very fluid.

### **8.3 Limitations of the study and suggested areas for further research**

There have been time and resource constraints to this study as it was undertaken as a PhD student. Access to more research case studies may have presented different perspectives as each individual socio-legal encounter is unique in its historical, social and cultural context. Likewise, access to more interviews with family members and people with dementia may have added more varied opinions. No claims are made here about the representations of the experiences of the participants for the entire population. The geographical area in which the people who were the focus of the individual research studies were located, north-west Sydney, is one that is predominantly residential with some rural margins. It has no heavy industry. Urban development accelerated after World War II and population increased substantially. Four of the five people who were the focus of the individual studies were post war migrants from four different European countries. They have similar characteristics in that they participated in the workforce, were married, bought their own homes, had excellent English speaking skills and generally blended into what could be described as an Anglo-Saxon "middle-class" economic status. It is suggested that more research is needed on socio-legal encounters which reflect the diversity of the Australian social and economic culture. Similarly, these people were aged

between 71 and 89 and therefore it is recommended that more research is required that reflects the diversity of the ages of people who are identified as needing a legal decision-maker.

As discussed in Chapter Four there were limitations imposed by the choice of using theoretical perspectives drawn from social constructionism and the consequent methodology chosen of a qualitative case study research design. In common with qualitative research, it is open to doubt how much the findings of this study may be generalised. Rather the purpose was to enable social workers to better understand the dynamics and the processes involved in socio-legal encounters. Similarly, interpretation was through the lens of the researcher's background and beliefs and how much this is reflected in coding and categorizing the data it is impossible to articulate. Likewise, estimating the impact of the insider status of the researcher is difficult. Particular challenges posed by a case study design included access to potential cases and the decision made to use Graham's research study case as the key case. Whilst boundaries of the cases became more explicit as the research progressed, it is possible these boundaries excluded potentially influential participants. A particular limitation of the theoretical approach in this study was that whilst there was a focus on the importance of pluralism and the necessity to consider the perspectives of all those involved in the social-legal encounters, this direction may have narrowed the extent to which wider theoretical perspectives were considered, such as the gendered nature of the power dynamics.

This study represents one step in the contributions towards understanding the impact of neoliberal policies in the Australian context on both social workers and older people and their families. Social workers are not a homogeneous group and, as M. P. Sullivan's (2009) research highlights, when professionally based values are juxtaposed against those supported within the official organisational discourse the tensions that arise may be resolved in different ways. It is these strategic responses where more research may be of benefit. Similarly, another area that may be taken further is critical investigation and research into the impact of neoliberal policies on non-government not-for-profit agencies in the Australian context. Here there may be incompatibility of the market values of privatisation with the values that have historically underpinned the significant and unique contribution of this social welfare sector.

It must also be borne in mind that this research was carried out during a period in time just prior to Australia's aged care system undergoing substantial restructuring and at the time of writing the sector is in considerable flux. These changes, substantially based on the recommendations of the Productivity Commission (Australian Government: Productivity Commission, 2011), support the ongoing transformation of the Australian welfare state into a mixed economy with free market principles. The Federal Government's Living Longer Living Better aged care reform package creates new entities such as the National Contact Service (Gateway) which aims to streamline access to services through one central referral point and the Aged Care Quality Agency, as well as introducing new financial arrangements. It remains to be seen how the implementation of these further structural changes will impact on social workers, other professionals and older people and their families. A submission to the Senate Community Affairs Legislation Committee by the Australian Association of Social Workers in April 2013 acknowledges the intention of the reforms to provide accessible, high quality services for older people. However, concerns regarding several issues related to the Bills before Parliament were put forward. These included that the National Contact Centre (Gateway) will provide older Australians with low-to-moderate needs with predominantly telephone assessments. The unease stems from the emphasis on the development of a website and call centre at the expense of establishing regional agencies with adequate resources to provide comprehensive information, needs assessment and structures to ensure continuity in services. Concern was also expressed regarding an increase in investment that may not be sufficient to respond to identified need, that increases in fees and bonds may result in financial disadvantage for some older people and their families, and that elimination of low and high care distinctions may introduce perverse incentives for providers to prioritise low care clients for whom the cost of services is lower (Australian Association of Social Workers, 2013). This is clearly an area recommended for further research as while this study was underpinned by a commitment to studying socio-legal encounters, the impact of the health and welfare systems in which these encounters are embedded has been substantially demonstrated.

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## Appendices

**Appendix 1: Letter to Senior Social Worker, Department of Geriatric  
Medicine, Westmead Hospital, with summary of proposed research**



**The University of Sydney**

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26 January 2008

Ms. Rosanne Walter  
Senior Social Worker  
Department of Geriatric Medicine  
Chesalon Villa  
Westmead Hospital  
WESTMEAD NSW 2145.

Dear Rosanne,

Following on from our telephone discussion on Friday, 18 January, as agreed attached is a summary of a proposed research study and what would be involved for the geriatric social workers at Westmead Hospital should they agree to participate in the study. The study aims to explore how social workers practice with people diagnosed as having dementia, their families and other professionals in complex situations where a guardianship/financial management application may be necessary.

As you know, the study would be undertaken as empirical research and will form the basis for my degree of PhD at the University of Sydney under the supervision of Professor Barbara Fawcett and Dr. Rosalie Pockett, Faculty of Education and Social Work. The project would be a collaborative study between the University of Sydney and Westmead Hospital Geriatric Social Workers and I hope would provide a focus for stimulating discussion and interaction on this very difficult area of social work practice.

If there is an interest in participating in the study I am happy to meet to answer any queries and to explain the project in more detail to yourself and colleagues, such as the Managers of the Social Work Department and Aged Care Assessment Team. I can be contacted on (m) 0413 960 187, (h) 9564 0131 and (w) 9767 5746 on Tuesdays, Wednesdays and Fridays. Looking forward to hearing from you.

Yours truly,  
Margaret Mills

## ***Dementia and guardianship: Challenges in decision-making and social work practice***

Below are details of a proposed study and what would be involved for the geriatric social workers at Westmead Hospital, should they agree to participate.

### **SUMMARY OF THE PROPOSED STUDY**

#### **Purpose of the study:**

The purpose of this research study is to improve professional practice in social work and provide knowledge that can be used for more effective intervention by social workers in the area of guardianship when a legal decision -maker may be needed for a person who is perceived as having dementia.

#### **Summary:**

The study aims to explore how social workers engage in practice with people diagnosed as having dementia, their families and other professionals in complex and ambiguous situations where a guardianship/financial management application may be necessary. The study will investigate the dilemmas and issues which are presented when it is perceived that a person with dementia can no longer make appropriate decisions and may need a legal guardian as the difficulties cannot be resolved informally. These issues can be extremely distressing and emotionally painful for those involved. There are competing interests surrounding the person with dementia, particularly in the areas of individual autonomy and protection from harm. From the social work practice perspective how dementia and incapacity are conceptualised and understood is very important as these understandings can dominate the interactions between those involved. A review of the literature shows that understandings of dementia have changed over the past thirty years from a biomedical condition with associated decline to a growing understanding of the importance of the person in their social, historical and cultural context. Australia has unique legislation on adult guardianship but this area has largely been ignored in the social work literature. There are contributions in social work practice contexts that identify the importance of advocacy, social justice, social work values and risk assessments in situations where a legal guardian may be necessary. However, these need to be taken further in this context to guide social work practice.

#### **Main Research Question:**

*How do Australian Social Workers engage in practice with people diagnosed as having dementia, their families and other professionals in complex situations where a guardianship/financial management application may be necessary?*

#### **Subsidiary questions:**

*What is the process of interaction and negotiation around issues that may necessitate an application for guardianship/financial management? Who makes decisions and why?*

*What are the values and tensions behind these negotiations and subsequent decision-making?*

*What is the impact in these situations of how dementia and incapacity are understood and what assumptions are made in these understandings?*

**Methodology:**

Two different methods will be used. Firstly, a case study design where a number of individual cases will be examined to provide insight into the process of how decisions are made around guardianship issues. In depth interviews with the social worker, family member or significant person and the person with dementia are proposed in each case. Secondly, a retrospective review and analysis of Guardianship Tribunal Orders will be undertaken.

**INVOLVEMENT OF WESTMEAD HOSPITAL GERIATRIC SOCIAL WORKERS**

If there is general agreement to participate in the study, the first step is approval of the study by the Ethics Committee at Westmead Hospital. This then needs to be ratified by the Ethics Office of Sydney University. This process can take some months. The application will be submitted by me, in collaboration with Westmead Hospital Social Work Department and the Department of Geriatric Medicine. The assistance and guidance of my PhD supervisors, Dr. Rosalie Pockett and Professor Barbara Fawcett of the Social Work Department, University of Sydney, will be valuable in this process. After this is approved the second step suggested is a meeting with the social workers from the geriatric wards and community teams to inform them about the study, what is involved and the time needed if they are willing to participate. Any participation is completely voluntary and individuals are free to withdraw at any time.

**What is involved**

The two methods will involve different levels of participation.

**1. Case study**

The number of case studies will be small. It is envisaged five cases will be chosen to be studied. In each case it is hoped that the social worker and other significant people, such as a family member/s and the person with dementia can be interviewed. Firstly, if a social worker is involved in a case they feel may be appropriate and would like to participate in the study it will be necessary to discuss the case with me to consider whether it meets the criteria for the study. These criteria are:

- The case will be considered typical in that it will be complex and arise from the perceived need for a legal decision-maker. This could be perceived by the social worker, family or other professional.
- The perceived need for a legal decision-maker is such that a guardianship application may be lodged within a short time frame (one to two months) or already has been lodged but the hearing has not taken place. This may be evidenced by the number of options used to try and resolve the issues unsuccessfully, high risk factors involved, amount of family conflict or amount of professional concern about safety issues.
- If possible, cases involving contrasting issues will be chosen. For example, some of these issues may be family conflict, family cohesion but dispute with the person with dementia, person living alone with no family supports, whether the person with dementia is an in-patient or community client.

If the case is included in the study this will involve the social worker in an interview for about an hour. The interview will be audio taped. The social worker will also be asked who else was involved in the case and the possibility of interviewing these people will be explored. The social worker may be requested to ask these other people if they would like to be involved in the study. If they agree I will follow up directly with them about what is involved. This would be an interview for about an hour which also will be recorded. If the person with dementia is willing to participate, and there is no objection by others such as family, this will involve a special process method of consent where information about this person, such as the best way to approach them, how they usually respond to situations and express themselves when happy or unhappy will be sought from the most appropriate person who may be family or the social worker.

## **2. Documentary analysis – retrospective analysis of Orders made by the Guardianship Tribunal of NSW**

The application to the Ethics Committee at Westmead Hospital will include a request to access medical records. The purpose of this is to access Orders made by the Guardianship Tribunal of NSW that are posted to those directly involved in a Guardianship Tribunal hearing, such as hospital social workers. These Orders are usually filed on the medical records by social workers as they may be needed to substantiate that a person with dementia, who is a client, has a legal guardian who may make decisions on their behalf in specific areas, for example such as accommodation. They summarise the circumstances that made the hearing necessary, the views of the person with dementia and their family and professionals. The legal officer of the Guardianship Tribunal has stated that, as long as none identifying data is used in the study, they have no objection to Orders being collected in this way, with the permission of the person to whom it was posted.

Through the social workers in geriatric medicine it is hoped to collect 20 to 30 Orders to be analysed. If willing to participate, social workers will be asked to identify cases where an Order was received so a copy of this Order may be accessed. I will then take out all identifying material for the analysis.

