A Grounded Theory of Care Management after Traumatic Brain Injury

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Statement of Authentication

The work presented in this thesis is, to the best of my knowledge original, except as acknowledged in the text. I have not submitted this material, either in full or in part, for a degree at this or any other institution.
## TABLE OF CONTENTS

Title Page ................................................................................................................ i  
Statement of Authentication ................................................................................... ii  
Table of Contents .................................................................................................. iii  
List of Tables ...................................................................................................... viii  
List of Figures ....................................................................................................... ix  
List of Appendices ................................................................................................. x  
Abstract ................................................................................................................. xi  
Acknowledgements .............................................................................................. xiii

### CHAPTER ONE: BACKGROUND TO THE STUDY ............................................. 1  
1.1 The Impact of Traumatic Brain Injury on Individuals and their Family .......... 2  
1.2 Long-Term Care ............................................................................................... 2  
1.3 The Need to Better Understand Care Decision-Making .................................. 3  
1.4 The Research Problem ..................................................................................... 4  
1.5 The Research Aim ............................................................................................ 5  
1.6 Significance of the Study .................................................................................. 5  
1.7 Scope of the Study ........................................................................................... 5  
1.8 Overview of the Thesis .................................................................................... 6

### CHAPTER TWO: REVIEW OF THE LITERATURE ........................................... 7  
2.1 Chapter Overview ............................................................................................ 7  
2.2 Traumatic Brain Injury ..................................................................................... 8  
  2.2.1 Incidence of Traumatic Brain Injury ....................................................... 8  
  2.2.2 Impact on the Person with Person with Traumatic Brain Injury .......... 9  
  2.2.3 Impact on Family Members ............................................................... 11  
  2.2.4 Impact on Society .............................................................................. 13  
2.3 Long-Term Care and Traumatic Brain Injury ............................................... 15  
  2.3.1 Definition of Long-Term Care ............................................................... 15  
  2.3.2 Characteristics of Long-Term Care ....................................................... 16  
  2.3.3 Funding of Long-term Care ................................................................. 18  
      2.3.3.1 Funding through Compensation .................................................. 19  
      2.3.3.2 Public Funding of Care ............................................................. 20  
  2.3.4 Providers of Care .................................................................................... 21  
      2.3.4.1 Family Carers ............................................................................. 21  
      2.3.4.2 Paid Carers ............................................................................... 22  
  2.3.5 Models of Care: Preferences of People with Disabilities ................. 23  
      2.3.5.1 The Paid Model of Care ............................................................. 24  
      2.3.5.2 The Consumer-Directed Model of Care .................................. 25  
      2.3.5.3 The Live-In Model of Paid Care ............................................. 27  
      2.3.5.4 Other Models and Characteristics of Care ......................... 28
2.3.5.5 Summary of Models of Care and Consumer Preferences ...29

2.4 Care Decision-Making .................................................................30
  2.4.1 Definition of a Major Decision ..............................................31
  2.4.2 Theories of Decision-Making .................................................31
  2.4.3 The Process of Decision-Making .............................................34
    Step 1: Seeking Information .........................................................34
    Step 2: Considering Alternatives .................................................35
    Step 3: Implementing a Course of Action .....................................36
    Step 4: Learning from Feedback ..................................................36
  2.4.4 Quality Decision-Making ......................................................37
  2.4.5 Factors that Influence Decision-Making ...............................38
  2.4.6 Use of Decision Aids .............................................................39
  2.4.7 Substitute Decision-Making ...................................................40

2.5 Theoretical Orientation and Methodology ...................................41

2.6 Chapter Summary .......................................................................41

2.7 Research Aim and Questions ....................................................43

CHAPTER THREE: RESEARCH METHODS .............................................44

3.1 Introduction to the Chapter .......................................................44

3.2 The Methodology: Grounded Theory ........................................44
  3.2.1 The Link between Grounded Theory and Symbolic Interactionism 45
  3.2.2 The Grounded Theory Debate .................................................46
    3.2.2.1 The Original Grounded Theory ........................................46
    3.2.2.2 The Straussian School of Grounded Theory .......................50
    3.2.2.3 The Glaserian School of Grounded Theory .......................50
  3.2.3 Substantive versus Formal Grounded Theory .........................52

3.3 Study Design ............................................................................52
  3.3.1 Setting ...................................................................................52
  3.3.2 Purposive and Theoretical Sampling ......................................53
  3.3.3 Eligibility Criteria: People with Brain Injury .........................54
  3.3.4 Participant Selection ...............................................................55
  3.3.5 Recruitment ..........................................................................57
  3.3.6 Sample Size and Characteristics ............................................59

3.4 Data Collection Methods ..........................................................63
  3.4.1 Method 1: Semi-Structured Interviews .................................63
    3.4.1.1 Interview Questions .......................................................63
    3.4.1.2 Reliability and Validity of Interview Responses ...............65
    3.4.1.3 Length, Order and Location of Interviews .....................67
  3.4.2 Method 2: Field Notes ...........................................................68
  3.4.3 Method 3: Diary Entries .........................................................68
  3.4.4 Method 4: Quantitative Measures .........................................69
    3.4.4.1 Choice of Quantitative Measures ....................................69
    3.4.4.2 Overview of Quantitative Measures ...............................70
      The Revised Craig Handicap Assessment and Reporting Technique 70
      The Sydney Psychosocial Reintegration Scale .........................72
      The Supervision Rating Scale .................................................73
      Hours of Direct Care and Supervision ..................................74
  3.4.4.3 Administration of Quantitative Measures ..........................74

3.5 Data Analysis ............................................................................75
  3.5.1 Analysis of Qualitative Data ................................................75

Page iv
8.7.1.1 Overcoming Risk Aversion ..................................................... 185
8.7.1.2 Education about Risk Management ......................................... 186
8.7.1.3 The Risk Management Team .................................................. 186
8.7.1.4 Risk Equalled Time Alone without Supervision ..................... 187
8.7.1.5 A Provisional Hierarchy of Risks .......................................... 187
8.7.2 ‘Care’ Management versus Case Management .............................. 188
8.7.2.1 People with Brain Injury needed face-to-face Visits ................. 188
8.8 Increased Autonomy: The Consequence of Successful Care Management 189
  8.8.1 Autonomy Defined ................................................................. 189
  8.8.2 Enhancing Autonomy Competency .......................................... 190
  8.8.3 Autonomy: More Important than Independence ....................... 191
8.9 Limitations of the Study ............................................................... 192
8.10 Implications for Practice and Policy ............................................ 194
8.11 Implications for Education .......................................................... 199
8.12 Implications for Future Research ............................................... 199
8.13 Conclusions .............................................................................. 199

REFERENCES ................................................................................. 201
LIST OF TABLES

Table 2.1  Criteria for Quality Decision-Making ..............................................37

Table 3.1  Total number of Participants (n=51) and Interviews (n=52) ..........60

Table 3.2  Level of Injury Severity of People with Brain Injury (n=14) .........61

Table 3.3  Characteristics of People with Brain Injury (n=14) ..................62

Table 4.1  Presentation of Cases according to Level of Supervision and Hours of Care .................................................................96

Table 4.2  Properties and Dimensions of the Four Ways of Living .............98

Table 5.1  The 10 Most Common Care-Related Decisions and Stage Post-Discharge .................................................................115
LIST OF FIGURES

Figure 3.1 Coding Scheme ................................................................................................. 79

Figure 4.1 The Care Management Cycle ......................................................................... 89

Figure 4.2 Levels of Handicap as measured by the R-CHART ................................. 91

Figure 4.3 Level of Psychosocial Reintegration based SPRS scores .................. 92

Figure 4.4 Level of Supervision on the SRS ................................................................. 93

Figure 4.5 Actual Hours of Direct Care and Supervision ......................................... 94

Figure 4.6 Mean Hours of Paid and Unpaid Care per Week ................................. 95

Figure 5.1 The Process of Care Decision-Making .................................................... 115

Figure 6.1 The Process of Care Maintenance ............................................................. 138

Figure 7.1 The Basic Social Process and Core Category: Optimising
            Care within a Preferred Way of Living.......................................................... 157
LIST OF APPENDICES

Appendix A  Suggestions for Occupational Therapists to Discuss with Solicitors /Insurance Company Representatives during Recruitment ................................................................. 232

Appendix B  Study Documentation:

B-1 Information Sheet ................................................................. 233
B-2 Consent Form for Person with Brain Injury ......................... 235
B-3 Background Information and Demographics ..................... 237

Appendix C  C-1 Interview Questions and Prompts (Early/Intermediate) ..... 241
C-2 Interview Questions and Prompts (Later Interviews) ............. 242

Appendix D  Quantitative Measures:

D-1 Revised-CHART .................................................................... 243
D-2 SPRS ................................................................................... 248
D-3 SRS ..................................................................................... 252

Appendix E  Raw Scores: Quantitative Measures:

E-1 Revised-CHART Raw Scores ............................................... 253
E-2 Total and Mean Scores on the SPRS Domains ................. 254
E-3 SRS Levels and Scores ....................................................... 255

Appendix F  Coding Tree ................................................................. 256

Appendix G  Ethics Approval:

G-1 Macquarie University, 1999 ................................................. 258
G-2 University of Western Sydney, 1999 ................................. 259
ABSTRACT

The consequences of a severe traumatic brain injury are substantial, both socially and financially, for the person affected, their family and society as a whole. The number of people needing long-term care and support, as well as costs, increase each year as more people survive their injury. Care in this context refers to a broad range of support services aimed at increasing societal participation by a person with brain injury. The majority of care costs following brain injury are for attendant care. Despite a general acceptance that long-term care is necessary, there are unexplained differences in the amount of compensation awarded, and the level of care and support required by people with apparently similar injuries. Therefore, the aim of this study was to explore the processes and conditions surrounding long-term care decision-making and care management after traumatic brain injury.

Grounded theory methodology and methods were used. Semi-structured interviews were conducted with a total of 51 participants in New South Wales, Australia. Sampling was purposive, then theoretical. The sample included 14 people with traumatic brain injury who had received compensation, and 37 other participants who either provided or coordinated care (family carers, paid carers, case managers, an Estate Manager and care agency directors). Triangulation of data sources was achieved by interviewing up to six participants associated with each of the 14 ‘cases’. A grounded theory of care management was developed through constant comparison of data and cases and identified a social problem, a core social process, strategies, conditions and consequences.

The basic social problem facing participants was the need for ongoing care, a problem which the person with brain injury and others managed collectively. Together, they determined an appropriate care location or living situation, configuration of carers and level of care. The basic social process for resolving this problem, and the core category of the study was Optimising Care within a Preferred Way of Living. Optimising care involved two sub-processes: care decision-making and care maintenance. Strategies used during care decision-making included gathering information, appraising alternatives and enacting a decision. Strategies used during care maintenance included monitoring the way of living, managing
conflict and supporting carers. The degree to which these strategies were used and the presence or absence of two conditions, mutual risk tolerance and a care manager, differentiated between those participants who did and those participants who did not experience optimal care. When strategies for care decision-making and care maintenance were used consistently, and when a care manager and mutual risk tolerance were present, people with brain injury experienced increased autonomy within their preferred way of living. This consequence was most evident when people with brain injury lived alone with low support and least evident when they lived in an institution. Autonomy was present to a lesser degree when a person with brain injury lived with their family, or lived alone with 24-hour care.

This grounded theory of care management provides a framework for understanding preferred ways of living with care after brain injury. Increased autonomy was a desired outcome. Living alone and spending time alone were associated with increased autonomy and increased risk. There is a need for models of care that provide opportunities for risk and autonomy. A series of strategies and processes are suggested that allow professionals and family carers to gradually increase risk, and share responsibility for risk management. The findings have implications for health professional and legal practice, education, research and policy.
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I am proud to have completed this study. The research is original, and makes an important contribution to knowledge, theory and practice. Nonetheless, the tasks of analysing, interpreting and writing up the findings could not have been completed without the help of several key people.

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CHAPTER ONE
BACKGROUND TO THE STUDY

Severe traumatic brain injury is a major social problem. Indeed ‘catastrophic injury’ is the term commonly used to reflect the impact of this condition on the person, their family and local community (Bowen, 2003; Bush, 1989; Hosack, 1998). Each year, approximately 2000 Australians sustain and survive a brain or spinal injury (Walsh, 2003). Of these, 120 with brain injury will need 12 or more hours of care and support\(^1\) every day for the rest of their life (Walsh et al., 2002). Family members provide much of this unpaid care, while governments and third party insurers fund additional paid care. The human and financial costs are substantial.

Long-term care is needed for several reasons. In addition to the more obvious physical changes, a person with brain injury may have cognitive and behavioural impairments (Ponsford, 1995a). The person may have poor awareness of these impairments, poor self-regulation, difficulty making decisions and difficulty remembering decisions that have been made. Everyday tasks such as taking a bus or train and money management become a major challenge. Such individuals are at risk of exploitation and further injury (Brain Injury Association of New South Wales [NSW], 1998; Brzuzy & Corrigan, 1996; Weed, 1999). Long-term care aims to compensate the person for lost skills and abilities, helping them to maintain important social roles and participate more fully in society (McCluskey, 2000; Motor Accidents Authority of NSW, 1994).

\(^1\) Although ‘support’ and ‘personal assistance’ are preferable and more empowering terms, ‘care’ is used widely in the literature and in practice by health and legal professionals. The term ‘care’ will therefore be used throughout this study. Care refers to a broad range of support services aimed at increasing societal participation by people with brain injury, and may be home or community-based. Services include: personal care, attendant care, respite care, financial management, extended case management, allied health services, and specialised disability equipment. In Australia, the majority of care costs following brain injury are for attendant care, which is typically provided by workers without special training or qualifications.
Despite the number of Australians with brain injury who need this type of care, and the substantial cost to society, surprisingly little is known about how these individuals experience long-term care and support, the way in which care needs are determined nor how care is managed in the long-term. This study aims to fill a gap in knowledge by exploring long-term care decision-making and care management after brain injury. This background chapter reviews the relationship between traumatic brain injury, long-term care, and care decision-making.

1.1 The Impact of Traumatic Brain Injury on Individuals and their Family

The impact on the person with brain injury is both physical and psychosocial, often resulting in a loss of roles such as parent, worker and friend (Leatham, Heath, & Woolley, 1996). Social isolation and loss of friends are common (Finset, Dyrnes, Krogstad, & Berstad, 1995). Consequently, they begin to rely on a small support network, most of whom are family members, paid carers or health professionals (Kozloff, 1987; McCluskey, 2000; Rowlands, 2000).

The impact of brain injury on families is both social and financial (Knight, Devereux, & Godfrey, 1998; Rees & Hannaford, 1996; Watanabe, Shiel, McLellan, Kurihara, & Hayashi, 2001). Spouses support the injured person and any children in the household, often at great personal cost (Man, 2002; Sinnakaruppan & Williams, 2001; Wade et al., 2002). A spouse or parent may give up paid work to care for the injured person. Economic loss is therefore high, both for the person and their family. Alternative long-term care arrangements are essential in any society, to support these family members as well as the person with brain injury (Motor Accidents Authority of NSW, 1994; Nosek & Howland, 1993; Walker, Kreutzer, & Witol, 1996).

1.2 Long-Term Care

In Australia, long-term care has been defined as the potentially wide range of services required by people with very severe injuries, and typically includes any or all of the following services:
Personal care, required on an ongoing basis... attendant care...home help, nursing care, allied health care, respite care, home maintenance, aids and appliances, transport, case planning and management, counselling and social support, financial planning and management (Foster v. Prospect County Council, 1999; Walsh et al., 2002).

A number of facts are known about long-term care for this population in Australia. First, there is an unmet need for specialised long-term care (Motor Accidents Authority of NSW, 1994). Second, inequalities exist between those with and without compensation (Bowen, 2003). People with similar levels of injury and need receive different services according to the cause of their injury, and whether or not they are eligible for compensation (Bowen, 2003; Walsh et al., 2002). For example, injuries sustained following an assault, during recreational activities or in the home are not typically compensable. Third-party compensation enables some people to buy care while others cannot. These inequities may lead to unwanted placement in an institution if there is no suitable place to live and no care funding (Brain Injury Association of NSW et al., 2002; Clough, 2003; Moseley, 2003).

Governments in Australia are slowly responding to community pressure for increased and more equitable funding of long-term care (Brain Injury Association of NSW et al., 2002; Physical Disability Council of NSW, 2003). For example, the topic featured as an agenda item at the August 2003 meeting of the Sixth Ministerial Council of Australian Governments (Bowen, 2003; Walsh, 2003). However, regardless of any impending legislative changes, transparent and accountable decision-making processes are required in relation to the allocation of compensation for care, and the allocation of care services.

1.3 The Need to Better Understand Care Decision-Making

Current processes and criteria for making decisions about care are inconsistent, at an individual and service level. Information is needed about factors that influence care decisions. We know intuitively, for example, that cost affects decision-making, since the cost over a person’s lifetime is so high. In this country, the average cost is approximately $250,000 to $300,00 Australian (AUD) per year for
24-hour paid care (Bloom & Associates, 1996; Hills, 2000). Although care costs are funded by taxes and insurance premiums, such as Worker’s Compensation and third party insurance, the manner in which these funds translate into services is unknown.

Courts make decisions about the allocation of long-term care costs based on expert medicolegal opinion. There are, however, no guidelines or formulae for determining long-term care needs or costs. Consequently, major variations are evident in the reasoning processes used by professional experts and by the courts. These variations are most evident when reviewing reported court cases. As a result of the lack of guidelines and empirical evidence, one expert may recommend 24 hours of care while another recommends two or three hours per day (Fitzgerald v. Dansey, 2001; Jones v. Bradley, 2003).

There is, therefore, a need for research that informs professionals and the courts about long-term care decision-making. Empirical data are required to answer questions about need, cost and other factors that may influence care use and decisions over the years. For example, individual preferences and values may influence care decisions. Family members have a keen interest in care and want to maximise their relative’s quality of life. However, limited information is available to family members when making important care-related decisions. By exploring the processes and conditions surrounding care decision-making and care management, care needs can be more accurately forecast and understood.

1.4 The Research Problem

Traumatic brain injury is a complex and challenging condition for the injured person, their family and the professionals who work with them. Long-term care aims to help people compensate for lost skills and abilities and to increase their social participation. Despite the potential benefits as well as the high cost of care, much remains unknown about how care decisions are made, how care is allocated and managed. There are likely to be a number of conditions, such as cost and compensation status, that influence care decisions and subsequent management. Identifying these conditions will help to explain variations. Such information will
benefit medicolegal professionals, family carers and others by providing ‘real life’ stories of people living with brain injury who need care. Further, the study will help insurers and government departments to plan for and allocate funding more appropriately.

1.5 The Research Aim

The aim of this study is to explore the processes and conditions surrounding care decision-making and care management after brain injury. No research was located that investigated care decision-making or management with this population.

1.6 Significance of the Study

By examining care decision-making and care management in a group of people with brain injury, and by using a qualitative methodology, new knowledge will be gained, specifically about: how long-term care is planned, implemented, managed and experienced; factors that influence care use and non-use; types of care decisions; and models of service delivery. Furthermore, the impact of care on a person’s living arrangements can be recorded. This new knowledge will potentially influence policy and practice by providing empirical data to people with brain injury, family members, professionals and policy makers.

This study also aims to develop a conceptual framework or theory that incorporates care decision-making and care management. Such a theory will have explanatory power and inform stakeholders about relationships between concepts, such as causal conditions and consequences, in this poorly understood area of community care.

1.7 Scope of the Study

This study will be limited to an investigation of adults with traumatic brain injury needing 24-hour care at the time of hospital discharge, and eligible for compensation. This group has the ability to purchase paid care, thereby increasing their options when they leave hospital.
1.8 Overview of the Thesis

In Chapter 2 (Review of the Literature), traumatic brain injury, long-term care and care decision-making are further examined, to clearly identify what is known and unknown about these domains. First, the incidence and impact of brain injury on the individual, their family and society are summarised. Second, characteristics and properties of long-term care are reviewed, about which decisions often need to be made. These include providers of care and different models or configurations of care. Third, what is known about the stages, process and theory of care decision-making will be critically analysed. No model or theory has been developed specifically for application to people with brain injury. Therefore, a case will be made for developing a new conceptual model of care decision-making and care management.

Chapter 3 describes the methodology and methods of grounded theory proposed for this study. Ethical considerations will also be reported, such as the conduct of interviews with people who have cognitive impairment.

Sample characteristics and ways of living with care are described in Chapter 4, providing context for the study. The dual processes of care decision-making (Chapter 5) and care maintenance (Chapter 6) are addressed next, followed by an integrated model of care management (Chapter 7) with case examples.

Chapter 8 presents a discussion of key findings in the context of existing literature, and highlights new knowledge and theory. This final chapter also addresses implications for practice, policy, education and research, and draws the study to a close with a conclusion.
CHAPTER TWO
REVIEW OF THE LITERATURE

2.1 Chapter Overview

This study seeks to explore and understand the processes and conditions surrounding care decision-making and care management after brain injury. Anecdotal reports suggest that these processes vary from one individual to another. These variations may lead to different services being provided, different management practices being used, and potentially different outcomes for people with brain injury. To help reduce some of these inconsistencies, there is a need to better understand how and why care decisions are made.