### **Time frame:**

Once the Ethics Committee has approved the study it is anticipated that the data collection phase will take about 18 months – from mid 2008 to the end of 2009. There are limits on my time as a researcher and more importantly, choice of cases is very important in a study such as this.

Margaret Mills  
PhD Student  
The University of Sydney



# Appendix 2: Human Research Ethics Committee Westmead Hospital Approval



**HUMAN RESEARCH ETHICS COMMITTEE (Westmead Campus)**  
 Research Office, Room 2020 Clinical Sciences  
 Westmead Hospital, Hawkesbury Road, Westmead NSW 2145

Telephone: 02 9845 8183  
 Facsimile: 02 9845 8352  
 Email: researchoffice@wmi.usyd.edu.au

Committee Secretariat:

**Professor Stephen Leeder AO**  
 Chair  
 Professor of Public Health &  
 Community Medicine

**Dr Jim Hazel**  
 Secretary  
 Medical Graduate -  
 Endocrinologist

Committee Members:

**Ms Therese Burke**  
 Clinical Trial Coordinator

**Mr Leonard Burney**  
 Layman

**Mrs Patricia Fa**  
 Clinical Trials Pharmacist

**Mr John Fisher**  
 Lawyer

**Ms Jillian Gwynne Lewis**  
 Patient Representative

**Dr Anthony Harris**  
 Medical Graduate - Psychiatrist

**Ms Jan Kang**  
 Diversity Health Institute

**A/Prof Ian Kerridge**  
 Haematologist and Bioethicist

**Ms Rada Kusic**  
 Research Manager

**Rev Sarah Plummer**  
 Minister of Religion

**Mr John Shaw**  
 Layman

**Dr Geoff Shead**  
 Medical Graduate - Surgeon

**Dr Howard Smith**  
 Medical Graduate - Endocrinologist

**Mrs Carol Walsh**  
 Laywoman

**Ms Shane Waterton**  
 Laywoman

**Ms Christine Wearne**  
 Clinical Psychologist

Our Ref: **HREC2008/7/4.5 (2828) AU RED 08/WMEAD/180**

24 February 2009

Professor Barbara Fawcett  
 Faculty of Education & Social Work  
 Building A35  
 The University of Sydney NSW 2006

Dear Professor Fawcett

Project title: Dementia and guardianship: challenges in social work practice

Thank you for your letter dated 15 September 2008 and subsequent correspondence addressing the matters raised in the HREC's letter dated 7 August 2008 following single ethical review of the above project at its meeting held on 29 July 2008.

This HREC has been accredited by the NSW Department of Health as a lead HREC to provide the single ethical and scientific review of proposals to conduct research within the NSW public health system. This lead HREC is constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research* and the *CPMP/ICH Note for Guidance on Good Clinical Practice*.

I am pleased to advise that the HREC has now granted ethical approval of this single site research project to be conducted at:

- Westmead Hospital - Chief Investigator Professor Barbara Fawcett and Principal Investigator Ms Rosanne Walter

The following documentation has been reviewed and approved by the HREC:

- Protocol Version 1.00, dated 11 June 2008
- Revised Participant Information and Consent Forms for Family Member or Significant Person, Version 3, dated 3 December 2008
- Revised Participant Information and Consent Forms for Person Responsible, Version 3, dated 3 December 2008
- Revised Participant Information and Consent Forms for Social Workers, Version 3, dated 3 December 2008
- Guide for interview for person with a diagnosis of dementia, Version 1, dated 11 June 2008
- Guide for Family/Significant People Interviews, Version 1, dated 11 June 2008

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Please note the following conditions of approval:

- The coordinating investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including unforeseen events that might affect continued ethical acceptability of the project.
- Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, are provided to the HREC to review in the specific format. A copy of all proposed changes is also provided to the relevant research governance officer.
- The HREC must be notified, giving reasons, if the project is discontinued at a site before the expected date of completion.
- The coordinating investigator must provide an annual report to the HREC and a final report at completion of the study, in the specified format. HREC approval is valid for 12 months from the date of final approval and continuation of the HREC approval beyond the initial 12 month approval period is contingent upon submission of an annual report each year. A copy of the Annual / Final Research Report Form is attached and can be obtained electronically from the Research Office on request.
- It should be noted that compliance with the ethical guidelines is entirely the responsibility of the researcher.

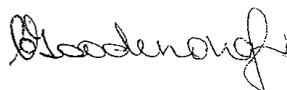
**You are reminded that this letter constitutes *ethical approval only*. You must not commence this research project at this site until separate authorisation from the Chief Executive or delegate of this site has been obtained. A copy of this letter and the approved Participant Information and Consent Forms must be forwarded to the Research Governance Officer.**

A summary of the HREC Standard Operating Procedures is attached for your reference. Should you have any queries about the HREC's Terms of Reference, Standard Operating Procedures or membership, please contact the HREC Executive Officer through the Research Office on 9845 8183 or emailing [researchoffice@wmi.usyd.edu.au](mailto:researchoffice@wmi.usyd.edu.au).

In all future correspondence concerning this study, please quote your approval number **HREC2008/7/4.5 (2828) AU RED 08/WMEAD/180**

The HREC wishes you every success in your research.

Yours sincerely



Ms Tina Goodenough  
HREC Executive Officer  
SWAHS Human Research Ethics Committee (Westmead Campus)

25 February 2009

Professor Barbara Fawcett  
Faculty of Education and Social Work  
Building A35  
The University of Sydney  
NSW 2006

Dear Professor Fawcett

**HREC reference number:** 08/WMEAD/180

**SSA reference number:** 08/WMEAD/188

**Project title:** Dementia and guardianship: challenges in alternative decision making and social work practice in a health care setting.

**Protocol number:** Version 1.00, dated 11 June 2008

Thank you for submitting an application for authorisation of this project. I am pleased to inform you that authorisation has been granted for this study to take place at the following sites:

- Westmead Hospital

The following conditions apply to this research project. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval:

1. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and which are submitted to the lead HREC for review, are forwarded to the Research Governance Officer once HREC approval is obtained;
2. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project, are to be submitted to the Research Governance Officer.

Yours faithfully



Ms Sonia Byrne  
Acting Research Governance Officer  
Sydney West Area Health Service

**COPY**

CC: Ms Rosanne Walter, Principal Investigator, Dept of Geriatric Medicine,  
Westmead Hospital

ABN: 70 667 812 600  
Post Office Box 63, Penrith NSW 2751  
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## Appendix 3: Ratification of Ethics Approval by University of Sydney



**The University of Sydney**

**Human Research Ethics Committee**

Web: <http://www.usyd.edu.au/ethics/human>

ABN 15 211 513 464

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**Gail Briody**

*Manager*

*Office of Ethics Administration*

**Marietta Coutinho**

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*Human Research Ethics Administration*

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The University of Sydney

NSW 2006 AUSTRALIA

Ref: MC/KR

15 May 2009

Professor Barbara Fawcett  
Faculty of Education and Social Work  
Education Building – A35  
The University of Sydney  
Email: [B.Fawcett@edfac.usyd.edu.au](mailto:B.Fawcett@edfac.usyd.edu.au)

Dear Professor Fawcett

**Title: Dementia and guardianship: challenges in alternative decision-making and social work practice in a health care setting. (Ref. No.11864)**

**PhD Student: Ms Margaret Mills**

Your application was reviewed by the Executive Committee of the Human Research Ethics Committee (HREC), and in doing so has ratified your study to include the PhD student – Ms Margaret Mills.

The Executive Committee acknowledges your right to proceed under the authority of *Sydney West Area Health Service Human Research Ethics Committee (Westmead Campus)*.

Please note, this ratification has been given only in respect of the ethical content of the study.

Any modifications to the study must be approved by *Sydney West Area Health Service Human Research Ethics Committee (Westmead Campus)* before submission to the University of Sydney Human Research Ethics Committee.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Marietta Coutinho', with a horizontal line underneath.

**Marietta Coutinho**

**Deputy Manager**

**Human Research Ethics Administration**

cc Ms Margaret Mills, c/o Professor Barbara Fawcett, Faculty of Education and Social Work, Education Building – A35, The University of Sydney [Email: [mmills@bigpond.net.au](mailto:mmills@bigpond.net.au) ]

## **Appendix 4: Guide for social worker or professional interviews**

### **SUBMISSION TO SYDNEY WEST AREA HEALTH SERVICE HUMAN RESEARCH ETHICS COMMITTEE, WESTMEAD CAMPUS**

**Title: Dementia and guardianship: challenges in alternative decision-making and social work practice in a health care setting.**

#### **GUIDE FOR SOCIAL WORKER/PROFESSIONAL INTERVIEWS**

This interview guide is based Mason's (2002) ideas regarding planning qualitative interviews. From the big research questions which the study is designed to explore, smaller or mini-research questions are developed. From these an overall loose structure/format and interview cards for the main topics to be covered is designed. These cards provide short hand information for the interviewer on the topic covered. This gives flexibility and prompts for the interviewer about the key issues and questions. However, with each interviewee lines of enquiry will be followed specific to their circumstances. The cards can be drawn on at any time during the interview. Areas of focus may be covered by the interviewee without having to draw on a particular card.

The primary research question is: *How do social workers engage in practice with people diagnosed as having dementia, their families and other professionals in complex situations where a guardian/financial management application may be necessary?* The four subsidiary questions are broken down as an interview guide to address this primary question.

Mason, J. (2002) *Qualitative Researching*. London: Sage.

#### **RESEARCH QUESTION 1.**

**What is the process of interaction and negotiation around issues that may necessitate an application for guardianship/financial management?**

#### **Mini research questions:**

1. Who was involved in the process and who has been left out?
2. Who initiated the process and maintained the negotiations?
3. Did the process follow an established professional procedure or guidelines?
4. In this process who made decisions and why?
5. What is your previous professional experience of guardianship proceedings?

**TOPIC CARD: History of process, professional practice, experience and decision-making**

**Who was involved in the process and who has been left out?**

Who are the people involved – i.e. person with dementia, family, professionals, service providers, neighbours. Get clear map of who is involved, how and why.

Who is not involved and why?

How long did the process take?

At what stage of the process did these people become involved?

**Who initiated and maintained the negotiations?**

Who made first move towards a guardianship application? Why?

Who put in the application? Why?

Who made contact with whom and how often?

Were the negotiations conflictual or supportive? Is this different with people involved? If there is conflict who is it between. If there is support who provides it?

What have the relationships been like between family and professionals, between professionals themselves?

Where does interviewee feel they are in this process of negotiations?

**Did the process follow an established professional procedure or guidelines?**

What professional guidelines were used?

In the professional involvement what helped and what hindered?

What was the team work involved? Was this supportive or not?

What pressures have there been?

What support has helped?

**In this process who made decisions and why?**

What decisions were made by family? Why?

What decisions were made by professionals? Why?

What is the reasoning/thinking behind these decisions?

How difficult has it been?

What were the expectations? Was the reality different? How?

**What is your previous professional experience of guardianship proceedings?**

History of experience with guardianship proceedings.

Professional history and experience.

Particular issues that were hard to manage professionally?

What professional education helped?

**RESEARCH QUESTION 2****What are the values and tensions behind these negotiations and subsequent decision-making?****Mini Research Questions:**

1. Was there an event that could be identified as a trigger event or ‘the last straw’?
2. What were perceived as the risks in the situation and who perceived these risks?
3. What were the differences in perceived risk between the people involved?