This chapter reviews three important topics relevant to the study aim: traumatic brain injury; long-term care; and care decision-making. First, background literature on traumatic brain injury in Australia will be examined, providing a context for the study. In addition to examining the incidence of traumatic brain injury, implications for the injured person, their family and society will also be considered. Second, the concept of long-term care for this population will be reviewed. Defining characteristics and models of long-term care will be reviewed, highlighting the preferences of people with disabilities. Third, the concept and theory of care decision-making will be considered. This section will explore the process and strategies used to make important care decisions, in addition to different styles and types of decision-makers. The limited literature will be examined, much of which focuses on older adults engaged in making decisions about institutional and community care. A case will be made for exploring these concepts and processes in a population of people with brain injury.

At the conclusion of this chapter, the strengths and limitations of different theories of care decision-making will be summarised, in addition to what is known and remains unknown. The chapter concludes with the aim of the study and research questions.
2.2 Traumatic Brain Injury

The term ‘traumatic brain injury’ refers to an injury to the brain resulting from trauma (O'Connor & Cripps, 1999). As a consequence of brain injury, there is usually loss of consciousness and some residual deficits. Motor vehicle and road-related accidents are the most common cause of injury in Australia and overseas (Brooks, Lindstrom, McCray, & Whiteneck, 1995; Fortune & Wen, 1999). Other causes of trauma include falls, injuries caused by a blow to the head and assaults.

‘Non-traumatic brain injury’ refers to an injury acquired by means other than trauma such as anoxia (lack of oxygen), tumours, stroke and cerebral haemorrhages. The term ‘acquired brain injury’ is an umbrella term encompassing injuries of traumatic and non-traumatic origin. For example, injuries from medical negligence or misadventure are mostly acquired through birth injuries and neurosurgery (Walsh et al., 2002). It is traumatic brain injury that will be the focus of the present study.

2.2.1 Incidence of Traumatic Brain Injury

As in many other countries, the incidence of traumatic brain injury in Australia still remains unacceptably high despite the introduction of random breath testing, compulsory seat belts, bicycle helmets and speed limits in most states and territories. The largest population sub-group affected by traumatic brain injury is 15 and 19 year old males (Fortune & Wen, 1999). There is also general agreement internationally (Brooks et al., 1995) and in Australia (Tate, McDonald, & Lulham, 1998) that more males than females sustain a traumatic brain injury.

Data on the incidence of traumatic brain injury in Australia are increasingly becoming available, and although imperfect, will be used in preference to overseas data. Best estimates in Australia are based on hospital separations (O'Connor & Cripps, 1999). Hospital records reveal 27,437 cases of newly diagnosed traumatic brain injury across Australia between July 1996 and June 1997 (Fortune & Wen, 1999). This number represents an annual rate of 149 per 100,000 population, and includes all levels of injury severity. The rate is higher than the 100 per 100,000 population reported by Tate et al. (1998) in NSW, and 69 per 100,000 population.
reported by Brooks et al. (1995) in Colorado, United States of America (USA). The high rate reported by Fortune and Wen (1999) possibly reflects the variety of hospital codes used to classify injuries in Australia. For example, the codes include skull fractures, which may or may not include an injury to the brain (Tate et al., 1998).

Of particular relevance to this study are those in need of long-term care as a result of brain injury. Approximately 16% of people with traumatic brain injury will be classified as moderate to severe (Kraus et al., 1984; Tennant, MacDermott, & Neary, 1995). In Australia, the proportion was recently recalculated using statewide and national actuarial data (Walsh et al., 2002). According to the severity of a brain injury, the following proportions of Australians are expected to need some long-term care: mild = 10%; moderate = 33%; and severe acquired brain injury = 100%. Although 27,435 people acquire a brain injury each year (Fortune & Wen, 1999), this only equates to 4,618 cases, and only about 500 of these people will need one or more hour of care per day (Walsh et al., 2002). These actuaries also estimated that each year, an additional 528 people nationally will need long-term care. The number of people nationally, therefore, with a newly acquired brain injury needing care each year will be between 500 and 600 (Walsh et al., 2002). This number will be cumulative, with a further 500 to 600 new cases every year. Many of those injured will be young men with a life expectancy similar to the general population, who will require care and support for many years.

2.2.2 Impact on the Person with Traumatic Brain Injury

Traumatic brain injury generally results in an immediate loss or impairment of consciousness, followed by a period of confusion known as post-traumatic amnesia (Snow & Ponsford, 1995; South Western Sydney Area Health Service, 1998; Teasdale & Jennett, 1974). Duration of post-traumatic amnesia and coma reflect the severity of an injury (Sbordone, Liter, & Pettler-Jennings, 1995; Teasdale & Jennett, 1976). When a person emerges from post-traumatic amnesia, they typically exhibit a range of sensorimotor, cognitive and behavioural impairments.
Cognitive and behavioural problems usually persist long after sensorimotor problems have resolved. In long-term studies, people with brain injury report poor memory, reduced concentration, fatigue, inappropriate and embarrassing behaviour, and difficulty making decisions as the most persistent problems affecting their lives (Koskinen, 1998; Olver, Ponsford, & Curran, 1996). Most of these problems are conspicuous and often socially embarrassing. Such individuals tend not to be well tolerated in the community partly because their behaviour is not recognised by the public as a consequence of brain injury. They become the ‘walking wounded’, often at risk of fights and further brain injury.

Attempts at return to work are frequently unsuccessful. In one study, more than 85% of participants with brain injury reported loss of their important worker role (Hallett, Zasler, Maurer, & Cash, 1994). The absence of a meaningful occupation leads to hours of inactivity each day, and boredom can escalate (Tennant et al., 1995). Social isolation is a secondary consequence of unemployment, because there are fewer opportunities to meet people (Kersel, Marsh, Havill, & Sleigh, 2001). Pre-injury friends often stop phoning and visiting, partly because of the injured person’s cognitive and behaviour problems (Glang, Todis, Cooley, Wells, & Voss, 1997; Kozloff, 1987; Rowlands, 2000).

Changes in the size and density of a person’s social network after brain injury are well documented. In one study, people with brain injury were found to have a mean social network size of 7.1 members, compared to people without disabilities who had a mean network size of 23.5 members (Zencius & Wesolowski, 1999). In that study, social network members were counted if they lived within 50 miles or a one-hour drive, and had been in verbal contact with the person in the previous three months. Family members (66%) and paid staff (14%) represented a large portion of these participants’ social network following brain injury. Another recent study found that paid carers were often considered a close friend by a person with brain injury (McCluskey, 2000), partly because they were in regular contact and spent many hours together each week.

Full-time care is often required to ensure the safety and well-being of people with brain injury, as well as the safety of the public. This need for care means that most...
people return home to live with their family. In a recent Australian study, 77.7% returned home from hospital to live with their family (Tooth et al., 2001). The family home is the most common discharge destination, despite many people with brain injury being at an age when they are preparing to live alone, assume greater responsibility and perhaps marry. Furthermore, very few manage to live alone even years after their brain injury. The proportion living alone ranges from 36% at two years (Ponsford, Olver, & Curran, 1995), to 33% at 10 years (Koskinen, 1998), and a low 14% at 14 years post-injury (Hoofien, Gilboa, Vakil, & Donovick, 2001). This ongoing dependence places considerable strain on family members.

2.2.3 Impact on Family Members

The person most likely to provide care in the community following brain injury is the person’s wife or mother (Frosch et al., 1997; Man, 2002; Nabors, Seacat, & Rosenthal, 2002; Struchen, Atchison, Carosellie, & Sander, 2002). This outcome reflects the high number of young males sustaining traumatic brain injury and the trend for more women than men to assume caring roles in society.

Common stressors impacting on family carers include cognitive, behavioural and personality changes, and loss of social contacts for both the injured person and their family (Rees & Hannaford, 1996). Family carers report personality change and threats of violence by the injured person as major problems (Brooks, Campsie, Symington, Beattie, & McKinlay, 1986). These problems may become worse over time. In the study by Brooks and colleagues, threats of violence were reported in 15% of the 142 families at one year post-injury, compared to a much higher 54% at five years. Dependence on family members also increased with time. At one year, 18% of people with brain injury could not be left in charge of a household, whereas this had risen to 43% at five years. In short, the impact on families may increase rather than decrease with time.

Fortunately, other more recent studies reveal that the performance and abilities of many people with brain injury do improve over time. Such improvements help to reduce dependence on family carers to some degree. For example, in one Australian study the proportion of people able to drive independently between two
and five years post-injury increased from 40% to 48% (Olver et al., 1996). In another study, significant improvements in work, leisure, initiative, independence, social and interpersonal functioning were reported between two and 10 years post-injury (Sbordone et al., 1995). However, the challenge for many family carers is how to best survive the early years post-injury. At this time, cognitive and behavioural problems are often at their most challenging, and care needs are high.

It has been suggested that parents may cope better than spouses because parents can share the carer role and support each other, whereas spouses are usually alone (Oddy, Coughlan, Tyerman, & Jenkins, 1985). However, spouse carers experience additional stressors to parents, such as caring for the person with brain injury and young children together in the same house (Oddy et al, 1985). They also typically have to manage additional home maintenance, household, financial and work responsibilities which would previously have been shared with their partner (Leatham et al., 1996). A recent Australian study found that between 30% and 50% of secondary and tertiary family members (including fathers, siblings and adult children) were also distressed, angry or fatigued as a consequence of their association with a relative with brain injury (Perlesz, Kinsella, & Crowe, 2000). Clearly, being the primary carer and living with a person with brain injury place a high burden on anyone, regardless of their role.

Finally, the rate of separation and divorce when one partner has a brain injury varies from around 20% in two larger studies with 430 and 275 participants respectively (Brown & Vandergoot, 1998; Steadman-Pare, Colantonio, Ratcliff, Chase, & Vernich, 2001), to nearly 50% in another study with 131 participants (Wood & Yurdakul, 1997). With regard to the general population in Australia, 2001 data show that 17% of couples divorce within the first five years of marriage, while a further 26% divorce after 10 years (Australian Bureau of Statistics, 2002). This high divorce rate of 43% over 10 years matches, and in some cases exceeds, the rate for couples where one partner has a brain injury.

Wood and Yurdakul (1997) noted that relationship breakdown rarely occurred in the first two years post-injury and was most common at, or after, five years. The watershed for relationship breakdown was around five to six years post-injury. If a
couple’s relationship survived the challenges of the early post-injury years, Wood and Yurdukal suggested they were more likely to continue living together. Also reported in that same study was the finding that separation occurred more commonly than divorce (33.6% compared to 15.3% respectively). A small proportion of partners (6%) had separated from the person with brain injury, yet did not intend to pursue a divorce. Instead, they planned to continue in their role as primary carer “so long as this did not mean cohabiting” with the injured person (Wood & Yurdukal, 1997, p. 499). Thus, separation was their way of managing the stressful carer role. Whether this model of care and way of living is considered an alternative by Australian spouse carers is unknown.

When family relationships break down, the impact of a brain injury cascades on to the community and society as a whole. At such times, alternative care and living arrangements become necessary, and problems that have largely been managed by family carers become a wider societal concern.

2.2.4 Impact on Society

The cost to society of traumatic brain injury is significant, both at state and national levels. The two major costs are economic loss for the individual and their family, and the ongoing cost of long-term care. The first cost to society, economic loss, results when a person is unable to work. This inability to engage in paid work represents a loss to the national economy as well as the individual. Further economic loss is incurred when family carers reduce or forego paid employment to care for their relative (Sevick & Bradham, 1997; Sevick, Kamlet, Hoffman, & Rawson, 1996).

The second cost to a society is for ongoing care. Total hospital and rehabilitation costs in the first year post-injury are between AUD $100,000 and AUD $150,00 (Jones v. Bradley, 2003). These costs are comparable with data from overseas, where the mean cost of early hospitalisation and medical care has been estimated at US $133,467 for a person with severe injuries (Brooks et al., 1995). However, the mean cost for follow-up services still remains substantial four years post-injury at US $10,656 per person per year. Furthermore, these follow-up costs can be
“dramatically skewed, with means well above medians particularly for more severe injuries” (Brooks et al., 1995, p. 7). Some participants in the study by Brook and colleagues incurred extreme costs. In Australia, the cost of 24-hour paid attendant care is a massive AUD $250,000 to $300,000 per year (Hills, 2000). The main message from clinicians and researchers across the globe is that the cost of care and support services will continue to remain high for many years post-injury (Hodgkinson, Veerabangsa, Drane, & McCluskey, 2000).

Finally, although intensive therapy and rehabilitation play an important part in recovery, these services are not an alternative to providing long-term care and support. Mark Johnston, a well-known researcher in the USA acknowledges this issue in one of his earlier outcome studies. He reported positive gains in independent living for people with severe brain injury after a mean of 8.8 months of intensive rehabilitation (Johnston, 1991). Participants engaged in residential rehabilitation during this period. The cost of the program was, on average US $106,000 per person. However, despite making short-term gains during this time, Johnston warns in his discussion that: “things began to fall apart after discharge” (p.164). This statement alludes to the important role that long-term support and case management may play in maintaining the stability of a person’s living arrangements after brain injury.

In summary, traumatic brain injury has an impact on the individual, family members and society in general. Between 500 and 600 people each year in Australia will sustain a moderate or severe traumatic brain injury, and this number is cumulative. A severe brain injury typically results in a need for long-term care and support, usually because of cognitive and behavioural sequelae. The following section focuses on the nature, funding and providers of long-term care for this population.
2.3 Long-Term Care and Traumatic Brain Injury

2.3.1 Definition of Long-Term Care

Long-term care refers to a broad range of support services that help people with disabilities to participate more fully in society. Services are intended to help a person engage in roles which they would otherwise be unable to sustain (Bowen, 2003; McCluskey, 2000; Physical Disability Council of NSW, 2003), to live in and be part of their local community (Family Caregiver Alliance, 2001; Nosek & Howland, 1993).

Unlike the United States and United Kingdom, terms such as ‘care’, ‘paid carer’ and ‘attendant carer’ are still widely used by people with brain injury (Fleming, 2003), health and legal professionals (Ponsford, Olver, Ponsford & Nelms, 2003) and policy makers in Australia (Bowen, 2003; Walsh et al., 2002; Walsh, 2003). These terms are, therefore, used consistently throughout this study. It is acknowledged, however, that terms such as ‘personal assistance’ and ‘support’ are more empowering, and reflect the terminology preferred by people who require and use these services (Batavia, DeJong, & McKnew, 1991; Physical Disability Council of NSW, 2002; Vasey, 2000).

Long-term care and support services include personal care, attendant care, nursing care, home care, domestic help, home maintenance, transport, respite care, and financial management (Nosek & Howland, 1993; Walsh et al., 2002; Weed, 1999). The provision of specialised disability equipment is also included in this definition. Furthermore, extended case management and allied health services are considered part of long-term care, since intermittent reviews of a person’s care and living arrangements are needed from time to time (Brooks et al., 1995; Motor Accidents Authority of NSW, 1994; Weed, 1999). For a person requiring 24-hour long-term care, the majority of costs in Australia are typically for personal and attendant care, regardless of a person’s living situation (Hills, 2000; Jones v Bradley, 2003).

Long-term care can be provided in a home setting or institution. Some people with brain injury live in the family home, with a family member providing most of their
day-to-day care. Others live alone and receive a combination of paid and unpaid care. Others still live in a nursing home, hostel, transitional living unit or other type of supported accommodation where they typically receive only paid care. Thus, a number of different configurations of care and carers will be possible. Decisions need to be made about the living situation, configuration of carers and other factors such as who will take responsibility for financial management if the injured person cannot do so themselves. Regardless of the location and provider, long-term care has a number of characteristics that distinguish it from acute and short-term care.

2.3.2 Characteristics of Long-Term Care

Long-term care can be differentiated from other types of care according to three characteristics: duration, complexity and cost. First, long-term care is expected to continue for many years, often for life (Bowen, 2003). Other types of severe acquired brain injury that may result in a need for lifelong care include stroke and anoxic brain injury. Conditions other than brain injury that may result in a need for lifelong care include high-level spinal cord injury, chronic mental illness and profound intellectual disability. An older person with dementia may also require long-term care for many years. Conversely, short-term care is expected to be required for weeks, perhaps months due to a temporary disability. Home care and gardening are examples of two services often required for several weeks after an orthopaedic injury, fracture or trauma.

Second, long-term care is complex. The term complex is often applied to people with special needs and multiple disabilities, such as those with profound intellectual disabilities, mental illness and challenging behaviours, as well as people with problems related to addiction (Reynolds, 1995; Seed & Kaye, 1994). Such individuals need support in several areas of their life. They may live alone and have little effective support from family or friends. These factors place an individual with special needs at risk of abuse and injury.

Complex care also refers to situations where individuals do not want or do not perceive a need for assistance, even when there is an objective need. That is, care may be needed but not well tolerated by the recipient. Furthermore, a person who
has lost their primary carer, or has difficulty keeping carers due to challenging behaviour (Wood, McCrea, Wood, & Merriman, 1999) would be classified as requiring complex care. People with difficulty communicating often require complex care, as do ageing parents caring for adult children with disabilities (Reynolds, 1995). Complexity of care does not necessarily correlate with physical dependency. Instead, the term relates to an interplay between factors which, when combined, make care needs more complex. Therefore, long-term care does not always equate to a high level of care.

Care is also considered to be complex when multiple service providers become involved and coordination is required (Reynolds, 1995). In these circumstances, roles, responsibilities and tasks need to be negotiated, managed and monitored. This coordination is typically conducted by a paid ‘care manager’, a term used more widely in England (London Borough of Richmond Social Services, 2003; Moore, Skelton & Patient, 2000; Seed & Kaye, 1994) and North America (Weed, 1999) than in Australia. Other types of care are simpler, may involve only a single service provider for one or two discreet areas of need, and therefore involve less decision-making. It is this multiplicity of factors that appears to make long-term care decision-making so challenging.

A third defining characteristic of long-term care is its high cost. By implication, care that is provided for a long duration (often for life), is complex and involves multiple service providers is going to be expensive (see pp. 13 and 14 for details of costs). Young people with severe disabilities in Australia are often forced to move to aged care institutions because the necessary funding for community-based care is not available to them (Brain Injury Association of NSW et al., 2002). An alliance of disability-related organisations in Australia recently highlighted the inadequacy of government funding for long-term community care. Furthermore, they note the limited range of community-based care options available to many younger Australians with disabilities because of under-funding of these essential services:
One argument used to justify admitting younger people with disability to residential aged care facilities is that the disability services sector does not have the capacity to provide for their needs. It is clear, however, that the real issue is much more likely to be about insufficient resources, and in rural and regional areas, a lack of resources and services (Brain Injury Association of NSW et al., 2002, p.5).

The authors of this 2002 report argue that people with compensation funds are able to purchase long-term care services privately, whereas those without have no purchasing power. As a consequence, they argue, people with compensation do not usually move into aged care institutions. However, this claim remains unsubstantiated. Anecdotal reports suggest that many people with compensation in Australia do move into aged care institutions because they cannot afford long-term care, or because services do not exist, are limited in availability or insufficiently flexible (Physical Disability Council of NSW, 2003). The availability and cost of care services are factors that are likely to affect care decision-making and warrant further investigation.

In conclusion, three characteristics differentiate long-term care from short-term or acute care: the duration, complexity and cost of care. These three characteristics are interrelated, and contribute to a need for coordination of long-term care. These characteristics also result in a need for ongoing care decision-making, as circumstances and funding availability change. The funding of long-term care in Australia, both private and public, will now be discussed.

2.3.3 Funding of Long-Term Care

In Australia, approximately two-thirds of people with traumatic brain injury will be eligible for compensation and, potentially, for funding of long-term care (Bowen, 2003; Walsh et al., 2002). This group typically has access to paid care services at the time of leaving hospital. The remaining one-third rely on family carers and publicly funded services such as HomeCare, Community Options and the Attendant Care Scheme (Physical Disability Council of NSW, 2003). Few have sufficient personal savings to afford private care over their lifetime.
2.3.3.1 Funding through Compensation

Existing compensation systems in Australia fall into four categories or schemes: Workers’ Compensation (10 schemes nationally); motor transport compensation (8 schemes nationally); public liability insurance (mostly private); and professional indemnity cover (mostly medical defence and private insurance) (Walsh et al., 2002). In most schemes, eligibility for compensation is contingent on the injured person proving negligence by a third party such as an employer, driver or medical professional. Compensation is based on common law, and available for three major classes or ‘heads of damages’: economic loss, general damages (‘non-economic loss’ or ‘pain and suffering’), and the cost of past and future care (Walsh et al., 2002). Each head of damages involves multiple assessments by medicolegal experts, to determine future need. The cost of expert reports is included in a person’s claim and ultimately borne by society through insurance premiums.

The amount of compensation awarded for long-term care is determined largely by the opinions of these medicolegal experts, including rehabilitation specialists, occupational therapists and commercial care agency directors. Not surprisingly, opinions vary about how much and for what reasons care might be needed, and according to whether the report is for a plaintiff or defendant solicitor (Chisholm, 2002; Freckleton & Selby, 2002). These variations and personal biases have been criticised by the media and in scientific journals (Dyer, 2002). Partisanship or an alliance towards the party contracting services can turn an otherwise objective professional into a ‘hired gun’ (Freckleton & Selby, 2002).