**TOPIC CARD: Perceptions on events seen as critical, risk factors and differences/similarities in perceptions, conflict and consensus**

**Was there an event that could be identified as a trigger event or ‘the last straw’?**

Was there an identified event? What led up to the event if so?

Was the event expected/unexpected?

Was there agreement within the family that the event was critical? Why or why not?

Was there agreement with professionals and family and between professionals?

Was there one event or a series of events?

What are the cultural issues? How relevant are they? What values are reflected?

**What were perceived as the risks in the situation and who perceived these risks?**

What was the person being protected from?

Who defined the need for protection?

What sort of risks were tolerated generally before the event or application?

What was done to try and minimise these risks?

What values are reflected in these risk factors? What was bad/hard to handle?

How did interviewee feel about the situation?

What are the benefits/negatives of the process?

How is the situation of the older person perceived after the application- what are the benefits/negatives?

**What were the differences in perceived risk between the people involved?**

Does the interviewee see family members working together? If so how?

How are the relationships between family/professions perceived in trying to resolve risks? What factors helped or hindered?

What conflict arose? Who created the conflict? Was the conflict pre-existing? Was the conflict seen as severe and if so why? Does the conflict still exist?

What were the relationships between the person with dementia and the people involved before the application? What are they like now?

**QUESTION 3.**

**What was the impact in these situations of how dementia is understood and what assumptions are made in these understandings?**

**Mini Research Questions:**

1. What is the social worker’s/professional’s understanding of dementia in this situation?
2. How has the social worker/professional learnt about dementia both formally and informally?
3. What behaviours are seen to be associated with the diagnosis of dementia?



4. How is dementia seen by the social worker/professional to affect the relationships in the family?

**TOPIC CARD: Professional education, perceptions about dementia and perceived changes in relationships due to dementia, assumptions being made**

**What is the social worker's/professional's understanding of dementia in this situation?**

In this situation what is seen as dementia by the social worker/professional?

Was there a formal medical diagnosis? By whom? Given to whom? How was this organised?

Was the diagnosis shared with the person concerned? Why or why not?

Does the person diagnosed with a dementia acknowledge/agree with the diagnosis? If so how or how not?

Does the family agree with the diagnosis of dementia? If so how? If not why not?

Do other professionals agree with the diagnosis?

What is seen as the future for the person with a diagnosis of dementia?

**How has the social worker/professional learnt about dementia both formally and informally?**

How long has the social worker/professional worked with people with dementia?

What formal/informal training has there been?

Have they had any personal experience with dementia?

**What behaviours are seen to be associated with the diagnosis of dementia?**

What behaviours are seen to be associated with the diagnosis of dementia?

Is there any different behaviour? Is the person with dementia seen to be changed? If so, how and by whom? What behaviours are seen as the same?

How critical are these changes seen?

**How is dementia seen by the social worker/professional to affect the relationships in the family?**

What role changes does the social worker/professional perceive in family relationships?

Is there any perceived difference between the way family and professionals view the person with a diagnosis of dementia? Why?

Are there differences within the family or significant people? Why?

**QUESTION 4.**

**What is the impact in these situations of how incapacity is understood and what assumptions are made in these understandings?**

**Mini research questions.**

1. What is the social worker/professional's understanding of capacity in this situation?
2. What differences are there in the perceptions of incapacity between the people involved?

**TOPIC CARD: Professional education, perceptions about capacity, differences in perceptions, assumptions**

**What is the social worker/professional's understanding of capacity in this situation?**

How was capacity assessed in this situation?

What is the professional background of those assessing capacity?

Are there any professional guidelines for assessing capacity? Do these differ?

What information is the social worker/professional using to assess capacity? What formal assessments were made, i.e. MMSE, neuropsychology? Who organised them?

**What differences are there in the perceptions of incapacity between the people involved?**

What events happened to question capacity? Who questioned it and how did this happen?

Is capacity seen as issue specific? What are the differences in perceptions?

What behaviour is seen as making the person incapable? In what areas? Why?

Is there agreement in understanding capacity between the people involved, i.e. professionals, family, and person with dementia.

Is there conflict? In which areas is there conflict and which areas agreement?

Why are there these differences and/or agreement?

## **Appendix 5: Guide for family or significant people interviews**

### **SUBMISSION TO SYDNEY WEST AREA HEALTH SERVICE HUMAN RESEARCH ETHICS COMMITTEE, WESTMEAD CAMPUS**

**Title: Dementia and guardianship: challenges in alternative decision-making and social work practice in a health care setting**

#### **GUIDE FOR FAMILY/SIGNIFICANT PEOPLE INTERVIEWS**

This interview guide is based Mason's (2002) ideas regarding planning qualitative interviews. From the big research questions which the study is designed to explore, smaller or mini-research questions are developed. From these an overall loose structure/format and interview cards for the main topics to be covered is designed. These cards provide short hand information for the interviewer on the topic covered. This gives flexibility and prompts for the interviewer about the key issues and questions. However, with each interviewee lines of enquiry will be followed specific to their circumstances. The cards can be drawn on at any time during the interview. Areas of focus may be covered by the interviewee without having to draw on a particular card.

The primary research question is: *How do social workers engage in practice with people diagnosed as having dementia, their families and other professionals in complex situations where a guardian/financial management application may be necessary?* The four subsidiary questions are broken down as an interview guide to address this primary question.

Mason, J. (2002) *Qualitative Researching*. London: Sage.

#### **RESEARCH QUESTION 1.**

**What is the process of interaction and negotiation around issues that may necessitate an application for guardianship/financial management?**

##### **Mini research questions:**

1. Who was involved in the process and who has been left out?
2. Who initiated the process and maintained the negotiations?
3. Do these negotiations follow a pattern established to resolve family issues or are they treated as an entirely separate matter?
4. In this process who made decisions and why?
5. What was the prior knowledge of the process of guardianship?

## **TOPIC CARD: History of process, relationships, interactions and decision-making**

### **Who was involved in the process and who has been left out?**

Who are the people involved – i.e. person with dementia, family, professionals, service providers, neighbours. Get clear map of who is involved, how and why.

Who is not involved and why?

How long did the process take?

At what stage of the process did these people become involved?

### **Who initiated and maintained the negotiations?**

Who made first move towards a guardianship application? Why?

Who put in the application? Why?

Who makes contact with whom and how often?

Were the negotiations conflictual or supportive? Is this different with people involved? If there is conflict who is it between. If there is support who provides it?

What have the relationships been like between family and professionals, between professionals themselves?

Where does interviewee feel they are in this process of negotiations?

### **Do these negotiations follow a pattern established to resolve family issues or are they treated as an entirely separate matter?**

History of relationships within the family

How have other significant life issues been resolved in the family?

Has the pattern of family response to guardianship been the same or different?

Relationship of family to professionals in the past.

Relationship of person with dementia to professionals in the past

Who gives the practical help?

What role did/does the person with dementia place in resolving issues within the family?

### **In this process who made decisions and why?**

What decisions were made by family? Why?

What decisions were made by professionals? Why?

What is the reasoning/thinking behind these decisions?

How difficult has it been?

What pressures have there been?

What support has helped?

What were the expectations? Was the reality different? How?

### **What is the prior knowledge of the process of guardianship?**

What plans had been put in place, e.g. powers of attorney, enduring guardianship.

In what way were the family prepared for the events of guardianship?

Who assisted the family with information about guardianship?

What was the process like for the interviewee?

## **RESEARCH QUESTION 2**

**What are the values and tensions behind these negotiations and subsequent decision-making?**

### **Mini Research Questions:**

1. Was there an event that could be identified as a trigger event or ‘the last straw’?
2. What were perceived as the risks in the situation and who perceived these risks?
3. What were the differences in perceived risk between the people involved?

### **TOPIC CARD: Perceptions on events seen as critical, risk factors and differences/similarities in perceptions, conflict and consensus**

#### **Was there an event that could be identified as a trigger event or ‘the last straw’?**

Was there an identified event? What led up to the event if so?

Was the event expected/unexpected?

Was there agreement within the family that the event was critical? Why or why not?

Was there agreement with professionals and family and between professionals?

Was there one event or a series of events?

What are the cultural issues? How relevant are they? What values are reflected?

#### **What were perceived as the risks in the situation and who perceived these risks?**

What was the person being protected from?

Who defined the need for protection?

What sort of risks were tolerated generally before the event or application?

What was done to try and minimise these risks?

What values are reflected in these risk factors? What was bad/hard to handle?

How did interviewee feel about the situation?

What are the benefits/negatives of the process?

How is the situation of the older person perceived after the application- what are the benefits/negatives?

#### **What were the differences in perceived risk between the people involved?**

Does the interviewee see family members working together? If so how?

How are the relationships between family/professions perceived in trying to resolve risks? What factors helped or hindered?

What conflict arose? Who created the conflict? Was the conflict pre-existing? Was the conflict seen as severe and if so why? Does the conflict still exist?

What were the relationships between the person with dementia and the people involved before the application? What are they like now?

### **QUESTION 3.**

#### **What was the impact in these situations of how dementia is understood and what assumptions are made in these understandings?**

### **Mini Research Questions:**

1. How was information about dementia obtained by the person with dementia, their family or significant person?

2. What behaviours are seen to be associated with the diagnosis of dementia?
3. What are the differences in relationships with the person with a diagnosis of dementia?

**TOPIC CARD: Information received, perceptions about dementia and changes in relationships, assumptions being made**

**How was information about dementia obtained by the person with dementia, their family or significant person?**

Was there a formal diagnosis? By whom? Given to whom?

Was the diagnosis shared with the person concerned? Why or why not?

Does the person diagnosed with a dementia acknowledge/agree with the diagnosis? If so how?

Does the family agree with the diagnosis of dementia? If so how? If not why not?

Do professionals agree with the diagnosis? Are there any differences of agreement?

What is seen as the future for the person with a diagnosis of dementia?

**What behaviours are seen to be associated with the diagnosis of dementia?**

Is there any different behaviour? Is the person with dementia seen to be changed? If so, how? What behaviours are seen as the same?

If there are changes how has this affected their lifestyle? How do these changes affect family and others? How are these changes seen by professionals?

How critical are these changes seen? What is different about the life of the interviewee? Why?

**What are the differences in relationships with the person with a diagnosis of dementia?**

If there are changes what are the most critical to the interviewee? Why? What changes don't matter? Why?

What role changes have there been in relationships?

Is there any perceived difference between the way family and professionals view the person with a diagnosis of dementia? Why?

Are there differences within the family or significant people? Why?

**QUESTION 4.**

**What is the impact in these situations of how incapacity is understood and what assumptions are made in these understandings?**

**Mini research questions.**

1. What information has been received about capacity?
2. How is incapacity perceived by the family/significant person?
3. What differences are there in the perceptions of incapacity between the people involved?

**TOPIC CARD: Information received, perceptions about capacity, differences in perceptions, assumptions**

**What information has been received about incapacity?**

What 'official' information has been given to the interviewee? By whom and shared with whom.

Is there agreement/disagreement with the information given? By whom?

What information has the interviewee sought out and how?

**How is incapacity perceived by the family/significant person?**

What behaviour is seen as making the person incapable? In what areas? Why?

How does the person with a diagnosis of dementia see decision-making and their part in it?

What does capacity mean to the interviewee? Is this different to before the application? If so, how?

**What differences are there in the perceptions of incapacity between the people involved?**

Is there agreement in understanding capacity between the people involved, i.e. professionals, family, and person with dementia.

Is there conflict? In which areas is there conflict and which areas agreement?

Why are there these differences and/or agreement?