Unfortunately, this loss of objectivity influences the funding of long-term care, often to the detriment of an injured person. As yet, no evidence-based guidelines have been developed to help professionals calculate long-term care needs for this population. However, consensus-based guidelines do exist to help professionals determine the level of care needed by people with spinal cord injury (Motor Accidents Authority of NSW, 2002). Similar guidelines are planned for people with brain injury who need high levels of care.
Nonetheless, there is still an urgent need for empirical evidence, beyond the level of expert opinion and consensus-based guidelines to inform professionals who make these important decisions. The current study will help to address this gap in knowledge, by examining the process and conditions surrounding care decision-making by health professionals. There is also a need to explore the impact that compensation has on care decision-making by people with brain injury and their family. The current study will help to address this gap in knowledge.

2.3.3.2 Public Funding of Care

Approximately one-third of people with traumatic brain injury do not have access to privately funded care. Instead, they rely on family members and public sector services, most of which are funded at a state or territory level. In NSW, the state where this research was conducted, the two government departments responsible for funding long-term care services are the NSW Departments of Health (DOH) and Ageing, Disability and Home Care (DADHC). The DOH has responsibility for providing nursing and allied health services. The DADHC provides most of the long-term care services except for nursing and allied health. Within DADHC, schemes that provide free or means-tested care services are known as Home and Community Care, Community Options and the Attendant Care Scheme (Barlow & Paterson, 1996). However, funding for all public services is finite and waiting lists are long. Apart from basic eligibility criteria, limited information is available about the way in which public care funding and services are allocated to people with traumatic brain injury. This is another gap in knowledge, but one that the present study does not aim to address.

In summary, as in other developed countries Australia has a mixture of private and publicly funded care services. People sustaining their injury through an accident who can prove negligence by a third party are eligible to seek compensation. One of the heads of damages or components of compensation is long-term care. The opinions of medicolegal experts are generally sought when decisions are made about future care. Unfortunately, these expert opinions vary markedly, with direct effects on the amount of compensation awarded. Empirical research is needed to
inform care decision-making by professionals and the courts, and reduce this variability. The present study will address this need by exploring the process of care decision-making in a compensable population of people with brain injury. Furthermore, the study will examine the impact that conditions such as funding have on subsequent care decision-making.

The following section examines some of the decisions that need to be made about long-term care and support. These include decisions about the provider, the configuration of carers, the location and level of care. Models of long-term care will then be critiqued, since underlying assumptions, values, and the philosophy of a model of care are likely to influence service provision.

2.3.4 Providers of Care

Once an individual need for care has been identified, service providers are determined. Providers are typically categorised as voluntary or involuntary, formal or informal, paid or unpaid. Family carers are voluntary, informal and usually unpaid. Commercial care providers and paid carers are involuntary, formal and paid. A combination of both is commonly used.

2.3.4.1 Family Carers

Family members who provide unpaid care are referred to as ‘informal’ carers (Forbes & Hoffart, 1998; Higham, 1998; Howe, Schofield, & Herrman, 1997). Informal carers are usually related to the person receiving care, such as a mother or wife (Man, 2002; Sinnakaruppan & Williams, 2001). However, informal carers may also include neighbours, friends and volunteers (Baum & LaVesser, 1994; McCann & Evans, 2002). In Australia, family members provide nearly three quarters of care to people who are frail, aged or have a disability (Australian Bureau of Statistics, 1995). Yet even when low-cost or subsidised paid care services are available, many families do not use them. In Australia, only 21.6% of family carers surveyed had received help from community services such as Home Care (Australian Bureau of Statistics, 1995), a low-cost, subsidised care service for.
Family carers of older Australians and those with physical disabilities sometimes do not use community services for a variety of reasons. Some family carers believe they should not ask for outside help. Others are concerned about privacy, do not know about available services or have encountered a lack of flexibility in service delivery in the past. Other factors affecting the decision to use or to not use formal services include the unreliability of, and prior negative experiences with, service providers (Bast, 1996; Payne & Erhlich, 1998; Twigg & Atkin, 1995). No such studies have been conducted specifically with family carers of people with brain injury to investigate how and why decisions about care are made.

In short, family carers provide the majority of care in Australia to older adults and people with disabilities (Australian Bureau of Statistics, 1995). Some family carers and people receiving care make an active decision to not use paid care services. Others do not know that services exist. However, it is unknown if these conditions apply to family carers of people with brain injury, or to individuals with brain injury who need care and support. The current study addresses this research gap by exploring the use of paid and unpaid care services, particularly by people with compensation. This group can afford to employ paid carers in addition to, or as an alternative to, family carers.

2.3.4.2 Paid Carers

Paid carers provide care services in exchange for money. They are also sometimes known as ‘formal’ carers. In Australia, the term ‘attendant carers’ is also used to describe this group of service providers (Bloom & Associates, 1996; Focus Learning Systems, 1998). In the United States (US), the terms ‘personal care attendants’, ‘personal care assistants’ or ‘PCA’s’ are typically used (Charles, 1986; Gilson & Casebolt, 1997; Mattson Prince, Manley, & Whiteneck, 1995; Opie & Miller, 1989). In the present study, the term ‘paid’ carers will be used to distinguish between paid and unpaid (family) carers.

A paid carer may be trained or untrained, may or may not have a nursing background, and may be engaged to perform one or many tasks (Motor Accidents Authority of NSW, 2003). In Australia, paid carers are typically employed by a
private care agency, a third party such as a community health service or insurer, or directly by a client and their family. Most paid carers are female, and many experience unsatisfactory working conditions such as low wages and little training relative to their roles and responsibilities (Donovan, 1989; Hutchins, Thornock, Lindgre, & Parks, 1978; McCluskey, 2000; Qureshi, Challis, & Davies, 1989). Most paid carers work alone in the home of a client and/or their family (Fleming, 2003). State and federal awards govern paid carers’ working conditions in Australia, and the industry primarily employs staff on a casual basis (Bloom & Associates, 1996).

People with disabilities have been asked about their preference for family versus paid care (Batavia et al., 1991; Nosek, 1991) and their preference for different models of care (Beatty, Richmond, Tepper, & DeJong, 1998). Studies have also evaluated the cost-benefits and health outcomes of different models of care (Mattson Prince et al., 1995; Nosek, 1993). Such information is helpful for professionals and organisations engaged in care decision-making, for and with people with disabilities. However, as will be noted shortly, no research has yet been conducted on models of care preferred by people with brain injury.

2.3.5 Models of Care: Preferences of People with Disabilities

A number of important messages emerge from the literature about the care preferences of people with a physical disability. First, paid care is preferred to informal family care because of the greater value for money and sense of control offered by paid care (Beatty et al., 1998; Nosek, 1990). Second, a consumer-directed model of care (Batavia et al., 1991; Mattson Prince et al., 1995) is preferred to one where care is directed by a funding agency or health professionals (the medically-supervised model), or by a care agency (the agency-directed model). Other characteristics of care that may be considered during care decision-making, but about which less is known, include whether paid carers should live in the home of their client or not, and whether or not paid carers should have professional qualifications, skills and prior experience (Motor Accidents Authority of NSW, 2003).
Much of the research on models of care has been conducted with people who have a physical disability and require a high level of physical care, particularly those with a spinal cord injury. Many of the same principles, although not all, apply to people with brain injury. The strengths, limitations and characteristics of different models of care will now be reviewed.

2.3.5.1 The Paid Model of Care

Nosek (1990) interviewed 19 people with physical disabilities, including people with high-level spinal cord injury, about their preferences for care provider. They found that the employment of a single, full-time paid carer rated higher than relying on family and friends, if cost was no barrier. Participants in that American study reported that a full-time paid carer contributed to increased feelings of personal control and autonomy. A full-time paid carer was also expected to increase the degree of dignity and comfort afforded to the consumer because full-time staff learn quickly to recognise a consumers needs. Sharing paid carers with other users, having multiple part-time paid carers, and a combination of family and paid care were secondary preferences. Institutional care was rated lowest, because this care configuration afforded little control and dignity and a lower quality of care for the person with disability. Dependence on a family carer such as a parent or spouse was also rated low in terms of feelings of control and dignity.

Although this study by Nosek was relatively small with a sample of 19 participants, the findings represent an important consumer viewpoint on preferred models of care. However, these participants were unusually well informed, articulate and politically active people who did not have cognitive impairments. All were leaders in the independent living movement in the United States. Therefore, this sample cannot be considered representative of people with disabilities more widely, particularly those with impaired cognition following brain injury. It would be valuable to ask people with brain injury about their preferences. Although many have significant cognitive problems, people with brain injury have opinions and preferences that need to be considered. The present study will address another gap in research literature by seeking their opinions about care and support.
2.3.5.2 The Consumer-Directed Model of Care

People with physical disabilities have also reported strong views about the process used to engage and manage paid carers. A consensus is evident across time and place. People with disabilities want to be more involved, and in many cases to manage their own staff without agency involvement. As the consumer of care services, they want paid carers and providers to be accountable to them, not to an insurer or third party (Batavia et al., 1991; Beatty et al., 1998; Mattson Prince et al., 1995; Physical Disability Council of NSW, 2002). However, the latter model of care still predominates in most developed countries, as summarised in the following quote:

*Historically, personal, in-home care has been provided...using a medically supervised model. Within this model, which is still in use in many rehabilitation centres and commercial insurance companies, survivors are viewed as patients who are sick and must relinquish caregiving and treatment decisions to health care professionals. Reimbursement flows from third party payors (sic) to designated home health care agencies. Generally, consumers use this model of care because their funders require them to do so* (Mattson Prince et al., 1995, p. 919).

An alternative consumer-directed model of care, also known as the independent living model, has been championed for over 20 years by Gerben DeJong and associates (Batavia et al., 1991; Beatty et al., 1998; DeJong & Wenker, 1979). A hallmark of this model is the accountability of paid carers or assistants to the consumer as opposed to supervising professionals, care agencies and other third parties. Proponents of the independent-living model argue that consumers who manage available resources and services are “able to gain control of their lives and to achieve a sense of independence that is not available through other models of …[service] delivery” (Beatty et al., 1998, p. 674).

Two studies have compared the effect of consumer-directed versus agency-directed care on outcomes such as autonomy, physical and emotional health and annual costs (Beatty et al., 1998; Mattson, Prince et al., 1995). Results of both studies are remarkably similar. Employing and directing carers independently is preferable to
management by an agency (Beatty et al., 1998; Mattson Prince et al., 1995). Participants directing their own carers felt more in control of their day-to-day lives and personal care, and were more satisfied with the availability and cost of care than those using an agency.

This finding, that satisfaction with care costs is greater when agencies are bypassed, is not surprising because agencies charge a significant administration fee. Employing and managing paid carers independently is one of the few ways that consumers can reduce care costs (Mattson Prince et al., 1995). As an example, those using consumer-directed carers spent approximately US $15,000 less per year for care than those using agency-directed carers. Furthermore, because the hourly cost of care was less, the former group could purchase more care hours (mean = 14.5 hours per day) for their money than those using an agency (mean = 8.1 hours per day). As a consequence, the former group relied less on family carers (Mattson Prince et al., 1995). This reduced reliance on family carers may have contributed to the increased sense of control reported by those managing their own carers.

Another message from the literature on care preferences is that the longer participants live in the community the more they gravitate towards a consumer-directed model of care (Mattson Prince et al., 1995). Whether this same trend is evident in Australia, and in a population of people with brain injury, is unknown. The sample reported by Mattson Prince and colleagues included adults with high-level spinal cord injuries. In the study by Beatty and colleagues (1998), participants had a variety of physical disabilities and received or were on the waiting list to receive consumer-directed care services. However, all had to be capable and willing to direct their own carers. It is unlikely that many people with brain injury would be able or willing to manage their own carers. This fact has been recognised by the Physical Disability Council of NSW, an organisation that has spoken out on paid care and models of service delivery in Australia. Recognising that not everyone will be capable of managing their own staff, they recommend:

...a continuum of services from those managed entirely by agencies to self-managed personal assistance arrangement (Physical Disability Council of NSW, 2002, p. 12).
In Australia at present, the majority of people with brain injury use agency-directed carers. However, a shared model of care management with co-direction by family members or a surrogate decision-maker may be a viable alternative for individuals with cognitive impairment. The current study will explore this alternative.

2.3.5.3 The Live-In Model of Paid Care

Employment of paid carers that live in the same house as the person with a disability is another way in which care can be delivered. However, little is documented about this model. A live-in carer typically has separate living quarters in or adjacent to the home of a person with disability (Charles, 1986; Vasey, 2000; Weil, 1979) whereas a live-out carer usually works an 8 to 12 hour shift and leaves (Bloom & Associates, 1996; McCluskey, 2000). No studies have evaluated or compared these different models, and little commentary is available from a consumer perspective. Most studies were conducted many years ago and sought the opinions of paid carers rather than people with disabilities. In one study, 9% of paid carers selected care work as a career option because their work offered a place to live (Atkins, Meyer, & Smith, 1982). Lack of privacy was a characteristic of live-in care that some disliked, although not sufficiently to resign.

Lack of privacy is one of the negative consequences of paid care, regardless of whether carers live-in or out (Charles, 1986). The presence of paid carers in the home, all day every day, removes the possibility of time alone for the care recipient and affects family privacy. The following narrative reveals the effect of paid carers on privacy for one consumer and his family:

From a personal viewpoint, the fact that I have not been alone for almost three years is almost unbelievable. I realize and accept that this is essential….but it is difficult not to have the opportunity for periods of solitude…. [As a family] we have lost a degree of spontaneity which is so important for family functioning….there is always a degree of restraint when someone else is present….we still feel as though our activities are being videotaped (Charles, 1986, p. 16).
It seems likely, therefore, that paid carers living in the home of a person with disability will impact more on the users’ privacy than live-out care. Another reason why live-in care may not be sustainable in the long term following brain injury is that cognitive and behavioural problems can make the user or client demanding and egocentric. Long shifts of eight hours or more become challenging and tiring. All carers, whether paid or unpaid, need respite from this role. Use of the live-in model of care has therefore been discouraged following brain injury by some health professionals (Ponsford, 1995b). Whether people with brain injury have a preference for, use or even know about live-in care as an option is unknown. The current study seeks to explore these gaps in knowledge. The present study will collect data on care arrangements, hours of care and the living situation of people with brain injury, and how decisions are made about these factors.

2.3.5.4 Other Models and Characteristics of Care

The preference for paid carers with, or indeed without, particular competencies, experience and qualifications are additional characteristics of care delivery about which little has been reported. There is a trend in Australia to recommend employment of registered nurses over attendant carers for people with brain injury. Care agencies and professionals argue the point regularly in reports and in court (Beck v State of NSW & Anor, 2001; Fitzgerald v Dansey, 2001). They argue that the length of training, participation in continuing education and a professional code of ethics make qualified nurse carers better at their work than unqualified carers. These recommendations are based on expert opinion, not empirical evidence and do not take account of consumer preferences.

The qualifications of paid carers were investigated as part of a study that examined cost of care (Bloom & Associates, 1996). This Australian study audited 27 insurer files of people with brain and spinal cord injuries that were receiving paid care. Qualified registered nurses did not appear to manage challenging behaviours any better than untrained carers. Care agencies were regularly asking insurers to fund behaviour management training for paid carers, regardless of qualifications. Nonetheless, care agencies and health professionals continue to recommend
employment of qualified nurses, anticipating that a professional background will improve the quality of care (Beck v State of NSW & Anor, 2001; Fitzgerald v Dansey, 2001). In addition, the study by Bloom and Associates (1996) found no relationship between carer qualifications and quality of care. They suggested instead that the quality of care might be more dependent on the personal characteristics of individual carers than on qualifications. The views of people with brain injury and their families have not been canvassed on this issue, to determine whether carer background influences care delivery. The present study will add to this gap in knowledge by exploring the experiences of people with brain injury who receive care from carers with different backgrounds.

Finally, the relationship between carer qualifications and the hourly cost of care deserves closer examination, because these factors may affect care decision-making. The qualification of paid carers has an impact on cost. Registered nurses cost more per hour to employ than unqualified carers. For example, employing registered nurses for eight hours a day, seven days a week cost AUD $106,000 a year in 1996 (Bloom et al., 1996). For the same hours, employing unqualified carers cost approximately AUD $40,000 (Bloom et al., 1996). The cost of care in the US appears to be roughly comparable. For example, Mattson Prince and colleagues (1995) reported a cost of approximately US $41,000 for equivalent hours in 1993, to employ unqualified carers through an agency. These two studies indicate ways that people with brain injury, family carers and professionals can potentially reduce care costs by using different models of care. However, the impact and outcomes of each model on a person with brain injury remains unknown.

2.3.5.5 Summary of Models of Care and Consumer Preferences

Existing research indicates that people with physical disabilities prefer paid care to unpaid family care. The paid care model is preferred because of the increased control, autonomy, dignity and accountability this arrangement offers users. Lack of privacy is one of the few negative aspects of this model. Lack of privacy is a factor that may influence care decisions by care users and their family, but has not been the focus of study to date.
Research also indicates a clear preference for consumer-directed care. People with physical disabilities prefer to recruit, select and manage their own staff, as opposed to involving an agency. A consumer-directed model of care offers increased control and autonomy. Reduced cost is another important benefit of this model. People with physical disabilities tend to gravitate towards self-managed care over time, instead of the more common medically supervised, agency-managed model of care. However, little is also known about the benefits or problems of the live-in model of paid care, or the need for staff with prior experience, competencies or professional qualifications. Whether these different models of care and options are available to or preferred by people with brain injury is unknown.

The present study aims to explore the processes and conditions surrounding care decision-making and care management by people with traumatic brain injury and their family. A family carer perspective is considered important, in addition to that of the person with brain injury, because of the impact of cognitive impairment on self-reporting. Due to impaired memory, some may have difficulty accurately describing names and details of carers, and current and past care arrangements. However, the views and opinions of people with brain injury about care will be relatively unaffected by impaired memory. The remainder of this chapter will focus on care decision-making.

2.4 Care Decision-Making

The final section of this chapter will identify, define and critically analyse theoretical concepts associated with decision-making more generally and care decision-making. Models and theories will be considered that explain: how individuals make decisions (the process); factors that limit or enhance a person’s ability to make a decision (conditions); and some of the risks and benefits of taking a particular course of action (the consequences). A modest body of literature exists on the process, conditions and consequences surrounding care decision-making, most relating to decisions facing older adults. No literature was located specifically on care decision-making after brain injury, the focus of this study.
2.4.1 Definition of a Major Decision

A decision is an act of choosing to take or not take a particular course of action, based on beliefs about the likely consequences (Baron, 1994). An informed, rational decision is one taken with information about the consequences of each course of action, and in accordance with the decision-maker’s values and beliefs (Bekker et al., 1999; Leigh, 1983).

A distinction is usually made between minor and major decisions. Minor decisions are those “routinized decisions a person faces when he looks over a menu, selects a movie or chooses a different route home to avoid a crowded freeway” (Janis & Mann, 1977, p. 4). On the contrary, major decisions are those involving considerable thought, discussion, stress and sometimes conflict for the individual. Major decisions are those with potentially serious consequences for an individual and others (Janis & Mann, 1977), and are often related to work, relationships, accommodation or health. In the context of the present study, many aspects of long-term care decision-making have serious consequences for a person with brain injury and their family. These consequences include institutionalisation, risk of injury and abuse and loss of autonomy. It is the process of making major care decisions and their potential consequences that will be the focus of much of the present study.

2.4.2 Theories of Decision-Making

A theory involves concepts that are labelled and then linked using statements of relationship (Walker & Avant, 1995). Three broad types of decision-making theory exist. These are: normative, descriptive, and prescriptive decision theory (Bekker et al., 1999).

First, normative decision theory describes what individuals should do when faced with a challenging decision, based on mathematical and statistical calculations (Bekker et al., 1999). Normative theory assumes that individuals know the alternatives available to them, are able to calculate the risks and benefits, know which alternative they prefer and value, and are able to make a timely, informed
quality decision about the best course of action. The best course of action is one that is rational and maximises expected utility (Baron, 1994). Normative decision theory is unlikely to apply to care decision-making until many months or years post-injury when behaviour and care arrangements have stabilised. In the early days, the person and their family, and indeed many paid carers are new to their roles and responsibilities. Most are unfamiliar with traumatic brain injury and care decision-making. Furthermore, challenging and unpredictable behaviours are often at their worst in the early years post-injury, leading to uncertainty and crises.

Second, descriptive decision theory describes what individuals actually do in real life when faced with difficult decisions. Rarely do individuals make decisions according to normative theory because of factors such as time, decision deadlines, stress and information overload (Bekker et al., 1999). Consequently, the process may be simplified. Instead of considering multiple possible alternatives, decision-makers may consider only two or three. This phenomenon has been termed ‘bounded rationality’ (Simon, 1976). Although the process may result in sub-optimal and premature decision-making, it enables an individual to make a choice that is ‘good enough’. This process may apply to people with disabilities, including those with brain injury and their family, as they engage in care decision-making for the first time. Most will be novices, unfamiliar with the available care alternatives and possible courses of action. In such circumstances, they may defer to professionals or care agencies.

Health professionals and care agencies, however, may also engage in restricted or sub-optimal decision-making, with or on behalf of their clients (Kane, 1995). Too often, professionals have insufficient time or experience to fully explore the range of possible options. There may be pressure to discharge a person home from hospital, in order to free up a bed, resulting in premature closure of decision-making. Furthermore, professionals may emphasise the risks of particular decisions such as living alone, while ignoring risks associated with ongoing family conflict or institutional living (Clemens & Hayes, 1997). Others have noted this phenomenon of sub-optimal decision-making by professionals in relation to long-term care of the elderly:
Mindlessness or lack of conscious decision making may occur because of limited categories or mind sets and automatic behaviour that dulls consciousness. Familiar contexts and perceptions of strained resources can dull professionals into mindlessness. Unfortunately, case managers, hospital discharge planners, and others who advise elderly people about long-term care are prone to this phenomenon, making less than adequate decision counselors (Kane, 1995, p. 91).

Thus, the second type of theory, descriptive decision-theory acknowledges that humans are imperfect. Clemens and Hayes (1997) reported that health professionals often have difficulty making care-related decisions. Some take too little time to consider alternatives, while others take too much time. These researchers interviewed 15 health professionals involved in aged care assessment with older adults in hospital or at home. The older adults were all considered at risk of falls, abuse or other problems associated with increasing frailty. Some of the professionals were classified as ‘snap decision-makers’. They made quick judgements about an at-risk elder accompanied by an immediate recommendation for action. Often a single criterion was used when making this decision about the future of an older person. Other professionals were classified as ‘agonizers’. They went to extreme lengths to maintain an older person’s autonomy in decision-making, weighing up numerous criteria and taking a long time to reach a decision. ‘Snap decision-makers’ had a lower tolerance for risk than the ‘agonizers’, and tended to reach a decision prematurely.

Both Kane (1995) and Clemens and Hayes (1997) suggest that professionals with a tendency for premature closure and a low tolerance for risk may be limiting the choices available to those with whom they work. In the current study, the role of professionals in care decision-making will also be explored.

Prescriptive decision theory is the third broad type of decision theory, and describes what individuals actually do when faced with a challenging decision, with the guidance of pre-determined strategies and decision aids (Goodwin & Wright, 1991). Prescriptive theory is based around modified normative theory. This type of theory recognises the influence of personal values, beliefs and preferences on decision-
making behaviour. For example, some individuals may view paid care as an invasion of their privacy, or a service used only by those without family. Prescriptive theory not only assumes that these values and preferences affect choice, but also seeks to explore them during the decision-making process (Conner & Norman, 1996; Goodwin & Wright, 1991).

2.4.3 *The Process of Decision-Making*

Decision-making involves more than simply expressing a preference for one course of action or another. It is a process with steps and stages, which may take minutes, weeks or years from start to finish. In brief, the process involves: seeking information about alternative courses of action; considering the benefits and risks of each alternative; implementing a decision while also having a contingency plan; then using feedback from the decision to learn from and alter future judgements (Carroll & Johnson, 1990; Janis & Mann, 1977; Turnbull, Turnbull, Bronicki, Summers, & Roeder-Gordon, 1989). Following is a summary of the key steps involved.

*Step 1: Seeking Information*

The first step involves seeking information about possible courses of action. Once a person has recognised the need to make a decision, they generally seek information about alternatives. For example, a person dissatisfied with their level of support, health or well being in the community may begin to seek alternative ways of living. A person who is in conflict with a carer may seek information about alternative carers or care agencies. Typically, a person will seek information and ideas from friends and colleagues, experts and specialists. They may even use the Internet to widen their search. Family members are an important source of support and information at this stage (Smerglia & Deimling, 1997). The aim is to widen the boundaries of possibility by forcing the decision-maker to think beyond the obvious. By implication, the decision-maker needs to be resourceful and identify two or more alternative courses of action. Otherwise, there is no decision or choice to be made, and no alternatives to consider.
Step 2: Considering Alternatives

When two or more alternatives have been identified, the decision-maker is in a position to make a choice. Considering alternatives involves identifying, appraising and comparing each one in turn. This comparison typically involves considering advantages and benefits versus disadvantages and risks. For example, one of the benefits of employing paid carers through an agency may be that someone other than family will manage staff administration and salaries. However, there could also be a risk that the cost of agency-managed care will prematurely exhaust an individual’s financial resources. Ideally, alternatives are tested one-by-one using this approach. Some decision-makers do so systematically, while others are more haphazard (Janis & Mann, 1977). Decision-makers often have a minimal cut-off point, testing each alternative in turn to see if it falls above or below their imaginary cut-off point.

Decision-making involves consideration of the future and, by implication, uncertainty (Leigh, 1983). An implicit assumption of this stage is that decision-makers have knowledge of potential consequences, about probability and uncertainty. However, those who are inexperienced and unfamiliar with particular contexts will be dependent on the expertise of others. A person with concrete thinking, poor awareness and slow information processing may also have difficulty making comparisons. Furthermore, family carers usually have little or no experience of choosing care agencies, managing challenging behaviour, or deciding what level of paid care is needed. Family members may, however, play an important role at this stage, since individuals tend to rely on their family instead of professionals when making care decisions (Smerglia & Deimling, 1997).

When an alternative course of action is deemed adequate, the decision-maker may or may not terminate their search. Some decision-makers will stop and short-circuit the process at this point due to lack of time, stress and information overload. However, according to Janis and Mann (1977) a second round of information seeking should ideally occur before committing to a course of action. This secondary checking process helps to ensure that potential alternatives are not overlooked. These new alternatives then undergo a second round of scrutiny, with
each being considered even if they do not support a decision-makers’ preferred course of action.

**Step 3: Implementing a Course of Action**

Once a choice has been made about an alternative, the decision-maker begins to take action. Some decisions can be implemented quickly and easily, such as contracting a care agency or cutting back on the level of care. Other decisions may take months or years to implement, such as helping a person move from a nursing home into the community with 24-hour care. This stage may involve consultation with other stakeholder groups, securing finances and services, and a change in attitudes, skill and behaviours. Concurrent with taking action to implement a decision, individuals should ideally have a contingency plan. Recognising that the process may not go according to plan, decision-makers typically have a ‘Plan B’ in the event of failure or changed circumstances.

The decision-making process may be terminated at any stage if a person decides to take no action. Choosing to do nothing and maintaining the status quo is one option available to decision-makers. However, when a conscious decision is made to not relocate or accept paid services, an observer cannot readily see that decision, nor distinguish between non-action and avoidance (Kane, 1995). Choosing not to act may occur in times of stress when an individual experiences information overload (Reaby 1996).

**Step 4: Learning from Feedback**

In many instances, feedback will be available about the outcomes of a decision. At this time, a decision-maker not only reflects on the quality of the process but also how satisfied or disappointed they are with the outcome (Zeelenberg, van Dijk, Manstead, & van der Pligt, 2000). Feedback also permits learning to occur and subsequent decision rules to be modified. For example, a parent experiencing a negative outcome after letting their teenage son or daughter go to a party will alter subsequent decision rules (Carroll & Johnson, 1990). In the future, the decision-maker may spend longer seeking information, eliminate or increase the number of alternatives considered, or take longer to implement the chosen course of action.
One study found that professionals with more experience working in the community with at-risk elders were less likely to make hasty decisions about the older person’s future care needs and living situation than professionals from acute hospital settings (Clemens & Hayes, 1997). This finding suggests that case managers, family members, care agencies and the person with brain injury should, in theory, make decisions differently with the benefit of experience.

2.4.4 Quality Decision-Making

Quality decision-making involves knowing and following the ‘ideal’ process or criteria for optimal decision-making (descriptive decision theory), knowing how to find support, and using prescribed strategies and decision aids to enhance the process (prescriptive decision theory) (Bekker et al., 1999). Criteria for optimal or quality decision-making have been defined and tested in a number of contexts by Irving Janis and Leon Mann (1977). The seven criteria are shown below in Table 2.1. When a decision-maker focusses on all seven criteria fully and equally, Janis and Mann described this as ‘vigilant’ information processing.

*Table 2.1 Criteria for Quality Decision-Making (after Janis & Mann, 1977)*

<table>
<thead>
<tr>
<th>Step</th>
<th>Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Actively searches for and canvasses a wide range of alternative courses of action to the best of the person’s ability</td>
</tr>
<tr>
<td>2</td>
<td>Surveys the full range of objectives to be fulfilled, and the values associated with each alternative</td>
</tr>
<tr>
<td>3</td>
<td>Weighs up the known costs, risks, and consequences of each alternative</td>
</tr>
<tr>
<td>4</td>
<td>Thoroughly searches for new information that might inform the decision, including previously unconsidered alternatives</td>
</tr>
<tr>
<td>5</td>
<td>Assimilates new information, even if it does not support the preferred course of action</td>
</tr>
<tr>
<td>6</td>
<td>Re-examines the positive and negative consequences of each alternative</td>
</tr>
<tr>
<td>7</td>
<td>Plans to implement the chosen course of action, while also having a contingency plan to fall back on, should this be necessary</td>
</tr>
</tbody>
</table>
By following the stages and processes outlined in Table 2.1, and attending to all seven criteria, an individual is more likely to make a high quality decision. The more criteria that are bypassed because of stressful circumstances or deadlines, the more likely it is that the decision-maker will be dissatisfied with the outcome or experience regret. Decision-makers also make a tacit decision about how much time, energy, and money to invest when searching for and deliberating over the alternatives. A quick scanning approach may suffice for some relatively unimportant decisions. However, important life decisions with serious consequences usually require vigilant information processing, and attention to all seven criteria.

2.4.5 Factors that Influence Decision-Making

A modest body of literature has been identified on the process of decision-making generally, most describing one or more aspect of the process and steps outlined in Table 2.1. Many studies focus on major life events such as changing jobs or ending a relationship (Baron, 1994; Janis & Mann, 1977; Levin, Jasper, & Forbes, 1998). Other studies focus on making decisions during a personal health crisis, such as when given a diagnosis of breast cancer (Charles, Redko, Whelan, Gafni, & Reyno, 1998). A more limited body of research was identified on care decision-making, mostly in relation to older adults (for example, Clemens & Hayes, 1997) and, to a lesser degree, people with intellectual disabilities (for example, Jenkinson & Nelm, 1994).

While these other studies provide useful information about different aspects of decision-making, people with traumatic brain injury represent a unique population with special needs. Factors such as the age and expected lifespan of the injured person are very different to those of older adults with dementia and increasing frailty. The prior independence and life experience of a person who has acquired a brain injury will also be different to that of a person born with intellectual disability. While both may be the same age, a person with intellectual disability would have received much more care and assistance throughout their life, than a person with a recently acquired disability. For these reasons, a study is required that involves people with traumatic brain injury, their family and others as participants, and explores the process, experience and quality of care decision-making.
A number of other factors and conditions are known to influence the process and consequences of decision-making. These factors include: the pressure of time, a perception of urgency and short deadlines; unfamiliarity with the focus of a decision; personal coping strategies used; information overload; attitude to risk and risk-taking; level of uncertainty; size of the decision network and number of people involved; decisional conflict; and the seriousness of the decision (Agich, 1995; Baron, 1994; Carroll & Johnson, 1990; Forbes & Hoffart, 1998; Garro, 1998; McGrew, 1998). The presence or absence of these conditions will affect both the quality of a decision and satisfaction with the consequences. One way to reduce the likelihood of post-decisional regret is by using decision-aids.

2.4.6 Use of Decision-Aids

Decision-aids are intended to enhance the quality of decision-making. They may be used by the decision-maker, or facilitated by a professional or family member. These aids have the potential to help people with brain injury engage more effectively in decision-making. One example of a decision-aid is the Options, Outcomes, Values, and Likelihoods (OOVL) decision-making guide (Lewis, Hepburn, Corcoran-Perry, Narayan, & Lally, 1999). The guide involves using a matrix to identify options, possible decision outcomes, and the value or importance associated with each outcome. Responses are then ranked. Also recorded is the likelihood of each option leading to a stated outcome. The likelihood is rated as low, medium or high. The OOVL guide aims to enhance decision-making, and can be used with assistance or independently. People with and without brain injury could learn to make decisions through practice using the OOVL; however, there are no reports to date of this occurring in the literature.

A second example of a decision-aid is informal decision analysis (Owens, Ashcroft, Leinster, & Slade, 1987). This method involves a facilitator helping the decision-maker to work through a defined process. Alternatives are considered in turn. Events that ‘might’ occur are ranked. Subjective ratings are given from 0 to 10 denoting the probability that an event will or will not occur (10 = absolute certainty that an event will occur; 0 = absolute certainty that an event will not occur). A rating is also given from 0 to 100 of the desirability of events occurring (0= not
desirable; 100 = very desirable). Scores are added and compared using a decision tree. Many people with brain injury would be able to engage in decision-making if informal decision analysis was used. However, to date use of this process has not been reported with a brain injury population.

A third strategy for enhancing decision-making involves skill training. Such a program was developed in South Australia, specifically for people with problem solving difficulties following brain injury (Rolan, Williams, & Crawford, 1996). The group program ran for a period of 17 to 32 weeks, with meetings twice a week. Training was intended to help participants become more effective decision-makers. They practised the cognitive skills intrinsic to each step of the process using ‘real life’ scenarios. Although this is one of the few strategies reported for enhancing decision-making after brain injury, no formal evaluation of this program has been reported.

When a person is able to communicate their preferences, shared or assisted decision-making is most likely to occur such as described. However, when this is not the case, substitute decision-making may be required.

2.4.7 Substitute Decision-Making

Substitute or surrogate decision-making involves the formal transfer of decisions to another person such as a spouse, son or daughter, or to an agency such as the Office of the Protective Commissioner in Australia (Office of the Protective Commissioner of NSW, undated). This type of decision-making is most often used when a person has severe cognitive impairments (Altman, Parmlee, & Smyer, 1999; Baskin, Morris, Ahronheim, Meier, & Morrison, 1998; McCullough & Wilson, 1995). Decisions may be major or minor, general or financial. Of particular concern to substitute decision-makers is the potential for loss of autonomy by the person concerned, when decisions that affect their life are made by others (Agich, 1995; Shawler, Rowles, & High, 2001). The challenge is striking a balance between risk and autonomy. Although this careful balance has been debated in relation to older adults (Agich, 1995; McCullough & Wilson, 1995) and people with intellectual disabilities (Racino, Walker, O'Conner, & Taylor, 1993; Shaddock, Rawlings, &
Guggenheime, 1993), there is a need to explore assisted and substitute decision-making, risk and autonomy with people who have brain injury.

In summary, the final section of this chapter has reviewed concepts associated with decision-making. The process of decision-making was noted to involve four main steps. Criteria for quality decision-making were described, including the allocation of adequate time and attention to each step. Other factors that limit or enhance a person’s ability to make a decision were also discussed. No literature was located specifically on care decision-making after brain injury, the focus of the current study.

Before presenting an overall chapter summary, the study aim and research questions, the proposed theoretical orientation of the study will be identified.

2.5 Theoretical Orientation and Methodology

While positivist methodologies could measure domains such as attitudes to care and levels of care, these were not designed to explore processes such as care decision-making (Coffey & Atkinson, 1996; Creswell, 1994; Creswell, 1998). The current study required a methodology capable of exploring processes and conditions. Grounded theory was selected because of its suitability for exploring social problems, processes and interactions, and for theorising about constructs and building theory (Dey, 1999; Glaser & Strauss, 1967; Strauss & Corbin, 1998). Further discussion and justification of this approach will be presented in the following chapter.

2.6 Chapter Summary

Up to 600 Australians each year acquire a traumatic brain injury and need long-term care primarily because of cognitive and behavioural impairments. By definition, long-term care will be required in some form for a large part of that person’s life. The aim of long-term care, particularly paid care, is to help a person with brain injury participate more fully in society and maintain important social roles. While the majority of care costs following brain injury are typically for attendant care,
long-term care also includes personal care, respite care, financial management, extended case management, allied health services and specialised disability equipment.

Long-term care is complex to organise because of a multiplicity of factors. Not only are multiple providers involved, the person with brain injury is particularly vulnerable and at risk because of their cognitive and behavioural impairments. They often need someone to coordinate care and assist with decision-making, as circumstances and funding availability change. Anecdotal reports suggest there are insufficient long-term care and coordination services to meet some individuals’ needs, regardless of the amount of compensation received. Research is needed to confirm or refute these reports, and identify areas of unmet need.

Health professionals and care agencies are frequently asked for their opinions when long-term care costs are being determined for compensation. Professionals are also required to give an opinion about the best model of care and configuration of carers. However, no empirical research data are available to guide these decisions. Of particular note is the absence of research on the views, preferences and experiences of care users. With regard to users’ preferences, research has been conducted with people who have physical disabilities but not those with brain injury. People with physical disabilities report a preference for using paid carers instead of relying on family, and for consumer-directed care over agency-directed care. The consumer-directed model increases feelings of personal control and autonomy, health and well being, and reduces reliance on family carers. This model also offers better value for money. Less is known about other configurations and models of care, and even less about the preferences of people with brain injury.

Care decision-making involves a number of constructs, including a process with steps and stages, and conditions that influence and are necessary for quality decision-making. The ideal process involves seeking information about alternatives, considering alternatives in terms of risks and benefits, and finally committing to a course of action. Decision-aids and strategies can be used to enhance the process, although it is unclear if these are used in practice. Conditions that influence quality and satisfaction with decisions include the pressure of time
and deadlines, information overload, personal coping strategies, conflict and the level of perceived risk. Quality decision-making involves vigilance on the part of the decision-maker, in order to maximise satisfaction and minimise regret after a decision has been made. Inexperienced decision-makers, and those less familiar with the choices are more apt to limit their options and terminate the process early. Health professionals have also been reported to engage in sub-optimal care decision-making when determining the future needs of at-risk elders. Some professionals have been identified as having either a reduced or increased tolerance for risk, which in turn influences the process and outcomes of their decision-making.

2.7 Research Aim and Questions

In order to address the gaps in knowledge identified throughout this chapter, the present study aims to explore the processes and conditions surrounding care decision-making and care management after brain injury. The study is guided by three questions in relation to people with traumatic brain injury:

1. Which models of care, paid and unpaid, are preferred?

2. What processes and strategies do the injured person, their family and others use when making decisions about, and managing long-term care?

3. What conditions influence care decision-making and care management?

Chapter 3 describes the way in which grounded theory methods were applied in the current study.
CHAPTER THREE
RESEARCH METHODS

3.1 Introduction to the Chapter

The aim of this study was to explore the processes and conditions surrounding care decision-making and care management after brain injury. Chapter 2 highlighted the personal and societal impact of brain injury. Demands on family members, services and communities remain high over time, particularly in relation to care. Much remains to be learned about long-term care. The preferences of people with brain injury have not been investigated in relation to models of care, nor have the conditions that influence care-use and care decisions. The current study focuses on these gaps in current knowledge.

Chapter 2 briefly introduced grounded theory, the methodology used for this study. Reasons for selecting this approach will be described shortly, followed by a description of how grounded theory methods were applied in this study, since the term ‘grounded theory’ applies to both methodology and methods. The primary data collection method was semi-structured interviewing. Secondary methods were written field notes, a research diary, and administration of four quantitative measures. These will be described, along with sample characteristics. Also presented is an overview of computer-assisted data management, which facilitated analysis and theory development. In addition to describing open, axial and selective coding procedures, issues of rigour, trustworthiness, and the place of the researcher are described. Finally, methods used to protect the rights of participants and ensure ethical conduct of the study are reported.

3.2 The Methodology: Grounded Theory

Methodology is the “branch of knowledge that deals with method and its application in a particular field of study” (Evans & Gruba, 2002, p. 89). The term describes how knowledge is acquired and interpreted, as well as the stance that a researcher takes when conducting a study. For example, a researcher can be an
objective observer, a participant in their own study, or the designer of an empirical experiment (Evans & Gruba, 2002). The present study required a methodology capable of exploring processes and building theory. As a methodology, grounded theory aims to explore, interpret and develop theories about social problems and processes from the perspective of symbolic interactionism (Dey, 1999; Glaser, 1978; Glaser & Strauss, 1967; Strauss & Corbin, 1998).

### 3.2.1 The Link between Grounded Theory and Symbolic Interactionism

Grounded theory emerged from, and is intrinsically linked to, symbolic interactionism (Blumer, 1969; Stern, 1994). Ian Dey, in his most recent text refers to this association and the reasons why grounded theory was first developed in the 1960s:

> ...the marriage of these two traditions...was intended to harness the logic and rigor of quantitative methods to the rich interpretive insights of the symbolic interactionist tradition (Dey, 1999, p. 22).