## Appendix 6: Participant information and consent forms for social workers



### PARTICIPANT INFORMATION SHEET AND CONSENT FORM FOR SOCIAL WORKERS

**Study Title: Dementia and guardianship: challenges in alternative decision-making and social work practice in a health care setting.**

**Chief Investigator: Professor Barbara Fawcett**  
**Faculty of Education and Social Work**  
**University of Sydney.**

**Principal Investigator: Ms. Rosanne Walter**  
**Westmead Hospital**

#### **Invitation**

You are invited to participate in a research study into how social workers practice with people with a diagnosis of dementia, their families and other professionals in situations where a guardianship/financial management application may be necessary. The study is being conducted by Margaret Mills and will form the basis for the degree of PhD at the University of Sydney under the supervision of Professor Barbara Fawcett, Faculty of Education and Social Work, University of Sydney. This study is in collaboration with the Department of Social Work and Department of Geriatric Medicine, Westmead Hospital. It is an independent study and not associated with the N.S.W. Guardianship Tribunal. Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

#### **What is the purpose of the study?**

The purpose is to investigate how decisions are made in individual cases in situations where a guardianship/financial management order has been lodged or is about to be lodged with the Guardianship Tribunal of New South Wales. The study is being conducted in order to improve professional practice by social workers by gaining knowledge that can be used by social workers and other professionals to understand these situations from the different perspectives of the people involved.

#### **Who will be invited to enter the study?**

You are eligible to participate in this study because you are a social worker involved in a case where an application has been lodged or is about to be lodged with the Guardianship Tribunal of N.S.W.

#### **Do you have a choice?**

Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect the treatment you receive now or in the future. Whatever your decision, it will not affect your relationship with the



staff of the Department of Geriatric Medicine, Westmead Hospital, or your employment with SWAHS. If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason.

### **What will happen on the study?**

If you agree to participate in this study, you will be asked to sign the Participant Consent Form.

You will be asked to identify a case that meets the criteria for the study. The case will be considered typical in that it will be complex and arise from the perceived need for a legal decision-maker. The perceived need will be such that a guardianship application has been lodged or is about to be lodged within a short time from (i.e. 1 to 2 months). This may be evidenced by the number of options used to try and resolve the issues unsuccessfully. High risk factors will be involved, such as dangerous wandering, unsafe use of electrical appliances. You will be asked who else is involved in the application, i.e. professionals and family members or significant people. The researcher will explore with you the possibility of interviewing these people and you will be requested to ask them if they would like to be involved. If this poses problems they can be discussed with the researcher. All information is confidential.

This study will be conducted over 18 months. It will involve you, as a social worker, other professional or family/significant person to a person with a diagnosis of dementia, to be interviewed by the researcher for about an hour. The interview will be audio taped. A follow up interview may be necessary for the researcher to clarify information with you. The interview will be conducted at a place of your choice.

### **Are there any risks?**

Social situations that give rise to applications to the Guardianship Tribunal to make decisions for a person with a diagnosis of dementia can be distressing for the people involved. If, during the course of an interview, you become distressed in any way the interview will be terminated and support obtained. If the interview has raised matters which have caused distress, then further counselling will be offered.

### **Are there any benefits?**

This study aims to further knowledge in decision-making in social situations where an application to the Guardianship Tribunal of NSW may be necessary for a person with dementia. Being able to tell your story about the events that lead to a guardianship application and how decisions were made in your unique situation, and the unique situation of the person with dementia, can be of benefit as it provides an opportunity to reflect on what was important to you.

### **Confidentiality / Privacy**

Any identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission, or except as required by law. Only the researchers named above will have access to your details. The audio tapes from the interviews will be held securely at the University of Sydney until the study is completed. All identifying material will be taken out when the tapes are transcribed. Your tape can be returned to you at the end of the study if you wish.

**Will taking part in this study cost me anything, and will I be paid?**

Participation in this study will not cost you anything.

**What happens with the results?**

If you give us your permission by signing the consent document, it is planned to discuss/publish the results in a referred journal, conference presentation, professional forums and community groups such as carer support groups. In any publication, information will be provided in such a way that you cannot be identified. A summary of the study will be provided to you, if you wish.

*Complaints*

This study has been approved by Sydney West Area Health Service Human Research Ethics Committee, Westmead Campus. Any staff member with concerns or complaints about the conduct of this study should contact:

The Secretary,  
SWAHS Human Research Ethics Committee  
Telephone No 9845 8183 or email [researchoffice@westgate.wh.usyd.edu.au](mailto:researchoffice@westgate.wh.usyd.edu.au)

who is the person nominated to receive complaints from research participants. You should contact them on 9845 8183 and quote HREC2008/7/4.5(2828) AU RED 08/WMEAD/180.

*Contact details*

When you have read this information, the researcher Margaret Mills will discuss it with you and any queries you may have. If you would like to know more at any stage, please do not hesitate to contact her on 0413 960 187. If you have any problems while on the study, please contact Professor Barbara Fawcett, Faculty of Education and Social Work, University of Sydney on 9351 4038 and/or Ms. Rosanne Walter, Department of Geriatric Medicine, Westmead Hospital on 9845 6903.

**If you wish to take part in it, please sign the attached consent form.**

**This information sheet is for you to keep.**

## CONSENT TO PARTICIPATE IN RESEARCH

**Name of Researcher: Margaret Mills**

1. I understand that the researcher will conduct this study in a manner conforming to ethical and scientific principles set out by the National Health and Medical Research Council of Australia and the Good Clinical Research Practice Guidelines of the Therapeutic Goods Administration.
2. I acknowledge that I have read, or have had read to me the Participant Information Sheet relating to this study. I acknowledge that I understand the Participant Information Sheet. I acknowledge that the general purposes, methods, demands and possible risks and inconveniences which may occur to me during the study have been explained to me by Margaret Mills, the researcher, and I, being over the age of 16 acknowledge that I understand the general purposes, methods, demands and possible risks and inconveniences which may occur during the study.
3. I acknowledge that I have been given time to consider the information and to seek other advice.
4. I acknowledge that refusal to take part in this study will not affect the usual treatment of my condition.
5. I acknowledge that I am volunteering to take part in this study and I may withdraw at any time.
- 6. I acknowledge that this research has been approved by the Sydney West Area Health Service Human Research Ethics Committee.**
- 7. I acknowledge that I have received a copy of this form and the Participant Information Sheet, which I have signed.**

*Before signing, please read 'IMPORTANT NOTE' following.*

**IMPORTANT NOTE:**

*This consent should only be signed as follows:*

1. *Where a participant is over the age of 16 years, then by the participant personally.*

**Name of participant** \_\_\_\_\_

**Date of Birth** \_\_\_\_\_

**Address of participant**

\_\_\_\_\_

**Signature of participant** \_\_\_\_\_

**Date:** \_\_\_\_\_

**Signature of researcher** \_\_\_\_\_

**Date:** \_\_\_\_\_

**Signature of witness** \_\_\_\_\_

**Date:** \_\_\_\_\_

## **Appendix 7: Participant information and consent form for family member of significant person**



### **PARTICIPANT INFORMATION SHEET AND CONSENT FORM FOR FAMILY MEMBER OR SIGNIFICANT PERSON**

**Study Title: Dementia and guardianship: challenges in alternative decision-making and social work practice in a health care setting.**

**Chief Investigator: Professor Barbara Fawcett  
Faculty of Education and Social Work  
University of Sydney**

**Principal Investigator: Ms. Rosanne Walter  
Westmead Hospital**

#### **Invitation**

You are invited to participate in a research study into how social workers practice with people with a diagnosis of dementia, their families and other professionals in situations where a guardianship/financial management application may be necessary. The study is being conducted by Margaret Mills and will form the basis for the degree of PhD at the University of Sydney under the supervision of Professor Barbara Fawcett, Faculty of Education and Social Work, University of Sydney. This study is in collaboration with the Department of Social Work and Department of Geriatric Medicine, Westmead Hospital. It is an independent study and not associated with the N.S.W. Guardianship Tribunal. Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

#### **What is the purpose of the study?**

The purpose is to investigate how decisions are made in individual cases in situations where a guardianship/financial management order has been lodged or is about to be lodged with the Guardianship Tribunal of New South Wales. The study is being conducted in order to improve professional practice by social workers by gaining knowledge that can be used by social workers and other professionals to understand these situations from the different perspectives of the people involved.

#### **Who will be invited to enter the study?**

You are eligible to participate in this study because you are a family member or significant person involved in a case where an application has been lodged or is about to be lodged with the Guardianship Tribunal of N.S.W.

**Do you have a choice?**

Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect the treatment you receive now or in the future. Whatever your decision, it will not affect your relationship with the staff of the Department of Geriatric Medicine, Westmead Hospital. If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason.

**What will happen on the study?**

If you agree to participate in this study, you will be asked to sign the Participant Consent Form.

You have been identified by a Social Worker from the Department of Geriatric Medicine, Westmead Hospital, as a person who is a family member or a significant person involved in a case that meets the criteria for the study. The case will be considered typical in that it will be complex and arise from the perceived need for a legal decision-maker. The perceived need will be such that a guardianship application has been lodged or is about to be lodged within a short time from (i.e. 1 to 2 months). This may be evidenced by the number of options used to try and resolve the issues unsuccessfully. High risk factors will be involved, such as dangerous wandering, unsafe use of electrical appliances. You have indicated to the Social Worker that you are interested in participating in the study. All information is confidential.

This study will be conducted over 18 months. It will involve you, as family/significant person to a person with a diagnosis of dementia, to be interviewed by the researcher for about an hour. The interview will be audio taped. A follow up interview may be necessary for the researcher to clarify information with you. The interview will be conducted at a place of your choice.

**Are there any risks?**

Social situations that give rise to applications to the Guardianship Tribunal to make decisions for a person with a diagnosis of dementia can be distressing for the people involved. If, during the course of an interview, you become distressed in any way the interview will be terminated and support obtained. If the interview has raised matters which have caused distress, then further counselling will be offered.

**Are there any benefits?**

This study aims to further knowledge in decision-making in social situations where an application to the Guardianship Tribunal of NSW may be necessary for a person with dementia. Being able to tell your story about the events that lead to a guardianship application and how decisions were made in your unique situation, and the unique situation of the person with dementia, can be of benefit as it provides an opportunity to reflect on what was important to you.

**Confidentiality / Privacy**

Any identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission, or except as required by law. Only the researchers named above will have access to your details. The audio tapes from the interviews will be held securely at the University of Sydney until the

study is completed. All identifying material will be taken out when the tapes are transcribed. Your tape can be returned to you at the end of the study if you wish.

**Will taking part in this study cost me anything, and will I be paid?**

Participation in this study will not cost you anything.

**What happens with the results?**

If you give us your permission by signing the consent document, it is planned to discuss/publish the results in a referred journal, conference presentation, professional forums and community groups such as carer support groups. In any publication, information will be provided in such a way that you cannot be identified. A summary of the study will be provided to you, if you wish.

*Complaints*

This study has been approved by Sydney West Area Health Service Human Research Ethics Committee, Westmead Campus. Any staff member with concerns or complaints about the conduct of this study should contact:

The Secretary,  
SWAHS Human Research Ethics Committee  
Telephone No 9845 8183 or email [researchoffice@westgate.wh.usyd.edu.au](mailto:researchoffice@westgate.wh.usyd.edu.au)

who is the person nominated to receive complaints from research participants. You should contact them on 9845 8183 and quote HREC2008/7/4.5(2828) AU RED 08/WMEAD/180.