These “rich interpretive insights” arise out of the three basic tenets of symbolic interactionism, as described by Herbert Blumer (1969). First, human beings act towards objects or ‘things’, such as paid carers or supervision, based on the meanings that these things have for them. Second, meaning arises out of the symbolic interaction with others. Third, meaning can change over time as a result of experience and interpretation, which occurs subconsciously. In the context of the current study, the way a person with brain injury acts towards care and carers may be quite different at the end of five years, from the way he or she acted upon leaving hospital. The more a person with brain injury is exposed to, and interacts with, paid carers the more his or her view and meaning will alter. A negative experience with paid carers may lead to subsequent problem behaviour, as the person with brain injury’s view of care changes. The methodology of symbolic interactionism was intended to study the way in which meanings such as these change over time, and from person to person.

One common feature of grounded theory and symbolic interactionism is a focus on social behaviour, problems and processes. Grounded theorists in the past have, for
example, explored the social processes of ‘becoming’ an alcoholic (Bigus, 1996), ‘cutting back’ after a heart attack (Mullen, 1993), and ‘acquiring’ specialist nursing expertise (Bonner, 2001). One difference between grounded theory and symbolic interactionism is at the level of procedure. The writings of Herbert Blumer did not provide guidance on how to proceed with the collection and analysis of data. This need was met, in part, by the publication of various texts on grounded theory by Glaser and Strauss, since these texts guide researchers in the process of collecting, analysing, interpreting and conceptualising data.

The present study used grounded theory, with its links to symbolic interactionism, as the methodology and method of choice. Several textbooks describe the methods used to conduct a study and build a grounded theory (Charmaz, 2000; Dey, 1999; Locke, 2001; Strauss, 1987; Strauss & Corbin, 1990, 1998). However, researchers are also encouraged to identify which theoretical orientation they are using: Glaserian, Straussian, or a combination of both.

3.2.2 The Grounded Theory Debate

There are two ‘schools’ of grounded theory: the Glaserian ‘school’, based on the writings of Barney Glaser, and the Straussian (or Strauss and Corbin) ‘school’, after Anselm Strauss and his apprentice Juliet Corbin (Dey, 1993, 1999; Melia, 1996; Morse, 2001; Robrecht, 1995; Stern, 1994). Although the original methodology was developed jointly by Glaser and Strauss in the 1960s, culminating in the classic text ‘The discovery of grounded theory’, the two sociologists no longer work together (Dey, 1999). Glaser has written a great deal since the 1960s on grounded theory (Glaser, 1999), and how his methods should be interpreted and applied (Glaser, 1998, 2001). He has also critiqued the work of Strauss and Corbin. Strauss and Corbin have focussed on explicating grounded theory methods of data analysis and theory construction (Corbin, 1986; Strauss, 1987; Strauss & Corbin, 1990, 1998).

3.2.2.1 The ‘Original’ Grounded Theory (Glaser & Strauss, 1967)

The first step in the process of developing a grounded theory is selecting a general subject or problem area, but without a preconceived theoretical framework or
hypothesis. A review of the literature was initially considered unhelpful by Glaser and Strauss (Dey, 1999; Schreiber, 2001) because views of other writers might bias a researcher entering the field. However, in later writings, both acknowledge that reading related and unrelated literature will help to sensitise researchers to their topic (Schreiber, 2001). This is a relief to many qualitative researchers, who would be unable to gain ethical approval, let alone research funding, without having first reviewed previous literature.

Next, the researcher selects a site to study the problem and begins collecting data. Data are collected primarily through a combination of observation, interviews, and documents. However, the various texts provide more detail on data analysis than they do on data collection. Much of the literature provides general principles. Grounded theorists aim for a combination of data sources and perspectives (Schreiber, 2001), perhaps using observation combined with interviewing, collecting data from multiple participants about the same subject, or from the same participant on more than one occasion. Initially, data collection is fairly general and unstructured but becomes more focussed as the study proceeds.

*Theoretical sampling* refers to the method of selecting sites and/or participants, based on their theoretical relevance rather than being predetermined (Glaser, 1978). Additional sites and participants are determined as the study progresses, and as constructs and relationships start to evolve. Sites and participants are selected based on their ability to develop, extend and compare concepts not for representativeness. As data are collected, the researcher concurrently engages in analysis, looking for similarities and patterns across participants and sites. Theoretical sampling may not involve recruiting new people into the study. Sometimes this method involves seeking further experiences from members of the existing sample. This type of sampling involves selecting participants that are most likely to contribute information to key categories and concepts that evolve during analysis. These participants are recruited to highlight ways in which the properties and dimensions of a category vary (Strauss & Corbin, 1998).

*Coding* involves analysis and sorting of data and is the first step in theory development (Charmaz, 2000), with categories being the outcome. Text is
examine closely, either line by line or using whole paragraphs. Data from
interview transcripts, field notes and archival data can all be coded. Raw text data
are grouped together on paper into categories, or entered into a computer software
program to be further sorted and condensed into manageable units (Coffey &
Atkinson, 1996; Morse, 1994).

Memoing is conducted to help a researcher record his or her thinking processes, and
may involve drawing models and diagrams of relationships to help progress theory
development. During coding, researchers are encouraged to keep detailed notes of
ideas and decisions, and to write memos as records of the process. Glaser argued in
his later work that:

...the bedrock of theory generation, its true product is the writing of
theoretical memos. If the analyst skips this stage by going directly from
coding to sorting or to writing – he is not doing grounded theory (Glaser,
1978, p. 83).

Categories are the product of coding and memoing. They are groupings of data
reflecting a common theme such as ‘trees’ or facets of ‘care’. Categories have
particular characteristics or ‘properties’ that a grounded theorist goes on to describe.
For example, a tree has the properties of colour, size, density, age and type. Care
involves different providers, configurations, levels and relationships. Categories
and their properties need to be analytic and include ‘dimensions’ along a
continuum. Continuing the previous examples, a tree can be tall or short (size),
have thick or thin foliage (density), be a sapling or a very old tree (age), and be
deciduous or coniferous (type). Care can be provided by paid or unpaid carers
(providers), involve short or long shifts and rosters (configuration), be provided 24
hours a day or occasionally (level), and involve a close friendship or a more formal
client-carer relationship. These are ‘dimensions’ along a continuum.

Theoretical sensitivity refers to the background knowledge, experience, literature
and intuition that a researcher uses to generate and compare categories while
coding. Researchers need to think theoretically and conceptually, looking for
relationships between concepts in the data without forcing a theory.
Constant comparison occurs during and after coding and involves going back and forth from one case or transcript to another, from one category to another to search for relationships between concepts. The main purpose of making comparisons is to generate or build a dense theory, with categories that are conceptual and abstract, and which have properties and dimensions (Glaser & Strauss, 1967). The elements of a grounded theory are conceptual categories and their properties, followed by hypotheses or relationships between these categories and their properties (Glaser & Strauss, 1967).

A core category is the central focus of a grounded theory, around which other categories converge. It is the central phenomenon or main concern for participants. As Glaser later noted, the purpose of grounded theory is “to account for a pattern of behaviour which is relevant and problematic for those involved” (Glaser, 1978, p. 93). A core category may be a process, a condition or a consequence and a storyline is often used to describe relationships between the core category and other concepts.

Theoretical saturation is the term used to indicate that new properties, categories and relationships have ceased to arise during analysis. That is, new participants confirm or add to the density of coding but suggest no new concepts or variations. This absence of new concepts signals that data collection is probably complete. The ‘saturation’ refers to concepts, not data, and refers to a point in the study where no further conceptualisation of data is considered necessary (Glaser & Strauss, 1967; Dey, 1999). When this stage is reached, new participants and cases only add quantity to the coded data but little to the theory (Murphy, Dingwall, Greatbatch, Parker, & Watson, 1998). At this point, the researcher may identify a core category (as opposed to lower level peripheral categories) through more selective coding.

While these procedures are characteristic of early grounded theory, some were elaborated upon and contested, and others added by Glaser, and by Strauss and Corbin. It is possible to recognise the preferred ‘school’ or theoretical orientation of a researcher based on the structure and concepts present in a grounded theory (Bonner, 2001; Cusick, 2001; Fagerhaugh, 1986; Robinson, 2000). The present study was influenced by, and used ideas from both schools of thought.
3.2.2.2 The Straussian School of Grounded Theory

Strauss and Corbin (1990) described a ‘coding family’ or ‘paradigm’ to help researchers achieve depth and density in their grounded theory. This paradigm included conditions, context, action/interactional strategies and consequences. They also added a ‘conditional matrix’ to grounded theory methodology. This matrix was described as a “complex web of interrelated conditions, action/interaction, and consequences” related to a phenomenon (Strauss & Corbin, 1990, p.161). The purpose of developing a matrix was to help researchers identify conditions and consequences (Dey, 1999).

‘Axial coding’ was a new level of coding described by Strauss and Corbin (1990, 1998). Glaser and Strauss and Corbin all agreed on the concepts of open (basic) coding, and selective coding, where only categories related to the core category are explored (Schreiber, 2001). However, Strauss and Corbin added axial coding as a middle step. This step involves putting data back together in new ways after open coding, by making connections between categories (Strauss & Corbin, 1990). Axial coding is achieved using the ‘coding paradigm’ described above.

3.2.2.3 The Glaserian School of Grounded Theory

Glaser also described multiple coding families or paradigms, 18 in total, and earlier than Strauss and Corbin (Glaser, 1978). These coding families include ways of coding data with the aim of developing a typology, social process or trajectory. Glaser’s aim was to give researchers the freedom to create new theories focussed around processes, problems, typologies, dimensions and strategies. On reviewing literature on grounded theory, the most commonly used coding paradigms appear to be ‘basic social processes’ and ‘basic social problems’.

A ‘basic social process’ or BSP is a central concept of many grounded theories, and one of the many coding families described by Glaser. A BSP is a particular type of core category, a process category around which the grounded theory evolves (Fagerhaugh, 1986; Glaser, 1996a, 1996b). Glaser called this the BSP model of grounded theory (Glaser, 1996b). By convention, when a BSP is the core category,
it is labelled with a gerund, or an ‘ing’ word such as ‘becoming’ or ‘managing’ (Glaser, 1996b; Schreiber, 2001). According to Glaser, a process had to have at least two stages, and may also involve:

Stages, staging, phases, phasing, progressions, passages, gradations, transitions, steps, ranks, careers, orderings, trajectories, chains, sequencing, temporalising, shaping and cycling (Glaser, 1978, p.74).

Glaser argued that change was basic to people’s lives, and the BSP model summarises what is occurring as participants resolve a social problem or concern in their lives. A BSP explains movement, change, and variations in behaviour. Examples of BSPs include ‘becoming alcoholic’ (Bigus, 1996), ‘becoming a clinician-researcher’ (Cusick, 2001), and ‘managing urinary incontinence’ (Robinson, 2000).

A ‘basic social problem’ is another central concept arising from the Glaserian school of thought, particularly Glaser’s more recent publications (Glaser, 1998, 2001). A basic social problem is the main concern of participants in a study. The behaviour and actions of participants, perhaps described during interviews or observed, will be directed at resolving the basic social problem. For example, Japanese women cope with a ‘traditional marriage’ (the basic social problem) by ‘enduring in silence’ (the basic social process; Glaser, 1998, p. 115). Emergency medics or ambulance workers engage in ‘covering’ (the basic social process) to ‘avoid accusations of neglect’ (the basic social problem; Glaser, 1998, p. 117). Professionals need to be cautious in identifying the basic social problem for the following reasons:

...the professional, preconceived problem, while of interest to the profession or some professional is often not there and if there, not of great concern to the participants….the professional problem is usually based on pet categories (eg self image) and pet interests. It usually is irrelevant to the participants and the research produces few or no findings of relevance (Glaser, 1998, p. 115).
3.2.3 Substantive versus Formal Grounded Theory

Glaser and Strauss appeared to agree that there are two types or levels of grounded theory: substantive theory and formal theory (Glaser & Strauss, 1967). Substantive theory is one that evolves from a study of phenomena in one context or setting. The current study aims to develop a substantive theory. In comparison, formal theory evolves from an existing substantive theory through studying phenomena in a range of situations or settings. For example, if the care decision-making experiences of people with a range of disabilities, living in different living situations, were studied and compared, this process could lead to formal theory.

In summary, grounded theory with its roots in symbolic interactionism was selected as the methodology of choice, because grounded theory allows a researcher to explore social problems and social processes. The present study required a methodology that could explore the processes surrounding care decision-making and care management. The study was guided by the ideas and writings of Glaser, Strauss and Corbin. The following section will describe and justify the application of grounded theory methods to the current study.

3.3 Study Design

3.3.1 Setting

The study was conducted in the state of NSW, Australia. The population of NSW is currently 6.691 million, which represents about one third of the national population (Australian Bureau of Statistics, 2003). NSW is the most highly populated state of Australia. While about two thirds of Australians live in capital cities, many live in rural and remote regions where access to services varies widely. Therefore, it was important to obtain the views and experiences of people living in rural NSW as well as in Sydney. For the purposes of this study, any residence 100 kilometres or more from the Sydney central business district was defined as rural or regional NSW.

There are currently 13 brain injury units in NSW (11 adult; 2 paediatric). Five units are based in Sydney; the other eight are located in rural and regional NSW. State
and federal governments fund these public services, which are free to Australian residents. There are also private service providers, particularly case management and attendant care services, in city and rural NSW.

Data were collected in the homes of people with brain injury and the offices of health professionals that worked with them. People with brain injury lived either in their own home or with their family\(^2\). For some, the primary carer was a spouse or parent who lived with them. However, in some cases no family member was involved on a regular basis. Instead, health professionals assisted with care coordination.

In the past, I had worked as a community-based occupational therapist for one of the NSW brain injury units. As a private occupational therapist, I had also provided independent rehabilitation services, and conducted medicolegal assessments to people with brain injury across NSW. This background experience helped me decide who to recruit, and how to ethically involve participants in the study.

### 3.3.2 Purposive and Theoretical Sampling

Sampling was purposive then theoretical. Purposive sampling implies that a researcher has used his or her inside knowledge to select participants with certain attributes, and with a specific purpose in mind (Berg, 1995). Although Berg wrote that purposive sampling was only “occasionally used” (1995, p. 179), this method is now commonly used for sampling by grounded theorists today (Strauss & Corbin, 1998; Dey, 1999).

In this study, the purpose of initial participant selection was to recruit two or three people with brain injury who lived alone and received 24-hour care (the highest level of care). It was anticipated that these individuals would employ a team of paid carers on a live-out basis. This approach to sampling allowed one model of care to be explored in depth with a similar group of participants. Comparisons were made, and a search conducted for similarities and differences between participants. Next, people

\(^2\) Footnote. Two participants with brain injury had experienced institutional living for 10 and 13 years respectively, but had recently moved into their own home.
with brain injury who lived with and received assistance from a family member were actively recruited. Later, those who had ceased using paid care services were sought, and so forth. With each new case, aspects of care decision-making and associated conditions were investigated. Additional criteria considered during sampling were gender and whether the person with brain injury lived in the city or country.

Theoretical sampling is a feature of grounded theory where decisions about recruitment are made as the research progresses, rather than being predetermined (Glaser & Strauss, 1967, Strauss & Corbin, 1998). The phenomena under investigation are broadly identified at the beginning of a study, and an initial sample planned. Subsequent participants are recruited to help discover variations among concepts, elaborate and exhaust categories (Strauss & Corbin, 1998).

3.3.3 Eligibility Criteria: People with Brain Injury

To be eligible for inclusion in this study, people with brain injury were required to meet the following criteria:

1. Be able to communicate responses verbally or in writing during a one-hour interview, without a carer needing to be present;
2. Be a recipient of paid care or domestic services, or have received such services in the six months prior to recruitment;
3. Be in receipt of compensation or be likely to have settled their compensation claim by the end of 2001 when data collection concluded, and;
4. Be aged 16 years or over.

The last criterion excluded children and adolescents under 16 who might have been receiving care from a guardian for reasons other than their brain injury. Also excluded were people with brain injury known to the researcher through clinical or medicolegal consultations. Prior contact may have influenced the nature of the questions asked and participants’ responses.

To meet the first criterion, a person with brain injury had to be able to independently communicate responses during an interview, orally or in writing.
This criterion excluded people who were in a coma, persistent vegetative state or dependent on a carer to answer questions or ‘translate’ responses. The decision to include or exclude a person with brain injury based on this criterion was made following discussion with someone who knew them well. Cognitive impairments did not exclude these individuals, who had views and opinions about care which were important to capture independently of their carers.

Family members and paid carers were asked to leave the room during an interview, because their presence may have unduly influenced or restricted participants’ responses. However, as will be reported shortly, accuracy of data was confirmed through triangulation. Two or more people associated with the person with brain injury were interviewed about similar issues. Furthermore, factual information such as names of carers was collected in writing before the interview, and could be used during interviews to prompt a participant with impaired memory.

To meet the second criterion, a person with brain injury had to be a recipient, past or present of paid attendant care or domestic services. This was because the use and non-use of long-term care services was a focus of the study. People who relied on unpaid family carers only for day-to-day support were not included in the sample. ‘Recent’ use was defined arbitrarily as six months. People with brain injury who had ceased using paid care within the previous six months were included. Their reasons for discontinuing care services could then be explored.

To meet the third criterion, people with brain injury had to be in receipt of, or expect to receive, a compensation payment before the end of 2001. Most non-compensable people with a brain injury in Australia do not have the option of using paid care services because of the cost. Therefore, the study was limited to people with brain injury who had received or expected to receive compensation.

3.3.4 Participant Selection

In the previous section, the need for more than one data source and perspective was highlighted when using an interpretive paradigm such as grounded theory (Schreiber, 2001). For this study, multiple perspectives on care decision-making
and care management were sought. Between two and five people associated with
the person with brain injury participated (three to six participants per case). All had
some involvement in the person’s care coordination, planning or provision.
Therefore, the sample included people with traumatic brain injury, family carers,
case managers, estate managers, paid carers and care agency directors. The term
‘case’ reflects this mixed group of participants.

Following ethics approval (see page 83 for further discussion), the person with
brain injury was the first person to be recruited in each case. The make-up of each
case was slightly different according to personal circumstances. For example, some
people with brain injury had little or no involvement with their family. In such
cases, no family members were interviewed. In all cases, the person with brain
injury decided who would be approached. With assistance, they nominated key
people for inclusion in the study.

Case managers in this context were either privately self-employed or worked in the
public health system for one of the specialist brain injury services. Most case
managers had occupational therapy or social work qualifications. Case
management primarily involved tasks such as finding alternative accommodation,
liasing with service providers and coordinating care services (Hosack, 1998; Motor
Accidents Authority of NSW, 1998). Sometimes a case manager became involved
when a person returned home from hospital. In other situations, a case manager
was employed months or years later.

One estate manager employed by the Office of the Protective Commissioner (OPC)
was interviewed. These health professionals are actively involved in the process of
care decision-making after brain injury. They typically become involved after the
courts have awarded a large compensation payment. An estate manager oversees
the compensation payment, pays bills on the injured person’s behalf, and allocates
money for expenses. Estate managers also initiate care reviews and sometimes
recommend the introduction of paid care to relieve family members.

Paid carers were included in the study because they have the potential to influence
care decision-making in a household. These workers have a close relationship with
clients and their family, spending many hours each week in the home. They provide different types and levels of care to different clients ranging from personal care to transport, companionship and budgeting (McCluskey, 2000).

Finally, directors of private for-profit care agencies were invited to participate in the study if they played a role in administering and coordinating care. Therefore, the final sample included a mixed group, with the person with brain injury nominating other participants for recruitment.

3.3.5 Recruitment

Participant recruitment began in late 1998 and concluded in late 2001. People with a brain injury and other members of a case were recruited with help of the following people: occupational therapists working in private practice or in a specialist brain injury service; directors of commercial care agencies; directors of community-based organisations, for example, HeadWay and Community Options; and rehabilitation advisors at insurance companies. Professionals from each agency had regular contact with, and provided services to, people with brain injury in the community.

First, the third party agency made contact with a person with brain injury. They were invited to participate. The professionals usually knew this person very well. The decision to use a proxy or relative to gain additional consent was made on a case-by-case basis, following discussion with the third-party agency, the person with brain injury and a family member when necessary. In one case, the third party agency and a family member wished to confer with the family solicitor before consenting. Their concern was that participation in my study might affect the forthcoming court case. This scenario had been anticipated. A list of issues had been prepared in advance for professionals to discuss with a solicitor (see Appendix A). In this case, the solicitor advised the family not to participate in the research until after their court case was concluded. The person with brain injury and their family member were subsequently interviewed one year later.

The second stage of recruitment involved telephoning the person with brain injury and a family member (when appropriate). A family member was often approached
at this stage because they were the legal guardian, or because the person with brain injury needed help to make decisions. They typically asked a range of questions about the purpose and expected outcomes of the study. In two cases, people decided not to participate at this stage. One person with brain injury declined. She and her family were too busy to participate. Another family member/guardian declined on behalf of the injured person who had recently experienced a stressful event.

The third stage of recruitment involved mailing an Information Sheet, two Consent Forms, a stamped addressed envelope, and a 5-page Background Information/Demographics form to participants and their family (see Appendices B-1 to B-3). These documents were written in ‘plain English’. The Information Sheet was enlarged to assist participants with low vision or information processing difficulties. Sometimes a proxy or family member co-signed the Consent Form, sometimes they did not. One Consent Form was retained for their records, and the other returned prior to the first interview along with the Background Information/Demographics form. This process temporally separated consenting from the stage of data collection.

Names and contact details of other people who provided or assisted with care management were obtained around this time. These people were then contacted by telephone. If they agreed to participate, they were sent an Information Sheet and two Consent Forms. A provisional interview date was also set several weeks after the person with brain injury had been interviewed. On the day of data collection, the Information Sheet was read aloud to each person with brain injury, along with the contents of their completed Consent Form. No cognitive screening assessment was administered. However, neither was any assumption made about a person’s ability to give consent, or to remember that they had previously given consent.

The first interview was conducted with the person with brain injury. Other participants, such as family members and paid carers read their own documentation at the time of interview. This process reminded participants of the purpose, potential benefits and (minimal) risks associated with the study. When the interview commenced and the tape recorder was switched on, acknowledgment was made of the fact that these documents had been read and informed consent obtained.
Confidentiality was reinforced, before and during interviews. Approval to tape record the interview was obtained and recorded on tape.

### 3.3.6 Sample Size and Characteristics

In this study, a total of 51 people were recruited and interviewed from across 14 different cases (see Tables 3.1 and 3.2, pages 60 and 61 respectively). Sample size depends on the scope of a qualitative study (Morse, 2000). For example, sample size depends on how quickly and easily a researcher is able to get to the topic under investigation, the nature of the topic and quality of data. The experience of a researcher and willingness of participants to ‘open up’ also influence the quality of data. The methodology and data collection methods used will also affect sample size.

Using grounded theory methods, with two or three *unstructured* interviews per participant typically results in a sample of 20 to 30 participants being required. In contrast, when *semi*-structured interviews are used and less data collected per question, a researcher may need 30 to 60 participants to obtain richness of data (Morse, 2000).

In the present study, the aim was to interview no less than 10, and up to 15 people with brain injury and their circle of associates, in order to collect data on a range of care decisions. If three to six members were recruited for each case, this would bring the total number of interviews to between 30 and 90. A total of 30 to 50 interviews were considered manageable if computer software was used for data management. Characteristics of all 51 participants are presented in Table 3.1.

Characteristics of the 14 people with brain injury are presented in Tables 3.2 and 3.3. Pseudonyms have been used to maintain confidentiality. There were eight male and six female participants. Seven lived in Sydney, and seven in rural or regional NSW. The mean age at time of interview was 36.5 years, median 38 years (range 19 to 56 years). The mean time post-injury at interview was 9.9 years, median 8.7 years (range 2.5 to 37 years).
As no medical records were available to confirm the accuracy of reports from family carers and others, data presented on level of injury severity should be considered estimates only. Furthermore, some data are missing.

Table 3.1 Total Number of Participants (n=51) and Interviews (n=52)

<table>
<thead>
<tr>
<th>Case No.</th>
<th>Person with Brain Injury</th>
<th>Family Member</th>
<th>Paid Carer</th>
<th>Care Agency Director</th>
<th>Case Manager</th>
<th>Estate Manager</th>
<th>n per Case</th>
<th>Interviews Conducted</th>
</tr>
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<tr>
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<td>1</td>
<td>0</td>
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<td>0</td>
<td>3</td>
<td>3</td>
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<tr>
<td>4</td>
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<td>1 (defacto)</td>
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<td>0</td>
<td>3</td>
<td>3</td>
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<tr>
<td>5</td>
<td>1</td>
<td>1 (wife)</td>
<td>2</td>
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<td>1</td>
<td>0</td>
<td>5</td>
<td>7&lt;sup&gt;b&lt;/sup&gt;</td>
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<td>0</td>
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<td>4</td>
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<tr>
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<td>1 (mother)</td>
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<td>3</td>
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<td>1 (mother)</td>
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<td>1</td>
<td>2&lt;sup&gt;c&lt;/sup&gt;</td>
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<tr>
<td>14</td>
<td>1</td>
<td>1 (husband)</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>3</td>
</tr>
</tbody>
</table>

Total 14 12 14 4 6 1 51 52

Notes.  
<sup>a</sup> Estate Manager at the Office of the Protective Commissioner.  
<sup>b</sup> Two interviews were conducted on two separate occasions with the person with brain injury and with his wife (four interviews in total).  
<sup>c</sup> The coordinator and person responsible for rostering were interviewed together.  
<sup>d</sup> Two family members were interviewed together.
Table 3.2: Level of Injury Severity of People with Brain Injury (n=14) *

<table>
<thead>
<tr>
<th>Case Number and Name</th>
<th>Gender</th>
<th>Age</th>
<th>Years after Injury</th>
<th>Duration of Post-Traumatic Amnesia</th>
<th>Loss of Consciousness</th>
<th>Period of Hospitalisation (Months)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Gareth</td>
<td>Male</td>
<td>28</td>
<td>11</td>
<td>Not Known</td>
<td>Not Known</td>
<td>12 – 18</td>
</tr>
<tr>
<td>2 Lara</td>
<td>Female</td>
<td>49</td>
<td>6</td>
<td>Not Known</td>
<td>12 weeks</td>
<td>18 – 24</td>
</tr>
<tr>
<td>3 Thomas</td>
<td>Male</td>
<td>49</td>
<td>2.5</td>
<td>Not Known</td>
<td>5 weeks</td>
<td>24</td>
</tr>
<tr>
<td>4 Sheila</td>
<td>Female</td>
<td>28</td>
<td>11.5</td>
<td>8 days</td>
<td>15 hours</td>
<td>6 – 12</td>
</tr>
<tr>
<td>5 Will</td>
<td>Male</td>
<td>37</td>
<td>2.5</td>
<td>10 months</td>
<td>1 week</td>
<td>6 – 12</td>
</tr>
<tr>
<td>6 Moira</td>
<td>Female</td>
<td>49</td>
<td>2.5</td>
<td>6 months</td>
<td>24 weeks</td>
<td>30</td>
</tr>
<tr>
<td>7 Gary</td>
<td>Male</td>
<td>23</td>
<td>7.5</td>
<td>7 months</td>
<td>8 weeks</td>
<td>12 – 18</td>
</tr>
<tr>
<td>8 Angus</td>
<td>Male</td>
<td>19</td>
<td>8</td>
<td>8 months</td>
<td>Not Known</td>
<td>6 – 12</td>
</tr>
<tr>
<td>9 Wendy</td>
<td>Female</td>
<td>56</td>
<td>35</td>
<td>Not Known</td>
<td>Not Known</td>
<td>1 – 6</td>
</tr>
<tr>
<td>10 Keith</td>
<td>Male</td>
<td>27</td>
<td>13</td>
<td>Not Known</td>
<td>Not Known</td>
<td>12 – 18</td>
</tr>
<tr>
<td>11 Dora</td>
<td>Female</td>
<td>38</td>
<td>3.5</td>
<td>1 month</td>
<td>2 days</td>
<td>1 – 6</td>
</tr>
<tr>
<td>12 Paul</td>
<td>Male</td>
<td>41</td>
<td>7</td>
<td>Not Known</td>
<td>2 weeks</td>
<td>24</td>
</tr>
<tr>
<td>13 Joe</td>
<td>Male</td>
<td>37</td>
<td>17.5</td>
<td>Not Known</td>
<td>1 week</td>
<td>24</td>
</tr>
<tr>
<td>14 Dayna</td>
<td>Female</td>
<td>50</td>
<td>8.5</td>
<td>5 months</td>
<td>4 weeks</td>
<td>6 – 12</td>
</tr>
</tbody>
</table>

Notes. *Estimated by family members and others. No medical records or reports were available for verification. **Pseudonyms have been used.

Table 3.2 shows that over half of the people with brain injury (n=8) were hospitalised for 12 months or more. Loss of consciousness when reported was measured in weeks or months not days for most participants. Post-traumatic amnesia when reported was also typically measured in months not days. These data indicate that the majority had sustained a very severe traumatic brain injury.
**Table 3.3 Characteristics of People with Brain Injury (n=14)**

<table>
<thead>
<tr>
<th>Case Number and Name</th>
<th>Years after Injury</th>
<th>Source of Compensation</th>
<th>Living Situation</th>
<th>Care Configuration Hrs/Day (Wk); no. of Paid Carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Gareth</td>
<td>11</td>
<td>Worker’s Compensation</td>
<td>Alone. Minimal family contact</td>
<td>24 hrs paid care/day (168 hrs/wk); 4 paid carers</td>
</tr>
<tr>
<td>2 Lara</td>
<td>6</td>
<td>Worker’s Compensation</td>
<td>Alone. Minimal family contact</td>
<td>12 hrs paid care/day (84 hrs/wk); 4 paid carers</td>
</tr>
<tr>
<td>3 Thomas</td>
<td>2.5</td>
<td>CTP (^a)</td>
<td>Alone. Daily family visits</td>
<td>24 hr paid care/day (168 hrs/wk); 6 paid carers + family</td>
</tr>
<tr>
<td>4 Sheila</td>
<td>11.5</td>
<td>CTP</td>
<td>With defacto. Intermittent family contact</td>
<td>8 hrs paid care/wk; 2 paid carers + family</td>
</tr>
<tr>
<td>5 Will</td>
<td>2.5</td>
<td>CTP</td>
<td>Alone. Daily family visits</td>
<td>6 hrs paid care/wk; 1 paid carer + family</td>
</tr>
<tr>
<td>6 Moira</td>
<td>2.5</td>
<td>CTP</td>
<td>With husband</td>
<td>42 hrs paid care/wk; 2 paid carers + family</td>
</tr>
<tr>
<td>7 Gary</td>
<td>7.5</td>
<td>CTP</td>
<td>With parents</td>
<td>9 hrs paid care/wk; 1 paid carer + family</td>
</tr>
<tr>
<td>8 Angus</td>
<td>8</td>
<td>CTP</td>
<td>With mother and sibling</td>
<td>30 hrs paid care/wk; 1 paid carer + family</td>
</tr>
<tr>
<td>9 Wendy</td>
<td>35</td>
<td>CTP equivalent in 1965</td>
<td>With parents</td>
<td>36.5 hrs paid care/wk; 7 paid carers + family</td>
</tr>
<tr>
<td>10 Keith</td>
<td>13</td>
<td>Non-compensable (^b)</td>
<td>Alone. Minimal family contact</td>
<td>28 hrs/wk paid care; 3 paid carers</td>
</tr>
<tr>
<td>11 Dora</td>
<td>3.5</td>
<td>CTP</td>
<td>With husband and child</td>
<td>No paid care; family only</td>
</tr>
<tr>
<td>12 Paul</td>
<td>7</td>
<td>Workers Compensation</td>
<td>Alone. Daily family visits</td>
<td>14 hrs paid care/wk; 2 paid carers + family</td>
</tr>
<tr>
<td>13 Joe</td>
<td>17.5</td>
<td>CTP</td>
<td>Alone. Daily family contact.</td>
<td>24 hr paid care/ day (168 hrs/wk); 7 paid carers + family.</td>
</tr>
<tr>
<td>14 Dayna</td>
<td>8.5</td>
<td>CTP</td>
<td>With husband.</td>
<td>No paid care; family only</td>
</tr>
</tbody>
</table>

**Notes.** \(^a\) CTP= Compulsory Third Party insurance. \(^b\) Compensation status confirmed at the time of interview; this participant was incorrectly categorised as compensable at the time of recruitment.

Table 3.3 shows that eight of the 14 people with brain injury lived alone. The remaining six lived with their family. These different living arrangements will be described later. All received some level of support whether this was paid, unpaid or a combination of both.
3.4 Data Collection Methods

The primary data collection method was a single semi-structured interview conducted with each participant. Secondary methods included written field notes, a research diary, and administering four quantitative measures.

3.4.1 Method 1: Semi-Structured Interviews

Interview types are typically classified as structured, semi-structured or unstructured (Fontana & Frey, 2000; Minichiello, Madison, Hays, Courtney, & St John, 1999; Morse & Field, 1996). Grounded theory studies most often use focussed questions and a semi-structured format (Glaser, 1978, 1992; Glaser & Strauss, 1967; Strauss & Corbin, 1990, 1998). A semi-structured interview refers to one that includes predetermined questions and/or topic areas (Berg, 1995), as occurred in the present study. Questions are asked of each participant in a systematic and consistent order, but with some freedom for the interviewer to digress and probe. A structured interview was considered unsuitable because little was known at the outset about the process of care decision-making or participants’ experiences. Mailed questionnaires were considered unsuitable for the same reason.

3.4.1.1 Interview Questions

Following the background review of literature on long-term care and decision-making, a list of questions was developed. Questions and interviews were guided by predetermined topic areas (Berg, 1995) but with flexibility in wording and ordering of the topics (Minichiello, Aroni, Timewell, & Alexander, 1990). The predetermined topics were: key life changes, events and decisions made since leaving hospital; review of their daily and weekly timetable; and characteristics of the care arrangements and carers that were preferred. The full set of questions is shown in Appendix C-1.

Formal pilot-testing of questions did not occur for three reasons. First, some of the questions had already been used successfully in an earlier study (McCluskey, 2000), for example, questions about paid and unpaid carers, and care preferences. Second, this previous study had helped to socialise me to the research environment and
potential challenges of interviewing people with cognitive and behavioural impairments.

In the early interviews, people with brain injury were initially asked a broad, open-ended question: “Tell me about some of the changes and events in your life since the accident”. This question was designed to allow participants the freedom to talk about any event, change or decision. Further information on care-related decisions could then be sought. If a participant had difficulty recalling an event or change due to memory impairment, details from the Background Information Sheet could be used to prompt a response (see Appendix B-3). For example, “I believe a number of paid carers were employed to help you at home when you first left hospital. Could you tell me about that time?”. Probes and prompts were developed in advance to help participants who might have difficulty responding to questions. These prompts are also shown in Appendix C-1.

Family carers and others were asked similar questions, and others related to their role as primary carer, decision-maker, care coordinator and the like. For example, questions included: “Tell me about your involvement with [the person with brain injury]” and “Tell me about some of the decisions that have to be made [since the accident]?”. These questions were designed to begin exploration of the decision-making process, steps in the process, primary decision-makers and influencing conditions.

It is usual with grounded theory to start with general questions (Dey, 1999). As interviews and the concurrent analysis progress, questions became more focussed on issues common to the sample and important to the developing theory (Wimpenny & Gass, 2000). For example, when a pattern of decisions started to emerge after the first six or seven cases, decision-making theory was applied and used to guide the interviews. Participants were asked about the process and steps involved in their decision-making, whether they had actively gathered information, and if so, from whom. Later still, questions were asked about the nature of risks associated with care decisions. This focussing of questions helps to saturate categories, establish relationships between categories and refine the emerging
theory (Dey, 1999). A later version of the interview schedule is also shown in Appendix C-2.

3.4.1.2 Reliability and Validity of Interview Responses

A number of concerns have been raised about the reliability and validity of interview responses given by people with an intellectual disability (Atkinson, 1989; Biklen & Moseley, 1988), mental illness (Dworkin, 1992), and dementia (Feinberg & Whitlatch, 2001). These concerns are that a participant may (a) misunderstand the meaning of questions and give seemingly unrelated answers, (b) try to please the interviewer, (c) have difficulty responding to open-ended questions and experience subsequent anxiety, (d) give the same answer repeatedly (perseveration) despite the question or topic changing, (e) give inconsistent responses and preferences from one occasion to the next, and (f) need help from a carer to answer questions, with the possibility that this person then becomes over-involved in the interview. In general, these concerns apply to people with brain injury.

Little has been written about obtaining responses from people with cognitive impairments following a brain injury. Only two sources were located. The first targets lawyers taking instructions from clients with impaired cognition, not researchers conducting interviews (D'Argaville & Bright, 1995). The second source was more relevant, and discusses the challenge of interviewing participants who have difficulty with recall, provide different versions of the same story, and become agitated or fatigued (Paterson & Scott-Findlay, 2002). These researchers also noted the importance of using questions economically in case of fatigue. However, all six participants with brain injury in that study had been screened to exclude speech and cognitive impairments, and three were interviewed in the presence of a family caregiver.

Difficulty understanding complex interview questions is not unique to participants with cognitive impairment. This potential difficulty needs to be addressed by any researcher interviewing children, or people with low levels of education and literacy. Similarly, participants who try to give the ‘right’ response, or one they think the researcher expects to hear, is a problem faced by researchers working with
the general population. The solution is to avoid questions which might encourage participants to give a particular answer, and to avoid leading questions (Wyngaarden, 1981).

Biklen and Moseley (1988), who have conducted several research studies with people who have an intellectual disability, suggest that researchers limit the use of open-ended questions such as “Tell me about your work?” because such questions may be confusing or too unstructured for participants. Instead, the authors suggest breaking complex questions into parts; for example, starting with a question like “When did you start going to this group? Was it this year, or a couple of years ago?” and then using probe questions to follow such as “Do you like going to the group?”.

Giving the same answer repeatedly, or perseverating on an issue, is a cognitive problem commonly observed in people with brain injury. Often they cannot ‘change cognitive set’ and may not have the mental flexibility to shift topics easily or quickly. Another concern is participants giving inconsistent responses from one occasion to another because of anxiety (Sigelman et al., 1981; Wyngaarden, 1981), impaired insight and lack of awareness. Sigelman and colleagues (1981) interviewed over 400 people with intellectual disability living in the community and institutions, on at least two occasions. These researchers also interviewed a proxy to confirm factual information, and then checked the reliability of responses. Participants with an intellectual disability tended to over-report on yes/no questions (they added extra, incorrect information), and under-report for open-ended questions (they omitted information).

To address the issue of possible response reliability by participants with brain injury and cognitive impairment in the current study, interviews were also conducted with others such as family members and case managers. Conducting joint interviews with a family member or significant other was considered, but rejected because of the risk of interference by others. While the other person can usually immediately confirm or correct dates and details that the cognitively impaired person may not know or remember, there is always the chance that they will answer on their behalf, or expand on responses with a different emphasis than that intended by the
cognitively impaired person (Biklen & Moseley, 1988). The greatest threat is that the family member or significant other will “act not just as a translator, but as a filter as well” (Biklen & Moseley, 1988, p. 159). For this reason, joint interviews were not conducted in the present study.

Instead, a series of interviews were conducted with significant others, including a family member where possible. With the consent of the person with brain injury, these significant others confirmed key events and people in their lives. Furthermore, written background information about the person with brain injury was obtained from a reliable source before any interviews were conducted. For example, information was obtained from a significant other about the injury, the person’s weekly schedule of activities, and the names and number of paid carers employed. This process of triangulation helped to overcome any information gaps and increase the reliability and validity of responses.

3.4.1.3 Length, Order and Location of Interviews

The length of interviews was between one and two hours. The interview process was expected to be therapeutic for some participants as they reflected on care decisions, care management, their roles, responsibilities and relationships (Minichiello et al., 1995). Many participants would not have had the opportunity to talk about their roles and responsibilities to an interested person.

The order of interviews was as follows. The person with brain injury was interviewed first, followed directly afterwards by an interview with a family member. This order helped to ensure that a consumer or care recipient perspective was obtained before that of a family or paid carer. The aim was to obtain the views, experiences and expectations of people with brain injury first, without influence from others. A period of 10 to 15 minutes was allocated between most interviews. This short break allowed time for reflection and making diary entries. If no family member was involved in the provision of care or decision-making, the second interview was conducted with a paid carer or case manager, usually on a separate day.
Participants were given a choice of location for the interview: their own home, my workplace, or an alternate venue such as a community centre. In most cases, the venue chosen was the participant’s home. However, some interviews were conducted at a community centre in a country town (n=1), at a participant’s workplace (n=11), in a hospital meeting room (n=2), and at my workplace (n=1). The aim was to find a quiet location with minimal distractions where participants could talk confidentially.

3.4.2 Method 2: Field Notes

In addition to tape recording the interviews, field notes were taken using the participant’s language. Field notes were kept primarily as an insurance against audiotape failure (Easton, McComish, & Greenberg, 2000). Tape failure occurred once, and dual tape recorders were used thereafter. Field notes were also used to help record data after the tape recorder had been switched off. At such times, important information was often shared. For example, valuable comments were recorded in a notebook during lunch with families, or when walking back to the car after the interview had finished. Field notes were used later when transcribing interviews, particularly when a word or phrase was inaudible.

3.4.3 Method 3: Diary Entries

Directly after each interview, impressions, ideas, reactions and insights were recorded in a diary. The aim was to synthesise key themes arising from an interview, and write prompts about issues to explore with subsequent participants. Events and strategies raised in previous interviews could then be followed up. Relationships between concepts were hypothesised, and could often be pursued in a second or third interview on the same day. Conditions that led to a crisis or prompted change, such as a paid carer resigning were identified. Antecedents and consequences of different decisions were noted.

The diary was also used for theoretical memoing, constant comparison and theory generation. Glaser (1978) described theoretical memoing as “the only way to store ideas” (p. 83) during the mechanics of coding, sorting and writing. He also added
that “the point of memos is to record ideas, get them out, and the analyst should do so in any kind of language – good, bad or indifferent” (Glaser, p.78, p. 84). Glaser also noted an important by-product of memoing: the increasing theoretical sensitivity of a researcher to their topic and data. Multiple diaries were used during the course of the study for recording ideas and insights, diagramming and memoing. Diary entries were reviewed from time to time but were not formally entered as data for analysis.