If you are a family member/significant person and have any concerns about the conduct of the study, or your rights as a study participant, you may contact:

Westmead Hospital Patient Representative, Ms Jillian Gwynne Lewis,  
Telephone No 9845 7014 or email [jillian.lewis@swahs.health.nsw.gov.au](mailto:jillian.lewis@swahs.health.nsw.gov.au)

*Contact details*

When you have read this information, the researcher Margaret Mills will discuss it with you and any queries you may have. If you would like to know more at any stage, please do not hesitate to contact her on 0413 960 187. If you have any problems while on the study, please contact Professor Barbara Fawcett, Faculty of Education and Social Work, University of Sydney on 9351 4038 and/or Ms Rosanne Walter, Department of Geriatric Medicine, Westmead Hospital on 9845 6903.

**If you wish to take part in it, please sign the attached consent form.  
This information sheet is for you to keep.**

## CONSENT TO PARTICIPATE IN RESEARCH

**Name of Researcher: Margaret Mills**

1. I understand that the researcher will conduct this study in a manner conforming to ethical and scientific principles set out by the National Health and Medical Research Council of Australia and the Good Clinical Research Practice Guidelines of the Therapeutic Goods Administration.
2. I acknowledge that I have read, or have had read to me the Participant Information Sheet relating to this study. I acknowledge that I understand the Participant Information Sheet. I acknowledge that the general purposes, methods, demands and possible risks and inconveniences which may occur to me during the study have been explained to me by Margaret Mills, the researcher, and I, being over the age of 16 acknowledge that I understand the general purposes, methods, demands and possible risks and inconveniences which may occur during the study.
3. I acknowledge that I have been given time to consider the information and to seek other advice.
4. I acknowledge that refusal to take part in this study will not affect the usual treatment of my condition.
5. I acknowledge that I am volunteering to take part in this study and I may withdraw at any time.
- 6. I acknowledge that this research has been approved by the Sydney West Area Health Service Human Research Ethics Committee.**
- 7. I acknowledge that I have received a copy of this form and the Participant Information Sheet, which I have signed.**

*Before signing, please read 'IMPORTANT NOTE' following.*



**IMPORTANT NOTE:**

*This consent should only be signed as follows:*

1. *Where a participant is over the age of 16 years, then by the participant personally.*

**Name of participant** \_\_\_\_\_

**Date of Birth** \_\_\_\_\_

**Address of participant**

\_\_\_\_\_

**Signature of participant** \_\_\_\_\_

**Date:** \_\_\_\_\_

**Signature of researcher** \_\_\_\_\_

**Date:** \_\_\_\_\_

**Signature of witness** \_\_\_\_\_

**Date:** \_\_\_\_\_

## **Appendix 8: Participant information sheet and consent form for ‘person responsible’**



### **PARTICIPANT INFORMATION SHEET AND CONSENT FORM FOR ‘PERSON RESPONSIBLE’**

**Study Title: Dementia and guardianship: challenges in alternative decision-making and social work practice in a health care setting.**

**Chief Investigator: Professor Barbara Fawcett  
Faculty of Education and Social Work  
University of Sydney**

**Principal Investigator: Ms Rosanne Walter  
Westmead Hospital**

#### **Invitation**

You are invited to participate in a research study into how social workers practice with people with a diagnosis of dementia, their families and other professionals in situations where a guardianship/financial management application may be necessary. The study is being conducted by Margaret Mills and will form the basis for the degree of PhD at the University of Sydney under the supervision of Professor Barbara Fawcett, Faculty of Education and Social Work, University of Sydney. This study is in collaboration with the Department of Social Work and Department of Geriatric Medicine, Westmead Hospital. It is an independent study and not associated with the N.S.W. Guardianship Tribunal. Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

#### **What is the purpose of the study?**

The purpose is to investigate how decisions are made in individual cases in situations where a guardianship/financial management order has been lodged or is about to be lodged with the Guardianship Tribunal of New South Wales. The study is being conducted in order to improve professional practice by social workers by gaining knowledge that can be used by social workers and other professionals to understand these situations from the different perspectives of the people involved.

#### **Who will be invited to enter the study?**

You are eligible to participate in this study because you are identified as a ‘person responsible’ for the person with a diagnosis of dementia who is the focus of the study. The Guardianship Tribunal of NSW describes the ‘person responsible’ as a spouse, unpaid carer or relative or friend who has a close personal relationship with the person with dementia.

**Do you have a choice?**

Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect the treatment you, or the person for whom you are responsible, receive now or in the future. Whatever your decision, it will not affect your relationship with the staff of the Department of Geriatric Medicine, Westmead Hospital. If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason.

**What will happen on the study?**

If you agree to participate in this study, you will be asked to sign the Participant Consent Form as the 'person responsible'.

Social workers from the Department of Geriatric Medicine, Westmead Hospital, will be asked to identify a case that meets the criteria for the study. The case will be considered typical in that it will be complex and arise from the perceived need for a legal decision-maker. The perceived need will be such that a guardianship application has been lodged or is about to be lodged within a short time from (i.e. 1 to 2 months). This may be evidenced by the number of options used to try and resolve the issues unsuccessfully. High risk factors will be involved, such as dangerous wandering, unsafe use of electrical appliances. Social workers will be asked who else was involved in the application, i.e. professionals and family members or significant people. The researcher will explore with the social worker the possibility of interviewing these people and the social worker will be requested to ask them if they would like to be involved. If this poses problems they can be discussed with the researcher. All information is confidential.

Consent is sought from you to interview the person with a diagnosis of dementia who is the focus of a possible application to the Guardianship Tribunal of NSW. Also, a special method of obtaining this person's consent directly will be used. This will involve obtaining from you information about this person, such as the best way to approach them, where is the best place to interview them, how they usually respond to situations and express themselves when happy or unhappy.

Once the researcher is confident that you and the person concerned are comfortable with the situation a very informal interview will take place which will include some observation as a method of understanding responses. The interview process with the person with a diagnosis of dementia may vary in time due to the sensitive nature of this type of interview. For example it may take one hour or two or three sessions of smaller amounts of time. The informal interview will be audio taped. When it is transcribed any identifying information will be removed.

**Are there any risks?**

Social situations that give rise to applications to the Guardianship Tribunal to make decisions for a person with a diagnosis of dementia can be distressing for the people involved. If, during the course of an interview, you or the person with dementia becomes distressed in any way the interview will be terminated and support obtained. If the interview has raised matters which have caused distress, then further counselling will be offered.

### **Are there any benefits?**

This study aims to further knowledge in decision-making in social situations where an application to the Guardianship Tribunal of NSW may be necessary for a person with dementia. For the person with dementia being able to tell their story about the events that may lead to a guardianship application and how decisions were made in their unique situation can be of benefit as it provides an opportunity to reflect on what their perceptions of the situation were. It will also ensure that it is acknowledged that it is important for their voice to be heard.

### **Confidentiality / Privacy**

Any identifiable information that is collected about the person with dementia in connection with this study will remain confidential and will be disclosed only with your permission, or except as required by law. Only the researchers named above will have access to your details. The audio tapes from the interviews will be held securely at the University of Sydney until the study is completed. All identifying material will be taken out when the tapes are transcribed. Your tape can be returned to you at the end of the study if you wish.

### **Will taking part in this study cost me anything, and will I be paid?**

Participation in this study will not cost you anything.

### **What happens with the results?**

If you give us your permission by signing the consent document, it is planned to discuss/publish the results in a referred journal, conference presentation, professional forums and community groups such as carer support groups. In any publication, information will be provided in such a way that you cannot be identified. A summary of the study will be provided to you, if you wish.

### *Complaints*

This study has been approved by Sydney West Area Health Service Human Research Ethics Committee, Westmead Campus. If you are a patient or family member/significant person and have any concerns about the conduct of the study, or your rights as a study participant, you may contact:

Westmead Hospital Patient Representative, Ms Jillian Gwynne Lewis,  
Telephone No 9845 7014 or email [jillian.lewis@swahs.health.nsw.gov.au](mailto:jillian.lewis@swahs.health.nsw.gov.au)

### *Contact details*

When you have read this information, the researcher Margaret Mills will discuss it with you and any queries you may have. If you would like to know more at any stage, please do not hesitate to contact her on 0413 960 187. If you have any problems while on the study, please contact Professor Barbara Fawcett, Faculty of Education and Social Work, University of Sydney on 9351 4038 and/or Ms. Rosanne Walter, Department of Geriatric Medicine, Westmead Hospital on 9845 6903.

**If you wish to take part in it, please sign the attached consent form.**

**This information sheet is for you to keep.**

## CONSENT TO PARTICIPATE IN RESEARCH

**Name of Researcher: Margaret Mills**

1. I understand that the researcher will conduct this study in a manner conforming to ethical and scientific principles set out by the National Health and Medical Research Council of Australia and the Good Clinical Research Practice Guidelines of the Therapeutic Goods Administration.
2. I acknowledge that I have read, or have had read to me the Participant Information Sheet relating to this study. I acknowledge that I understand the Participant Information Sheet. I acknowledge that the general purposes, methods, demands and possible risks and inconveniences which may occur during the study have been explained to me by the researcher, Margaret Mills, and I, being over the age of 16 years acknowledge that I understand the general purposes, methods, demands and possible risks and inconveniences which may occur during the study.
3. I acknowledge that I have been given time to consider the information and to seek other advice.
4. I acknowledge that refusal to take part in this study will not affect the usual treatment of condition or my relationship with the staff of Westmead Hospital.
5. I acknowledge that is volunteering to take part in this study and may withdraw at any time.
- 6. I acknowledge that this research has been approved by the Sydney West Area Health Service Human Research Ethics Committee.**
- 7. I acknowledge that I have received a copy of this form and the Participant Information Sheet, which I have signed.**

*Before signing, please read 'IMPORTANT NOTE' following.*

**IMPORTANT NOTE**

*This consent should only be signed as follows:*

- 1. Where a participant has impaired capacity, intellectual disability or is unconscious, then specific approval for the process for obtaining consent must be sought from the Human Research Ethics Committee. This approval has been sought and given.*

Name of participant \_\_\_\_\_ Date of Birth \_\_\_\_\_

Address of participant \_\_\_\_\_

**Signature of participant** \_\_\_\_\_ **Date:** \_\_\_\_\_

Name of person responsible \_\_\_\_\_

Address of person responsible (where applicable)

\_\_\_\_\_

**Signature of person responsible (where applicable)**

\_\_\_\_\_ **Date:** \_\_\_\_\_

**Signature of researcher** \_\_\_\_\_ **Date:** \_\_\_\_\_

Signature of witness \_\_\_\_\_ Date: \_\_\_\_\_

## **Appendix 9: Interview guide for person with dementia**

### **SUBMISSION TO SYDNEY WEST AREA HEALTH SERVICE HUMAN RESEARCH ETHICS COMMITTEE, WESTMEAD HOSPITAL**

**Title: Dementia and guardianship: challenges in alternative decision-making and social work practice in a health care setting.**

#### **Guide for interview for person with a diagnosis of dementia**

Process consent with the person who has a diagnosis of dementia, as outlined by Dewing (2007) will be used. This involves:

- Background preparation of the biography of the person and information about how and when the person can be best approached.
- Establishing basis of consent. This may be an adapted informed consent and/or knowledge of the person's usual presentation and level of well-being and how a decrease in the level of well being may be triggered or recognised, how the person usually consents to other activities within their day to day life. Tools such as descriptions of facial expressions may be used.
- Assessment of the person's cognitive abilities and preferred ways of taking on information. Includes extensive notes about location, time, information given and evidence to account for how consent is given for inclusion in the research.
- Monitoring of initial consent and note taking regarding this.
- Feedback to carers with permission of the person.