3.4.4 Method 4: Quantitative Measures

In addition to collecting interview data, writing field notes and diary entries, a series of four quantitative measures were used. They were used because the level of cognitive and physical disability of a person with brain injury was expected to influence care decision-making. For example a person with a high level of cognitive disability might be expected to need a high level of care. The measures provided baseline descriptive data on the level of mobility, cognitive and physical independence, psychosocial functioning and care levels of each person with brain injury. It was not intended to engage in formal hypothesis testing, because of the nature and size of the sample. However, similarities, differences and patterns could be identified across participants. Quantitative data provided context for the rich qualitative, interpretive data.

3.4.4.1 Choice of Quantitative Measures

Researchers typically measure participants’ level of disability or activity limitation (Perenboom & Chorus, 2003; World Health Organization, 2001). However, there is a growing interest among researchers in measures of handicap (Hall, Dijkers, Whiteneck, Brooks, & Krause, 1998; Harwood, Rogers, Dickinson, & Ebrahim, 1994; Tate, Hodgkinson, Veerabangsa, & Maggiotto, 1999), community integration (McColl, Davies, Carlson, Johnston, & Minnes, 2001) and participation (Cardol, DeJong, & Ward, 2002; Pepin, Dumont, & Hopps, 2000; Perenboom & Chorus, 2003; World Health Organization, 2001).
This change has occurred because a person’s level of disability may not change over time, but level of handicap may decrease and participation increase. For example, a person may be very physically disabled but be able to participate fully in society as a worker, parent or homemaker if support and equipment are available. Participation, integration into the community, and resumption of valued societal roles imply a good rehabilitation outcome (Steadman-Pare et al., 2001).

Consequently, no disability measures were used in the present study. Instead, two different measures of handicap and psychosocial reintegration were used, along with two measures of care and supervision. Copies of each measure are shown in Appendices D-1 to D-3. The measures used were:

1. The Revised Craig Handicap Assessment and Reporting Technique (R-CHART, Mellick, Walker, Brooks, & Whiteneck, 1999);
2. The Sydney Psychosocial Reintegration Scale (SPRS, Tate et al., 1999);
3. The Supervision Rating Scale (SRS, Boake, 1996) and
4. Number of hours of care and supervision.

3.4.4.2 Overview of Quantitative Measures

The Revised Craig Handicap Assessment and Reporting Technique (R-CHART).

The R-CHART (Mellick et al., 1999) measures level of handicap. A handicap exists when a person cannot fulfil one of more life roles considered normal for someone of that age, gender and culture. The original CHART (Whiteneck et al., 1992) was designed for use with people who have spinal cord injury, not those with a cognitive impairment. The R-CHART was published in 1999 to overcome this gap, and added a new Cognitive Independence sub-scale (Mellick et al., 1999). There are six domains or sub-scales in the R-CHART: Physical Independence; Cognitive Independence; Mobility; Occupation; Social Integration; and Economic Self-Sufficiency (see Appendix D-1).

Each of the six sub-scales of the R-CHART has between two and seven questions, with a maximum score of 100 for each sub-scale, and a maximum total score of
Lower scores indicate a high level of handicap and low levels of social and community participation. All but one sub-scale was completed for the current study. The Economic Self-Sufficiency sub-scale was omitted because research participants often refuse to supply financial details. Furthermore, some participants with memory impairment may not have known their annual income. Hall and colleagues (1998) note that data are commonly missing for the Economic Self-Sufficiency sub-scale for these reasons. Therefore, only five sub-scores are reported for the R-CHART.

**Internal consistency** has not been reported for either the CHART or R-CHART. **Inter-rater reliability** between a person with spinal injury and a proxy who knows them well is high for CHART total scores \( r = .83 \); Whiteneck et al., 1992). A similar result \( r = .81 \) was obtained for R-CHART total scores (Mellick et al., 1999). Good agreement on CHART sub-scores has been reported between the person with disability and a proxy for all domains \( r = 0.69 \) to 0.84\) except Social Integration \( r = 0.28 \) (Whiteneck et al., 1992). **Test-retest reliability** for the original CHART total score is high \( r = .93 \) following a one-week interval by the same assessor (Whiteneck et al., 1992). Test-retest reliability for the more recent cognition sub-scale is slightly lower \( r = .87 \) after a two week interval (Mellick et al, 1999).

The original CHART is able to discriminate between people with high and low levels of impairment (Whiteneck et al., 1992). Furthermore, the R-CHART cognition sub-scale is able to discriminate between subjects with cognitive impairment due to brain injury or stroke, and subjects with physical impairments only such as burns, amputations or spinal injury (Mellick et al., 1999). Hall and his colleagues found the R-CHART cognition sub-scale was one of the few measures with no ceiling effect when used with community-based individuals with brain injury (Hall, Bushnik, Klakisic-Kazazic, Wright, & Cantagallo, 2001). In short, the R-CHART is a valid, stable and reliable measure of handicap in people with cognitive impairment.

In the present study, the R-CHART was used to give a profile of the level of handicap of the 14 participants with brain injury. For the purposes of presentation
in this thesis, and to give an approximation of level of handicap, three broad groupings were determined: ‘high handicap’ (scores between 0 and 33); ‘moderate handicap’ (scores between 34 and 66); and ‘low handicap’ (scores between 67 and 100).

The Sydney Psychosocial Reintegration Scale (SPRS)

The SPRS (Tate et al., 1999) measures level of handicap as well as changes in psychosocial functioning following brain injury. This scale was used as a second measure of handicap because unlike the R-CHART, the SPRS was designed for use with a brain injury population. Psychosocial reintegration refers to the ability of a person to resume valued societal roles such as worker, parent and spouse.

The scale comprises three domains and 12 questions, four questions for each domain. The three domains are: Occupational Activities; Interpersonal Relationships; and Independent Living Skills. The 12 questions are scored using a 7-point rating scale, from zero to six. A score of zero refers to extreme change in a domain compared to a person’s pre-injury status. A score of six refers to no change (see D-2). The maximum score for each of the three domains is 24, which implies that a person has achieved good psychosocial reintegration for that domain.

Internal consistency of the SPRS overall is excellent (alpha coefficient of .90 for the total score). Internal consistency of the three domains ranges from good to excellent, with an alpha coefficient of .69 for Interpersonal Relationships, .77 for Living Skills, and .89 for Occupational Activities (Tate et al., 1999). Inter-rater reliability and test stability over a one-month period are high, (ICC = .95 and .90, respectively). Therefore, the SPRS is a valid, sensitive, stable and reliable measure.

For the purpose of presentation in this thesis, and on the advice of the author of the scale (Robyn Tate), mean scores will be presented for the three domains. This mode of presentation enables direct comparisons to be made with the 7-point rating scale. There are three broad groupings according to the amount of change in a domain post-injury, based on mean scores. These three broad groupings are: ‘major change’ (poor reintegration, scores 0, 1 or 2); ‘some change’ (limited reintegration,
scores 3 or 4); and ‘no significant change’ (good reintegration, scores 5 or 6). A full copy of the rating scale is presented in Appendix D-2.

**The Supervision Rating Scale (SRS)**

The SRS measures the level of supervision that a person with brain injury receives from family members or paid carers (Boake, 1996). Supervision refers to all forms of assistance requiring the physical presence of a carer including nursing care, physical assistance and verbal prompting. The SRS comprises a 13-point ordinal rating scale (see Appendix D-3). A rating of one indicates that a person is living alone or with others but requires no supervision. At the other extreme, a rating of 13 indicates that the person requires full-time direct supervision and physical restraint.

A 5-point classification is also used to discriminate between monitoring/ prompting and hands-on physical assistance. The five SRS classifications are: Independent (Level 1); Overnight Supervision (Level 2); Part-Time Supervision (Level 3); Full-Time Indirect Supervision (Level 4); and Full-Time Direct Supervision (Level 5).

*Inter-rater reliability* of the SRS is reported to be stronger for the 13-point scale (ICC = .86) than the 5-point scale (weighted kappa = .64; Boake, 1996). In the present study, a single person administered the scale, and both the 13-point and the 5-point scales of the SRS were reported, since the 13-point scale was used to determine a person’s 5-point SRS classification.

The SRS is reported to have good predictive validity (Boake, 1996), with SRS ratings being closely associated with type of living arrangement. When individuals were categorised as either living independently, living with support in the community, or in an institution, a positive association was reported between living arrangement and SRS ratings, using a non-parametric analysis of variance (ANOVA) ($\chi^2 = 32.0, p <.0001$). Participants who lived more independently also received less supervision based on the 13-point SRS ratings. A similar association was reported between SRS ratings and percentage independence scores in self-care and instrumental activities of daily living (ADL). Using the five SRS levels, the
two types of ADL independence were strongly associated with level of supervision, again using a non-parametric ANOVA. A strong association was noted between level of supervision and percentage independence in self-care ADL ($\chi^2 = 50.2, p < .0001$) and instrumental ADL ($\chi^2 = 61.1, p < .0001$). In summary, absence of supervision was associated with more independent living arrangements and the ability to perform activities unassisted. Further concurrent validity was demonstrated through a strong association between SRS ratings and ratings on the Disability Rating Scale (Rappaport, Hall, Hopkins, Belleza, & Cope, 1982) and Glasgow Outcome Scale (Jennett & Bond, 1975).

One limitation of the SRS is the absence of a category for rating off-site prompting and supervision. For example, a person who lives independently but requires prompting to pay bills or initiate leisure activities is rated as ‘Independent’ on the SRS. Yet such a person is not truly independent. Hall and his colleagues (2001) also reported a ceiling effect with some community-based individuals. However, at the time of designing the current study, no better measure of care was available. Boake (1996) suggested using another measure such as the CHART in addition to, or instead of, the SRS to overcome some of these limitations.

**Hours of Direct Care and Supervision**

The hours of paid and unpaid care, as well as any supervision received at the time of interview, were calculated after leaving the interview site. If a person with brain injury was rarely or never left unsupervised, 24-hour care was recorded. In other cases, the hours of unpaid care were estimated, and combined with the hours of paid care. Unlike the SRS, care hours were included whether they involved the physical presence or distant supervision of a family member; for example, off-site telephone support.

**3.4.4.3 Administration of Quantitative Measures**

Directly after each person with brain injury had been interviewed, the R-CHART and SPRS were completed with interviewees. The measures were completed again later, by or with a family carer (if a family carer participated). If a discrepancy existed between ratings, the response provided by a family carer was recorded for
analysis. Their response was felt to be more accurate and reliable for questions such as ‘In a typical week, how many days do you get out of your house and go somewhere?’. After leaving the interview site, SRS ratings and the number of hours of care received were calculated.

3.5 Data Analysis

3.5.1 Analysis of Qualitative Data

The following section describes the process of examining, categorising and then interpreting data from the interviews, field notes and diary. The reader is reminded that analysis occurred concurrently with data collection. Interviews for each new case were conducted one to two months apart, allowing time for analysis before subsequent interviews were completed. Thus, analysis began shortly after the first interview was completed in early 1999. However, for ease of reading the process of analysis will be described in a linear fashion.

3.5.1.1 Data Management

The first aim of qualitative data analysis was to reduce the large volume of text data into manageable units. This process is sometimes described as data reduction, data preparation or data management (Coffey & Atkinson, 1996; Miles & Huberman, 1994). In the current study, each interview resulted in approximately 20 to 30 pages of transcribed text, which when multiplied by the total number of interviews resulted in hundreds of pages of data. To manage this large volume of data, a good management system was required. Therefore, after each interview had been transcribed and edited, the document was imported into a computer software program in preparation for coding (see pages 77 to 81 for details of coding).

3.5.1.2 Computer-Assisted Analysis

Computer-assisted analysis refers to the facilitation of coding, indexing and sorting (Kelle, 1995b). Analysis has traditionally been managed manually; for example, by employing a ‘cut and paste’ method. This method involves cutting up photocopied
transcripts and putting text relating to each category in a separate folder, envelope or paper bag (Lofland & Lofland, 1984). Computers make the management of such data less onerous, particularly when large numbers of interviews are involved. The process of making comparisons between cases also becomes less onerous than searching manually through a box of transcripts.

It has been argued that coding is more systematic and transparent with the aid of computer software, thereby enhancing the trustworthiness of a study (Gibbs, 2002; Richards & Richards, 1994). One critic has even suggested that it is near impossible to conduct grounded theory and adequately cross reference concepts without using a computer for analysis, because of the multitude of possible connections and linkages which may exist between text passages (Lonkila, 1995). Thus, computers allow the researcher to make, and then illustrate on the screen, relationships between categories through the use of diagrams and visual networks.

There are also critics of computer-assisted analysis. Initially many qualitative researchers were sceptical of computers, and considered them inappropriate for text analysis in much the same way that quantitative approaches to content analysis were considered inappropriate (Kelle, 1995a); for example, counting instances where an issue is raised by participants. These ‘new’ methods were seen to be too simplistic and fragmenting to capture the content of a social experience or phenomenon. Such concerns were slowly overcome in the 1980s, as the strengths and possibilities of word processors for sorting, searching and retrieving data were realised.

Another criticism levelled at users of computer-assisted analysis is the assumption that coding and analysis are synonymous (Coffey & Atkinson, 1996). These processes are not synonymous. The computer program stores and retrieves data; however, the researcher must still conduct the analysis. A third criticism of computer-assisted analysis is that the researcher will become alienated or distanced from the data, and that it will ‘take over’ the analysis. Some researchers may wish that this were so. However, the reality is that analysis is an iterative process, where the researcher goes to and from the original audiotapes, transcripts, and coded text on the computer screen. The limitations of computer software programs were noted by Tesch (1991):
Chapter 3. Research Methods

The computer does not make conceptual decisions, such as which words or themes are important to focus on, or which analytical step to take next. These analytical tasks are still left entirely to the researcher (pp. 25-26).

In the current study, the NVivo software program was used to assist with data management (Bazeley & Richards, 2000; Gibbs, 2002). Transcribed text documents were imported into NVivo and read line-by-line during the process of coding. Categories were established, many of them ‘stand alone’ categories with no links to other categories. In the NVivo program these categories are called free nodes (Bazeley & Richards, 2000). Memos and comments were written about particular passages of text, the meaning of a phrase or to ask and answer questions about the text. Coding the first interviews was a slow process, but coding became faster as patterns were seen across cases. An example of the coding ‘tree’ and nodes developed during the current study using NVivo is shown in Appendix F.

3.5.1.3 Open Coding: Getting Started

Open coding was the first stage of analysis (Glaser & Strauss, 1967; Strauss & Corbin, 1998) and involved “breaking down, examining, comparing, conceptualising and categorising data” (Strauss & Corbin, 1998, p. 61). Identifying categories or codes was the primary task during open coding (Dey, 1999). Words, lines of text and phrases were compared with other like-text, and grouped accordingly.

The unit of text coded initially was a single line. Later phrases and whole paragraphs of text were coded. Glaser (1978) suggested that line-by-line analysis be used initially to interrogate the data. However, it is usually necessary to progress from a close, detailed examination of the data to a paragraph-by-paragraph approach. Most researchers cannot sustain a fine-grained approach to analysis throughout an entire project (Dey, 1999), and instead move to a coarser analysis of phrases or paragraphs, as occurred in this study.
It is also generally considered necessary to ask questions of the data while coding, as this ‘opens up’ the data and enables the researcher to consider the “conditions, consequences and associated interactions and strategies” of each category (Strauss, 1987, p. 154). Coding procedures from three sources were used (Richards, 1997; Strauss, 1987; Strauss & Corbin, 1998). Coding involved asking questions about particular words or phrases, for example “What strategies are being used here?”, “Under what conditions does this phenomena occur?”, and “What are the consequences of these actions?” For example, participants who engaged in risk-taking behaviour such as going to the shops or spending a night alone were compared with other participants, taking note of the antecedents and consequences of each risk-taking incident.

The basic social problem or concern shared by participants was sought during analysis (Glaser, 1998, 2001). When investigating a process and developing a theory based on qualitative data, the basic social problem is one that drives participants’ behaviour. Actions and behaviour are aimed at managing, dealing with and resolving this main concern. In this study, I was interested in what phenomena drove participants when making decisions about care.

Another aim during coding is often to generate ‘action’ codes or gerunds (Charmaz, 2000; Glaser, 1996b). That is, to name codes with action words such as ‘Seeking’ or ‘Managing’. Glaser called this approach to analysis gerund grounded theory (Glaser, 1996). This process helps the researcher to consider what it is that participants or actors are doing, and facilitates the constant comparison of actions, views, accounts and experiences (Charmaz, 2000; Glaser, 1978). As an example, in the present study, when an event, behaviour or process involved an element of conflict management, the text was labelled ‘Managing Conflict’. Thus, data needed to have a common theme to be grouped or coded together in a category (Morse, 1994).

Not all text was meaningful, therefore not all text was coded. The most interesting and meaningful phrases were identified, pasted together in one computer file and assigned a label or tag (Coffey & Atkinson, 1996). For example, text about different ‘Configurations of care’ was grouped together in one file. In the NVivo
software program, these files or groupings of text are called ‘nodes’ (Bazeley & Richards, 2000). Nodes were then clustered together into categories and given conceptual names (Miles & Huberman, 1994). For example, when participants prepared to implement a course of action, such as helping a person with brain injury to establish their own home and employ a team of paid carers, this category was provisionally called ‘Harnessing Resources’. Thus coding was the process and categories were the outcome. Coding was a time consuming but necessary first step in analysis.

Two examples of how text data were managed in the early stages of open coding are presented in Figure 3.1. The figure also illustrates how these categories were re-labelled in the later stages of data analysis.

<table>
<thead>
<tr>
<th>Quote</th>
<th>Early Category labels (Open Coding)</th>
<th>Later Category labels (Selective Coding)</th>
</tr>
</thead>
<tbody>
<tr>
<td>[After an argument or conflict] I would say “OK. Talk about what happened”.</td>
<td>Care Problems → Negotiation → Client-Carer Relationship</td>
<td>Care Maintenance/ Supporting Carers/ Being There</td>
</tr>
<tr>
<td>“What were the triggers? “ “Why do you think it happened?”</td>
<td>Triggers</td>
<td>Care Maintenance/ Managing Conflict/ Eliminating Triggers</td>
</tr>
<tr>
<td>“Let’s try to work this one out so it doesn’t happen again”</td>
<td>Care Problems → Eliminating Triggers</td>
<td></td>
</tr>
<tr>
<td>Now [I live alone] there’s no answering to anyone.</td>
<td>Rules and Boundaries</td>
<td></td>
</tr>
<tr>
<td>I get out when I want to.</td>
<td>Community Integration</td>
<td>Increased Autonomy</td>
</tr>
<tr>
<td></td>
<td>Increasing Independence</td>
<td></td>
</tr>
</tbody>
</table>

Figure 3.1 Coding scheme
3.5.1.4 Axial Coding: Linking Categories

Axial coding was the second phase of analysis (Strauss, 1987; Strauss & Corbin, 1990; 1998). Links and relationships were sought between categories. Themes and patterns were identified. Dey (1993) called this stage of analysis connecting, where coded data are linked in some way. These relationships later develop into a framework or provisional theory, which can be represented diagrammatically.

Open and axial coding did not occur in a linear fashion. There was continual switching between the two modes (Lonkila, 1995). However, when developing a grounded theory, the important analytical work lies in creating these links through axial coding, not in the mundane work of identifying and labelling categories (Coffey & Atkinson, 1996). If open coding involves the fragmentation of data, with the aim of identifying new categories, then axial coding involves putting the data back together again in new ways, making connections between categories and subcategories (Strauss & Corbin, 1998).

Creating links and relationships between data also involved constant comparison (Glaser & Strauss, 1967; Strauss & Corbin, 1998). Axial coding involved selecting and ‘fitting’ alternate models or theories to the data. This meant developing and testing alternative explanations against the data until the best fit was obtained (Morse, 1994). This stage of coding took over 12 months. Morse described this challenging work as “an active, continuous and rigorous process of viewing data as a puzzle” (Morse, 1994, p.32). The process involved speculation and conjecture, revision and rethinking.

The relationships that develop between categories, and make up the resulting theory are intended to be a simple way of “linking diverse and unrelated facts in a useful and pragmatic way” (Morse, 1994, p.32). A theory should ideally be parsimonious and make sense to anyone who knows the topic well. In the current study, relationships between categories in the evolving theory were tested in two ways. First, theoretical sampling was used. This method of sampling involved recruiting people with brain injury that either did or did not possess certain characteristics: for example, certain living arrangements, configuration of carers. Relationships were
checked with subsequent participants. The second method of checking the evolving grounded theory was by presenting papers at multiple professional conferences in Australia and overseas between 1999 and 2003, and to groups of interested health professionals in Sydney.

3.5.1.5 Selective Coding: Building Theory

Selective coding refers to a process where only data that relate to the core category are used to explain the evolving theory (Dey, 1999; Glaser, 1978). Such categories are validated or verified through theoretical sampling, while other categories may need to be further refined and developed (Dey, 1999; Strauss & Corbin, 1998). This third phase of analysis involves interpreting the data, and building a provisional theory. By this time, categories had been developed, labelled, and related to other categories. Comparisons were made using text from within and across cases. Interpretations were made of the processes, strategies and social interactions (Coffey & Atkinson, 1996). Text examples and quotes were used to illustrate the provisional theory. The most important category, the core category was eventually identified and the other categories oriented around it. This process involved proposing, then checking relationships between the core and other categories. Finally, a storyline was written to explain the relationships.