Dewing, J. (2007). Participatory research: A method for process consent with persons who have dementia. *Dementia*, 6(1), 11-25.

Mason, J. (2002) *Qualitative Researching*. London: Sage.

## **INTERVIEW STRUCTURE**

The interview may take more than one session depending on the particular circumstances. As appropriate conversational interviews/unstructured interview will be used. The pace of the interview will be dictated by the needs of the interviewee. The topics to be covered address the interview questions and are:

Outline of person/social circumstances



Interviewee's perceptions about guardianship, how the process came about, interactions with others regarding this and decision-making.



What event was seen as critical, risk factors and how these were perceived by others, conflict and consensus in the family or with significant others.



What information the person received and their understanding of dementia or their current abilities.



What information the person received and has about capacity and how this is understood.



Debrief the interviewee and ensure in comfortable surroundings.

## **OBSERVATION TECHNIQUES**

As the person with dementia may have memory problems, confusion, difficulties in verbal expression and other individual difficulties in communication observation will be taking place throughout the interview. Observation notes will be taken, if appropriate during the interview but if not appropriate as soon as possible after the interview has concluded. These notes will include the behaviour observed and what was happening or being said at the time it was observed. Particular attention will be paid to relationships, values and tensions, understandings of dementia and incapacity. These observations can be followed up with family, if appropriate, to verify.



## Appendix 10: Tree nodes and nodes

### NVivo Tree Node

### Nivo Node

aftermath			
	aftermath		
	aftermath for spouse		
	we'd still like to be together		
constructions of risk			
	differences in perceptions of risk and conflict		
	family perceived risks		
	level of risk tips balance		
	maintaining risky situations		
	service provider perceived risks		
	social worker perceived risks		
constructs of capacity			
	family understanding of capacity		
	Guardianship Tribunal capacity		
	professional understanding of capacity		
	person with dementia understanding of capacity		
	service provider understanding of capacity		
	social worker understanding of capacity		
constructs of dementia			
	family understanding of dementia		
	professionals understanding of dement		
	person with dementia understanding of dementia		
	service provider understanding of dementia		
	social worker understanding of dementia		
constructs of the process			
	family perceptions of process		
	private to public		
	person with dementia background		
	person with dementia perceptions of the process		
	service provider perceptions of the process		
	social worker perceptions of the process		
critical events			

	family perceptions of critical events		
	person with dementia perceptions of critical events		
	service provider perception of critical events		
	social worker perceptions of critical events		
decision-making			
	decision-making before critical event		
	family decision-making		
	Guardianship Tribunal summary		
	person with dementia decision-making		
	service provider decision-making		
	social worker decision-making		
	social worker ethics		
	who made decisions and why		
family relationships			
	family member perceptions of their relationship		
	impact of family situation		
	lack of responsible person		
	person with dementia perceptions of family relationships		
	service provider perceptions of family relationships		
	social worker perceptions of family relationships		
negotiating responsibility			
	family ambivalence		
	it was always down to me		
	negotiating responsibility		
	taking responsibility		
	what difference will guardianship make		
	you must not let him go home		
personhood			
	individual personality		
	intimate relations		
	'normalisation' of experience		
	objectification		
	seeing the person first		
	vicarious experience		
power			

	being excluded		
	collusion or alliances		
	conflict		
	lack of control		
	power by noncompliance		
	power through control		
	power through professional language		
	powerful family members		
	professional power		
professional support and experience			
	service provider professional experience		
	service provider professional support		
	social worker professional experience		
	social worker professional negotiation		
	social worker professional support		
	social worker use of guidelines, professional knowledge		
protection			
	duty of care or obligation to act		
	family protecting self		
	financial protection		
	protection from physical harm		
	protection from self (person with dementia)		
	protection from spouse		
	protection of staff going into the home OH&S		
	social worker protection of self		
sustaining self			
	feeling defensive		
	I'm alright		
	sustaining self		

## Appendix 11: Thematic analysis diagrams

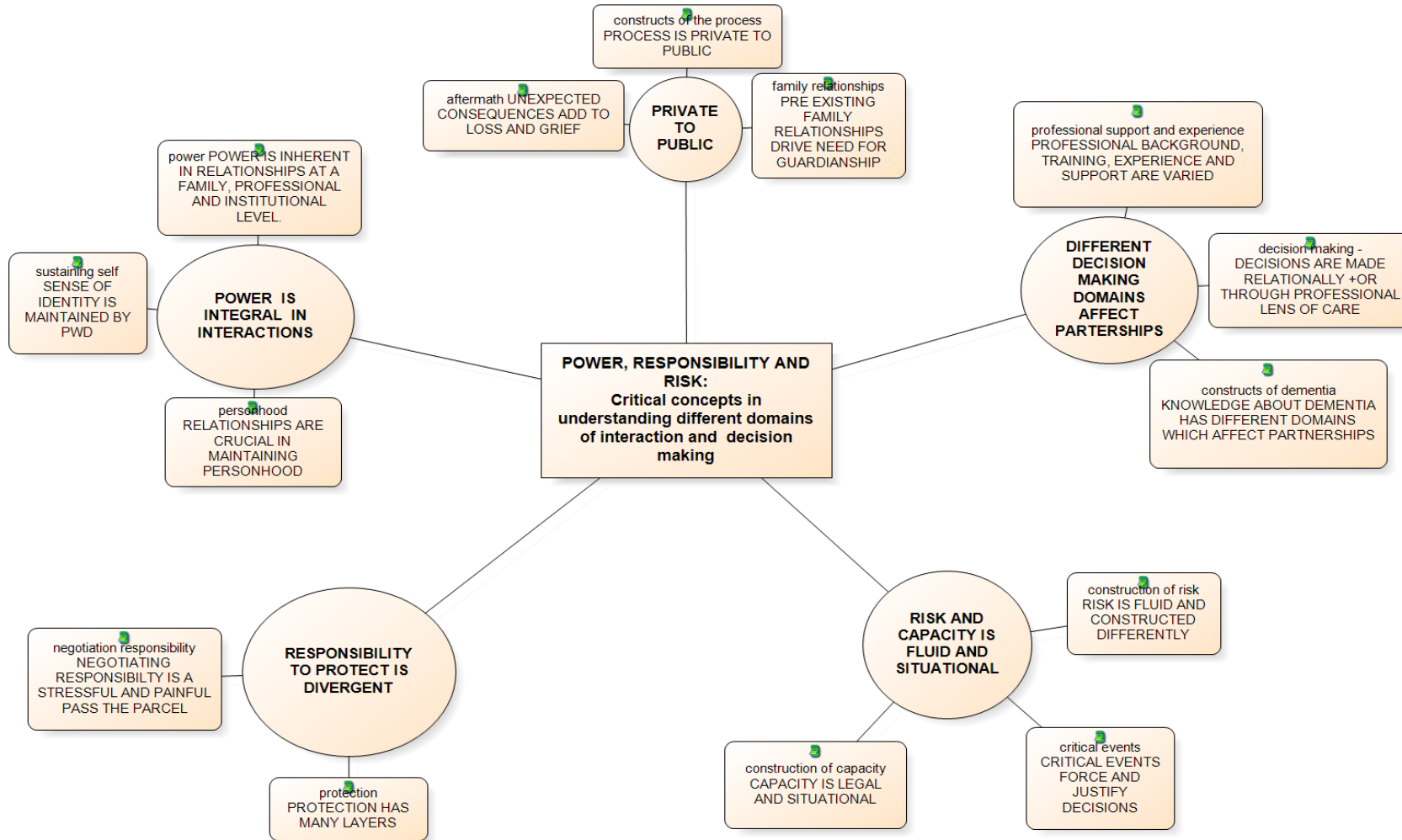


Figure A11.1: Thematic network analysis 1

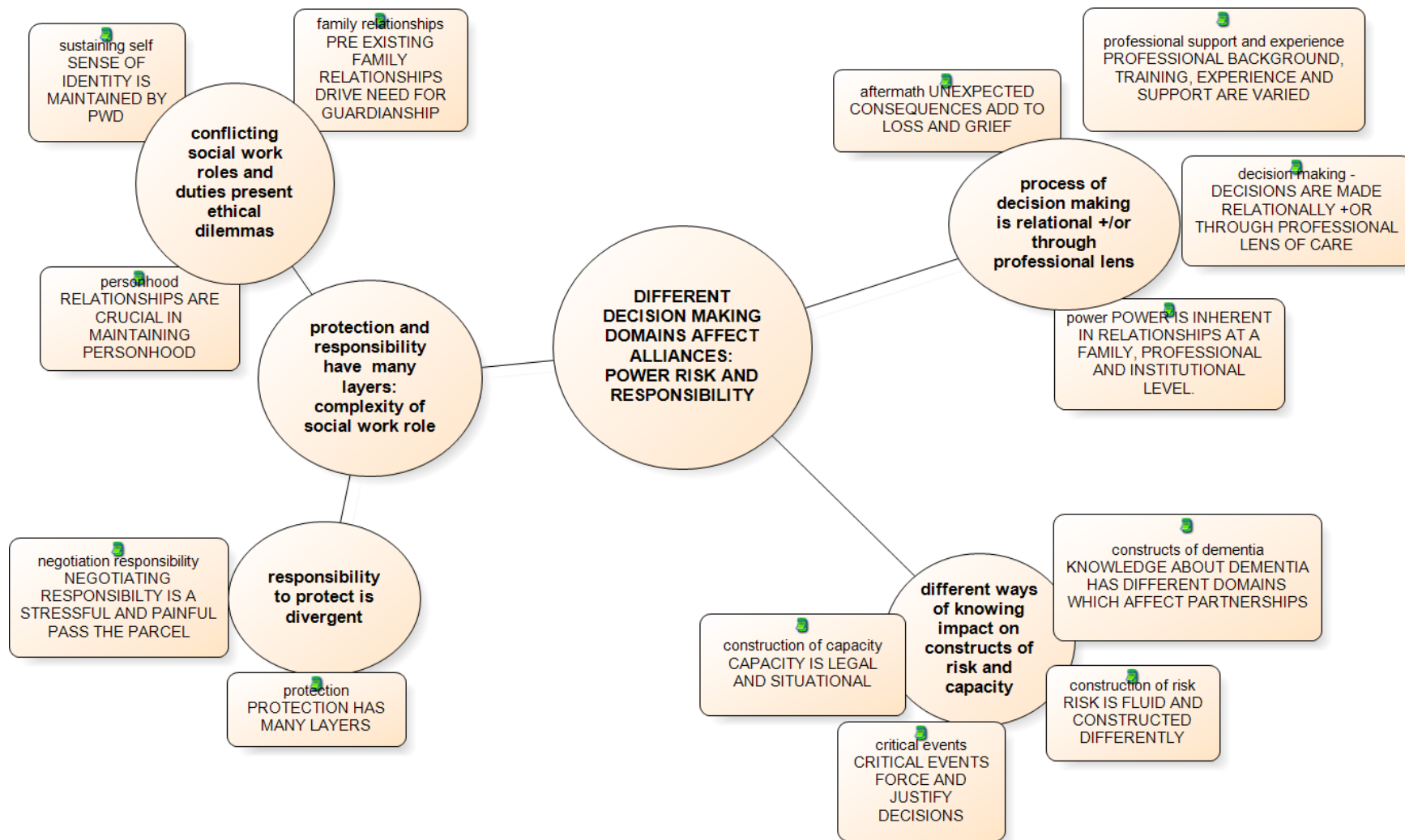


Figure A11.2: Thematic network analysis 2

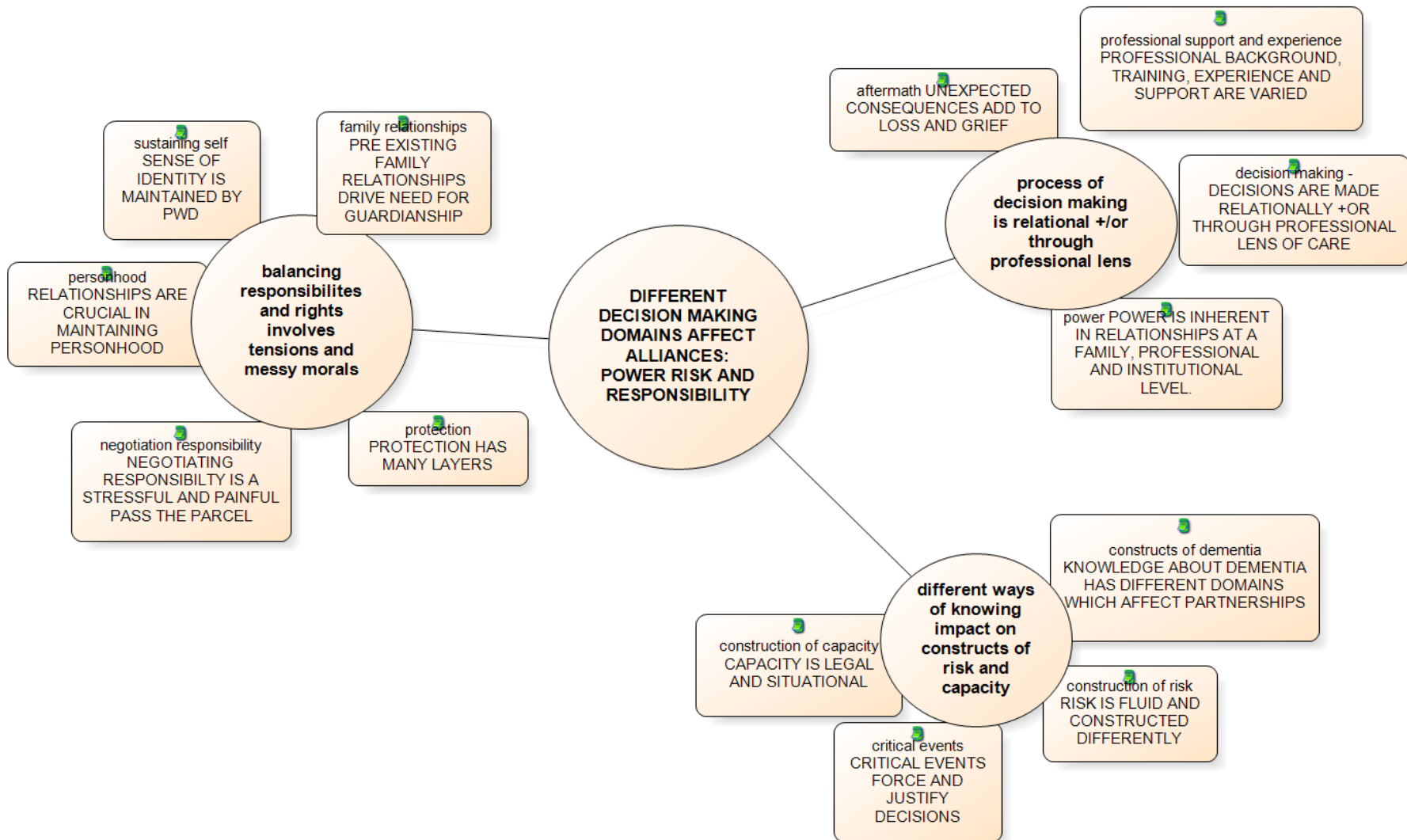


Figure A11.3: Thematic network analysis 3

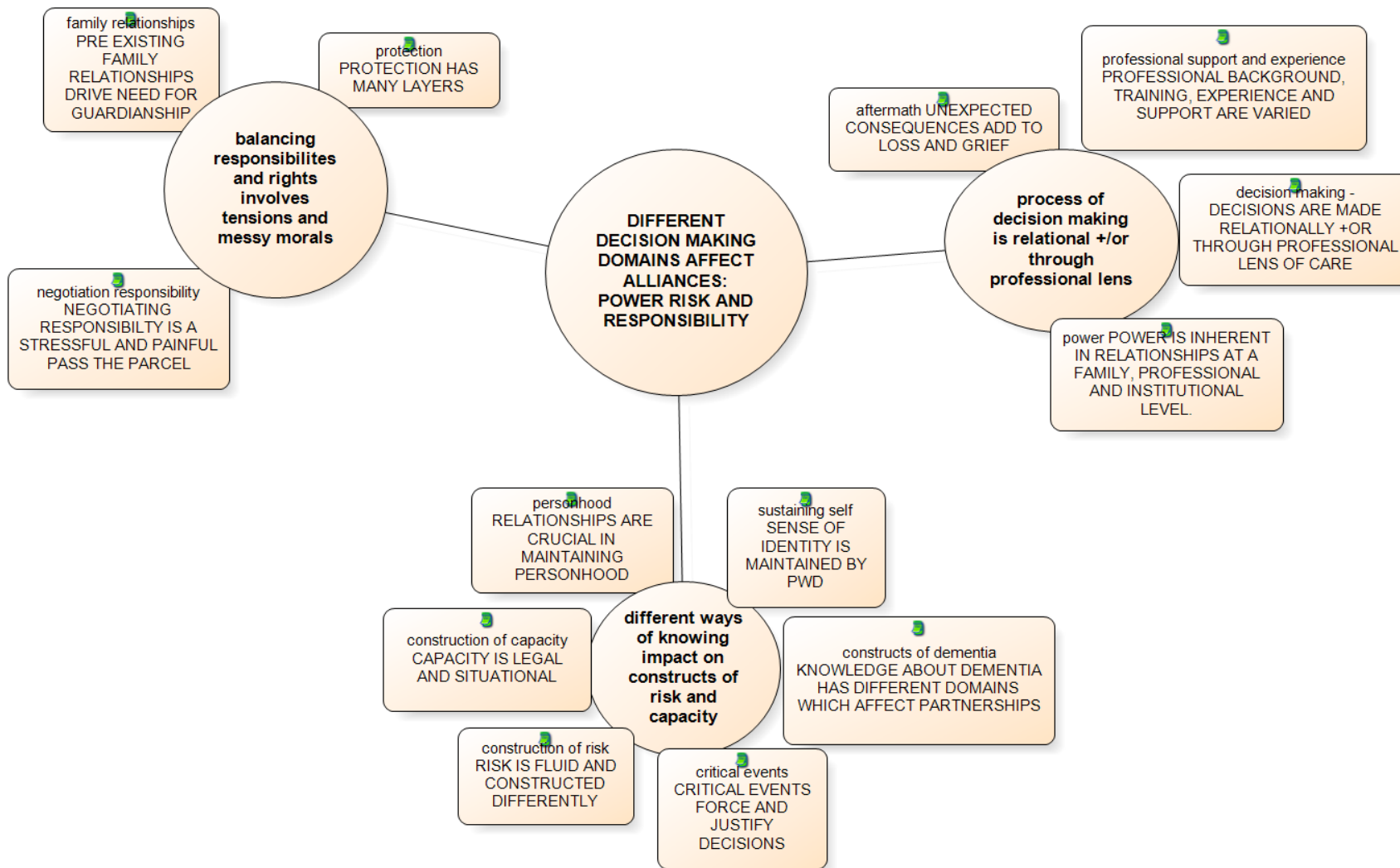


Figure A11.4: Thematic network analysis 4

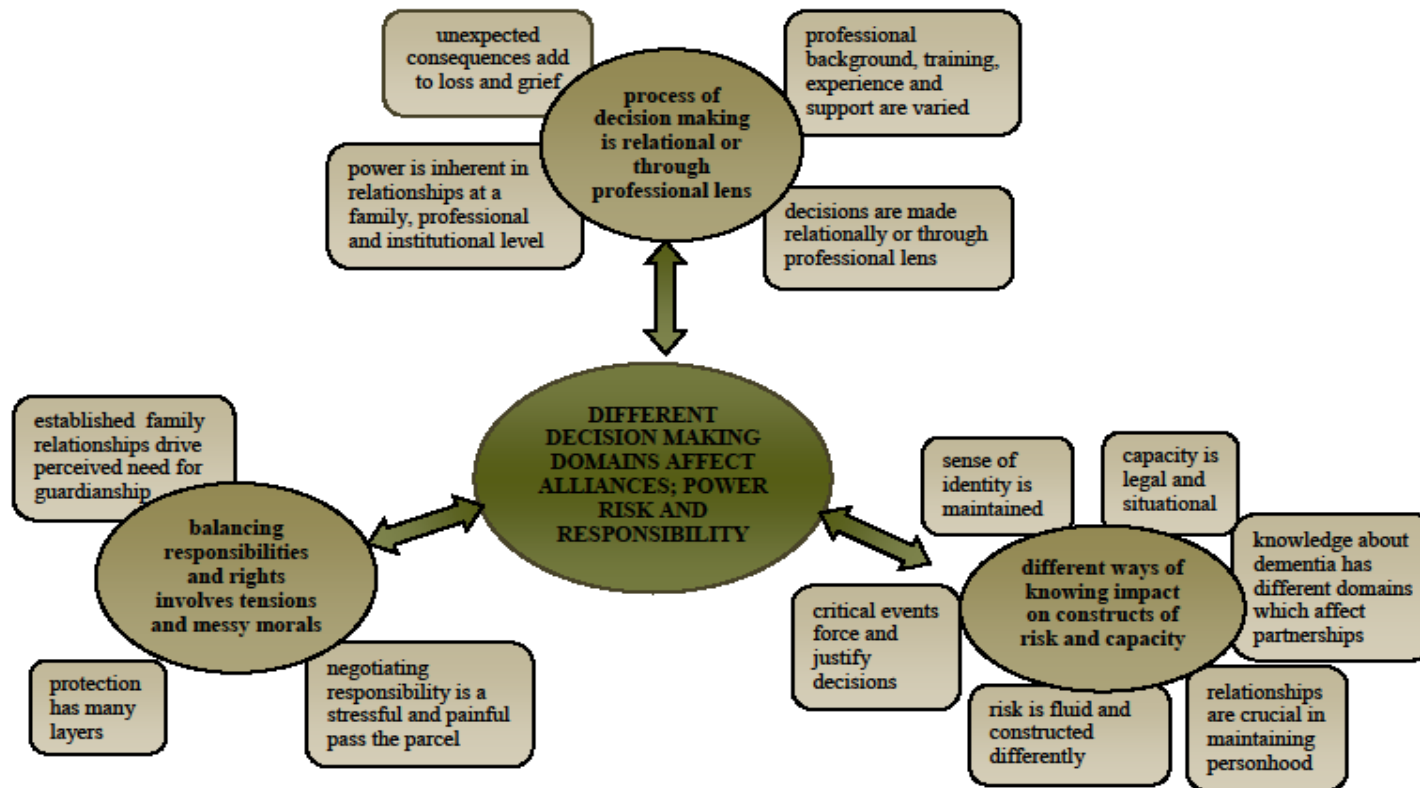


Figure A11.5: Thematic network analysis 5



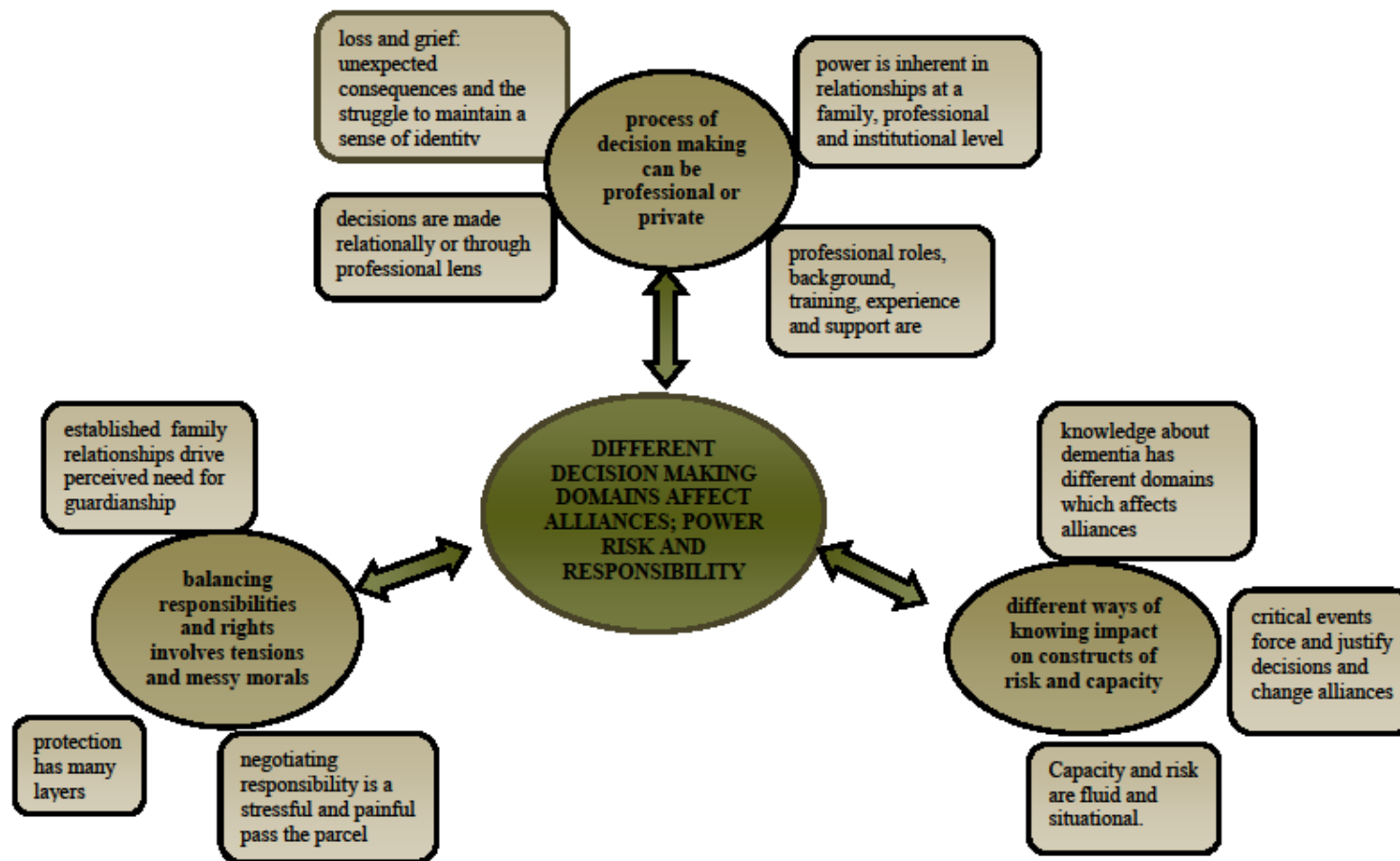


Figure A11.6: Thematic network analysis 6

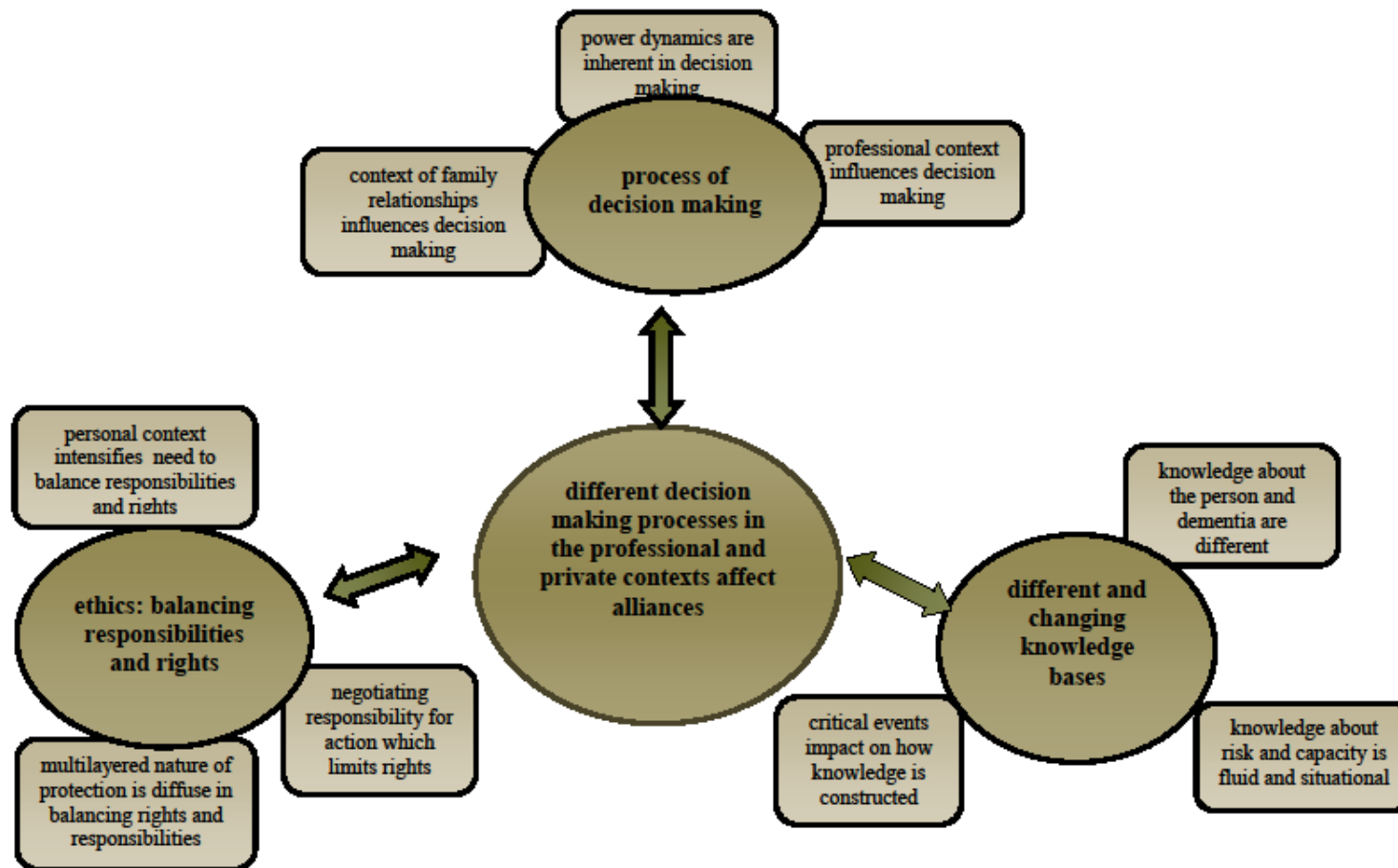


Figure A11.7: Thematic network analysis 7



Figure A11.8: Thematic network analysis 8

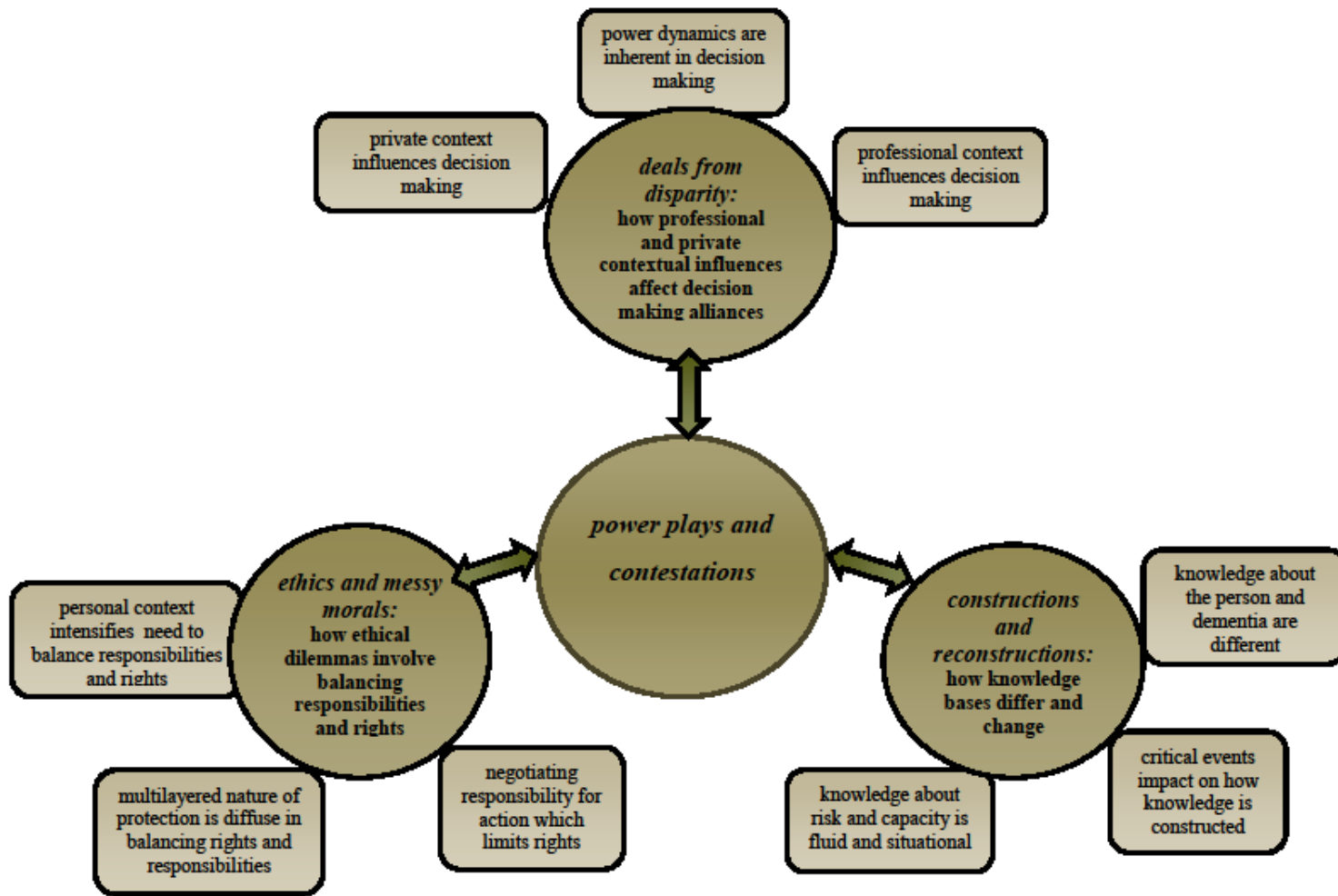


Figure A11.9: Thematic network analysis 9