3.5.1.6 Trustworthiness

Trustworthiness in qualitative research refers to the credibility, believability and faithful interpretation of participants’ experiences (Cutcliffe & McKenna, 1999; Guba, 1981; Lincoln, 1995; Seale, 1999). Regardless of the paradigm used, a researcher is still required to show that a study is valid, credible and rigorous. The positivist notion of validity has been reconceptualised, and replaced with terms such as trustworthiness and credibility. However, unlike studies based upon the positivist tradition, qualitative researchers often do not use standardised methods of data collection. Consequently, a more detailed and elaborate record of the research process is required than might be expected for quantitative studies (Murphy et al., 1998; Strauss & Corbin, 1990). This record is sometimes called an audit trail.
(Murphy et al., 1998), and allows a reviewer to judge authenticity and trustworthiness. A number of strategies are used to establish trustworthiness in qualitative research, including: triangulation; prolonged engagement of the researcher in the field; researcher background; member checking; and the use of negative or deviant cases.

*Triangulation* as a term originates from naval, military and surveying contexts (Nolan & Behi, 1995) where the position is plotted using three separate reference points (Speziale & Carpenter, 2003). However, the term is also used in qualitative research and refers to:

...an approach to data collection in which evidence is deliberately sought from a wide range of different, independent sources and often by different means (Mays & Pope, 1995, p. 110).

A primary aim of triangulation is to enhance validity and reduce bias (Minichiello et al., 1995). Triangulation can refer to multiple sources of data, investigators or analysts, ways of interpreting the same data set, or methods (Denzin, 1989). In the present study, interviews conducted with multiple participants about the same issue helped to triangulate data. Between three and six participants were interviewed for each ‘case’. Data could then be corroborated and compared across participants within and across cases.

Peer checking is a second method of triangulation, where more than one person reads and codes sections of a transcript using the existing coding framework (Mays & Pope, 1995). In the current study, verification of categories was achieved by asking two experienced research supervisors to routinely read transcripts alongside the coding framework. Furthermore, on two occasions a small group of doctoral students met to review data and the evolving theory. The benefits of peer checking have recently been acknowledged by (Barbour, 2001) who states that “it can be useful to have another person cast an eye over segments of data or emergent coding frameworks” (p. 1116).
Prolonged engagement in the field: By implication, prolonged immersion in one area of study will improve the likelihood of a true interpretation of participants’ experiences. In my case, ten years had been spent working clinically with people who had brain injury and their families in the community. This experience sensitised me to the population. During the course of this study from 1997 to 2003, a further six years were spent exploring and theorising about the relationship among brain injury, long-term care and decision-making.

Researcher background: Researchers using an interpretive methodology recognise that their own background can affect the credibility of a study. For example, it matters whether a researcher has special ‘inside’ knowledge and insights or, on the contrary, comes to the study as an ‘outsider’ with no prior knowledge or prejudices about a group (Minichiello et al., 1995). There are arguments for and against each. Insiders have the advantage of gaining easy access to participants because of people they know and past associations with members of a group. These relationships can also work against a researcher and limit access to participants. Conversely, outsiders may take longer to recruit their sample and to become familiar with the culture, the language of a group, political issues and the like. While a researcher’s gender, age, expertise or ethnic identity can limit or enhance study outcomes, the reality is that most researchers work with what they have, or with the resources they have to hand (Minichiello et al., 1995).

In the present study, I was well known to most of the third parties, which was a distinct advantage during recruitment. Clinical experience also provided valuable knowledge about the medicolegal and compensation system, the healthcare system, and the range of services available to people with brain injury. But probably of most importance were the skills that had been acquired over the years in communicating with people with brain injury who had cognitive impairment and challenging behaviour. Without this insider experience, interviews could have become fraught with difficulty, due to temper outbursts, sexual advances, perseverative responses and poor memory.

Member checking: This strategy for improving trustworthiness involves telling participants about relationships and emerging theory, and checking if they agree or
disagree with a researcher’s interpretation (Creswell, 1998). Since one aim of grounded theory is to provide a convincing account that ‘fits’ with participants’ experience of a phenomenon, it makes sense to check their responses to a new theory. In the present study, ideas and theory were checked during later interviews with participants to see if the provisional theory and model of decision-making ‘fitted’ their experience. Participants were not sent a copy of their transcript or drafts of the evolving theory because of the demands this would place on an already stressed population. Furthermore, some authors have found that the topic and content of transcripts can sometimes be distressing for participants (Barbour, 1998).

Another strategy used for checking theory was presenting findings to professional peers at national and international conferences, and local brain injury research forums. Many of these professionals had engaged in decision-making with families following brain injury. They were interested in the study findings and keen to provide feedback on the evolving theory. The final theory was also presented in mid-2003 to a family carer of a person with brain injury who received 24-hour paid care. This family carer knew nothing of the research but had more than four years experience making decisions about care for her husband. She was asked informally to describe her experience of care decision-making and management, then to confirm if the developing framework fitted with her experience, which she did. No new issues arose that changed the theory in any way.

*Use of negative or deviant cases:* Qualitative researchers also look for and examine ‘negative’ or ‘deviant’ cases, those which make the theory appear weak or may not fit with the findings (Dey, 1999; Glaser & Strauss, 1967; Glaser, 1978; Mays & Pope, 1995; Strauss & Corbin, 1998). In such instances, as occurred in the present study, the aim is to give an account of why these differences may be so, and use negative cases to explain variations in behaviour.

3.5.2 Analysis of Quantitative Measures

The R-CHART, SPRS, and SRS data, and hours of care and supervision for the 14 people with brain injury were analysed in Excel using descriptive statistics. Raw data and frequencies, showing participant characteristics are presented graphically
in the following results chapter (Chapter 4, pages 89 to 96). A complete data set, with raw scores, is presented in Appendices E-1 to E-3.

3.6 Ethical Issues

Ethics approval was granted by the Human Ethics Review Committee at Macquarie University prior to study commencement (Appendix G-1) and later at the University of Western Sydney (Appendix G-2). Published guidelines for the conduct of ethical research were used when designing the study (National Health and Medical Research Council, 1999). Several authors have written about ethical and methodological issues that need to be considered when conducting research with people who have cognitive impairment (American Geriatrics Society, 1998; Baskin et al., 1998; Dworkin, 1992; National Health and Medical Research Council, 1999; Sachs, 2000). Strategies recommended include making accommodations in the consent process, and checking consent more than once during the conduct of a study.

3.6.1 Obtaining Informed Consent

Informed consent implies that a participant has received information at a level that matches their level of comprehension about the purpose, methods, risks, possible discomforts and outcomes of a study (National Health and Medical Research Council, 1999). Being provided with information is, therefore, only part of the consent process. Participants also need to understand the process, particularly the consequences of signing a consent form and taking part in a study. Determining comprehension becomes more difficult when a person has cognitive impairments.

People with brain injury frequently experience cognitive impairments (Olver, Ponsford, & Curran, 1996; Ponsford, 1995a; Tennant et al., 1995). One of the most persistent impairments is poor short-term memory. This impairment can cause a person to forget the aims, risks and benefits of a research study before the consent form has even been signed. Speed of information processing and problem solving are also commonly impaired. Such a person may become overloaded with large amounts of written or verbal information. Because the process of obtaining
informed consent has legal and ethical ramifications (National Health and Medical Research Council, 1999), a review of the literature was conducted to check this process was conducted in an ethical manner.

A small body of literature was located about the process of obtaining consent from people with dementia (Alzheimer Scotland, 2000; American Geriatrics Society, 1998; Baskin et al., 1998) and mental illness (Dworkin, 1992). Limited literature was found pertaining to people with brain injury (Sachs, 2000). However, this associated literature suggested a number of procedures that can help ensure these vulnerable populations are adequately consulted and informed before giving consent.

First, information in consent forms may need to be adapted for people with brain injury to accommodate lack of practice at decision-making and cognitive impairment (Jenkinson & Nelm, 1994; Shaddock et al., 1993). Adaptations include the use of simple language, large print, pictures or photographs. Procedures for obtaining consent should also be suited to participants’ cognitive and intellectual abilities and their competence in decision-making (Dworkin, 1992).

Second, obtaining consent from a person with cognitive impairment in their own home may also lead to better retention of information than consent obtained in unfamiliar surroundings, such as a hospital ward or a research laboratory (Lavelle-Jones, Byrne, Rice, & Cuschieri, 1993). In the current study, data collection was conducted in participants’ homes.

Third, separating the consenting process temporally from data collection can also help participants to make more informed decisions. For example, a researcher might make initial contact with a participant to explain the purpose and potential benefits of the research, visit later to obtain consent, and then on the third contact, begin data collection (Hartley, 1982). This process was used in the current study.

Fourth, decision-making capacity has been described as being task specific (Sachs, 2000). That is, some cognitively impaired people may still be able to make informed and unassisted decisions about research participation, despite needing
assistance with other tasks (American Geriatrics Society, 1998). Administration of cognitive screening assessments such as the Mini Mental Status Examination (Fohlstein, Fohlstein, & McHugh, 1975) is not recommended as a means of measuring a person’s capacity to give informed consent (Feinberg & Whitlatch, 2001; Sachs, 2000). Such assessments do not adequately evaluate comprehension, reasoning or judgement, nor are they specific to the task of giving informed consent.

A fifth point raised in the literature related to the term ‘assent’. This term refers to a willingness to participate in a procedure, based on less than full understanding (European Alzheimer Clearing House, undated). Assent is not a substitute for informed consent, but is preferable to leaving the person with cognitive impairment out of the consenting process or research studies completely. Ideally both the participant and a proxy, such as a family member, should be consulted. Dual signatures or a tape-recorded oral agreement can be obtained, as occurred in the present study.

Finally, researchers sometimes sense resistance or dissent from a participant after consent has been obtained. For example, the person may be irritable, agitated or verbally aggressive. Such behaviours may indicate that the person wishes to cease involvement in the study but may be unwilling to tell the researcher (European Alzheimer Clearing House, undated). In the current study, it was anticipated that participants with memory problems may forget they had previously agreed to take part, or may become irritable during a lengthy interview, due to limited attention. Therefore, consent was considered an ongoing process (Dworkin, 1992).

In summary, a number of procedures have been described and were used in the current study to enhance the process of obtaining informed consent. A quality consenting process was required, particularly when recruiting people with brain injury who had cognitive and behavioural problems.
3.7 Chapter Summary

The focus of this chapter has been to explicate grounded theory methodology and describe the specific methods used for data collection and analysis. The study was undertaken in a community setting in NSW, Australia, and involved 51 participants from 14 different cases. Of the 51 participants, 14 had a traumatic brain injury, 12 were family members, 14 were paid carers, 6 were case managers and the others were either care agency directors or an estate manager. Of the 14 people with brain injury in the sample, the mean age was 36.5 years, and mean time post-injury was 9.9 years. All but one had received compensation for their injuries, enabling them to purchase private care services.

The primary data collection method used for this qualitative, interpretive study was semi-structured interviewing. Participants were interviewed once between 1999 and 2001, in their home or local community. Special consideration was given to consenting and interviewing people with brain injury in view of their anticipated cognitive impairments. Interviews were taped, transcribed and entered into a computer software program in preparation for data management, although data collection and analysis occurred concurrently. Secondary data collection methods included written field notes and a research diary. The final data collection method was administration of four quantitative measures to provide context for the rich qualitative data. The measures were: The Revised Craig Handicap Assessment and Reporting Technique (R-CHART), the Sydney Psychosocial Reintegration Scale (SPRS), the Supervision Rating Scale (SRS), and hours of care and supervision received. These data allowed similarities, differences and patterns to be identified across the 14 participants with brain injury.

The following four chapters present the findings of this study. First, characteristics of people with brain injury in the sample and their four different ways of living are described (Chapter 4), providing context for the remaining chapters. Next, the processes of care decision-making (Chapter 5) and care maintenance (Chapter 6) will be presented. In Chapter 7, a storyline is reported, showing the relationship between categories and processes, conditions that influence care decision-making and the overarching theory of care management.
4.1 Introduction

This chapter is the first of four that describe and interpret study findings. To review, the aim was to explore the processes and conditions that surround care decision-making and care management in relation to people with brain injury. A short summary of the two key processes will be described before summarising characteristics of the people with brain injury and their ways of living.

Participants engaged in two processes, care decision-making and care maintenance, as part of a larger care management cycle (see Figure 4.1 below). The process of care decision-making began before a person with brain injury left hospital, and continued intermittently for many years. Around the time of hospital discharge, important decisions were made about the preferred way of living. Care decision-making involved three sub-processes: gathering information about possible ways of living; appraising alternatives in terms of risk and benefits; then enacting a decision.

The process of care maintenance began after hospital, and involved three sub-processes: monitoring the way of living, managing conflict, and supporting carers. Care maintenance served a preventative function, helping to avert crises and the need for change. There were times, however, when change was necessary, even desirable. At such times, family carers and others engaged again in care decision-making, in order to achieve a better way of living, and the care management cycle continued.

Figure 4.1 The Care Management Cycle
Four ways of living or patterns of care were identified. These were: institutional living, living with family, living alone with high support, and living alone with low support. These ways of living reflected different combinations of living situation, carer configurations and care levels. Family carers and others worked actively with and on behalf of the person with brain injury to establish and then maintain a preferred way of living.

Two conditions, the presence of an identified care manager and mutual risk tolerance were necessary for attaining a preferred way of living. Although a care manager was necessary, health professionals were not always involved. Sometimes the care manager was a family member. However, if there was no identified care manager, the way of living typically remained unsatisfactory for many years. The second condition for attaining a preferred way of living was mutual risk tolerance. This term refers to acceptance by the person with brain injury, the identified care manager and any significant others that some degree of risk was necessary for a preferred way of living to be achieved. The primary consequence of achieving a preferred way of living and tolerating greater risk was increased autonomy for the person with brain injury. Autonomy involved spending more time unsupervised, and having privacy.

This chapter presents characteristics of participants with brain injury, followed by the four ways of living. When the term ‘participants’ is used, this refers collectively to the various sub-groups interviewed (people with brain injury, family carers, paid carers, professionals and others). However, sometimes the term ‘participants’ will refer to one sub-group only, such as paid carers. When this occurs, the sub-group will be identified.

4.2 Characteristics of People with Brain Injury

4.2.1 Level of Handicap

R-CHART data are presented in Figure 4.2. The figure reveals that most participants had a low level of physical and mobility handicap, with the majority scoring between 67 and 100 for the Physical Independence and Mobility domains.
A low handicap implies that participants were able to mobilise indoors and outdoors, and perform daily activities without much assistance, regardless of their level of disability. A variety of handicap levels were recorded for the Cognitive Independence and Occupation domains. The level of handicap recorded in relation to Social Integration of the R-CHART was generally low, with nine participants scoring between 67 and 100. This implies that participants had a number of existing social relationships.
4.2.2 Level of Psychosocial Reintegration

Data from the SPRS, presented in Figure 4.3, reveal that most participants had a ‘major change’ in the Occupational Activity domain due to their injury, with the mean scores for 11 participants falling between 0 and 2. Furthermore, the majority had ‘major change’ (n=7) or ‘some change’ (n=6) in the Interpersonal Relationships domain, and ‘major change’ (n=8) in the Independent Living Skills domain due to their injury. Thus the sample overall experienced change in areas of psychosocial functioning and reintegration due to their injury, as measured by the SPRS.

![Figure 4.3. Level of Psychosocial Reintegration based on SPRS scores (n=14)](image)

*Note.* For definitions of ‘major’, ‘some’, and ‘no significant’ change, see pages 72-73.
4.2.3 Level of Care and Supervision

SRS data are presented in Figure 4.4. This figure shows that participants required a range of different levels of supervision. Four participants were categorised as ‘Independent’ (Level 1), three required ‘Part-Time’ supervision (Level 3), and seven required ‘Full-Time’ supervision (Levels 4 and 5).

![Levels of Supervision on the SRS](image)

Figure 4.4. Levels of Supervision on the SRS (n=14)

Note. Level 1 = Independent (may live alone or with one or more person; usually unsupervised overnight). Level 2 = Overnight Supervision. Level 3 = Part-Time Supervision (supervised overnight but spends at least one hour alone during waking hours). Level 4 = Full-Time Indirect Supervision (at least one person always present but they do not need to check on the patient more than once every 30 mins). Level 5 = Full-Time Direct Supervision.

Actual hours of care and supervision, both paid and unpaid are presented in Figures 4.5 and 4.6 and reveal three distinct sub-groups. First, there were people with brain injury who received less than 30 hours of care and supervision a week (2 to 4 hours per day). Second, there were some who received between 84 and 105 hours a week (12 to 15 hours per day). Third, there was a larger group that received 168 hours a week (24 hours per day). The minimum number of hours received per week was 13,
and the maximum was 168. The latter equates to 24-hour care or supervision, seven days a week. Eight people with brain injury, more than half the sample, received 24-hour care.

Figure 4.5 Actual Hours of Direct Care and Supervision

Figure 4.6 (page 95) presents the hours of paid and unpaid care received by each of the 14 participants. Two participants had ceased using paid care, relying instead on their spouse; however, the 12 other people with brain injury all used some paid care. Three participants had no family involvement at all, and relied entirely on paid carers for their day-to-day support. The number of paid carers employed per household ranged from one to seven.

Finally, a comparison is presented in Table 4.1 (page 96) of SRS scores, hours of care and supervision received, and paid and unpaid hours for each of the 14 people with brain injury. This table again shows three major sub-groups: those who received less than 30 hours of care and supervision a week, those who received between 84 and 105 hours a week, and the largest group, those who received 168 hours a week.
The minimum number of hours received per week was 13, and the maximum was 168. The latter equates to 24-hour care or supervision, seven days a week. Eight people with brain injury, more than half the sample, received 24-hour care.

![Figure 4.6](image)

**Figure 4.6.** Mean Hours of Paid and Unpaid Care per Week.

*Note.* Maximum number of hours per week = 168, which is equivalent to 24 hour care, seven days a week. Where a range of care hours were provided, the mean has been recorded.

In short, data presented in this section have allowed similarities and differences to be noted across the 14 participants with brain injury. Most were physically able and independently mobile but had difficulty with psychosocial functioning. A range of levels of cognitive independence and occupational functioning were evident. A range of levels of care and supervision were also evident. Eight people with brain injury — more than half the group — received 24-hour care, seven days a week. There were three clear sub-groups: those receiving less than 30 hours a week (2 to 4 hours per day), those receiving between 84 and 105 hours a week (12 to 15 hours a day) and those receiving 168 hours a week (full-time 24 hour care). Three people with brain
injury had no family member involved in their care or day-to-day management. These participants relied entirely on paid carers.

**Table 4.1** Presentation of Cases according to Level of Supervision and Hours of Care

<table>
<thead>
<tr>
<th>Person with brain injury</th>
<th>Case no.</th>
<th>Level of supervision (SRS score)</th>
<th>Level of supervision (SRS level)</th>
<th>Total hours of care/wk</th>
<th>Paid care (hrs / wk)</th>
<th>Unpaid care (Hrs per wk and provider)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Will</td>
<td>5</td>
<td>1 (n=2)</td>
<td>Independent (1)</td>
<td>13</td>
<td>6</td>
<td>4-7 hrs – wife visits or phones daily</td>
</tr>
<tr>
<td>Paul</td>
<td>12</td>
<td></td>
<td></td>
<td>21</td>
<td>14</td>
<td>4-7 hrs wife visits or phones daily</td>
</tr>
<tr>
<td>Sheila</td>
<td>4</td>
<td>2 (n=2)</td>
<td></td>
<td>22</td>
<td>8</td>
<td>7-14 hrs- close family friend</td>
</tr>
<tr>
<td>Keith</td>
<td>10</td>
<td></td>
<td></td>
<td>28</td>
<td>28</td>
<td>Nil</td>
</tr>
<tr>
<td>No cases</td>
<td>3 (n=0)</td>
<td>Overnight (2)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dora</td>
<td>11</td>
<td>4 (n=1)</td>
<td>Part-time (3)</td>
<td>105</td>
<td>Nil</td>
<td>100-105 hrs - husband</td>
</tr>
<tr>
<td>No cases</td>
<td>5 (n=0)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lara</td>
<td>2</td>
<td>6 (n=2)</td>
<td></td>
<td>84</td>
<td>84</td>
<td>Nil</td>
</tr>
<tr>
<td>Gary</td>
<td>7</td>
<td></td>
<td></td>
<td>168</td>
<td>9</td>
<td>159 hrs - parents and brother</td>
</tr>
<tr>
<td>No cases</td>
<td>7 (n=0)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gareth</td>
<td>1</td>
<td>8 (n=4)</td>
<td>Full-time Indirect (4)</td>
<td>168</td>
<td>168</td>
<td>Nil</td>
</tr>
<tr>
<td>Angus</td>
<td>8</td>
<td></td>
<td></td>
<td>168</td>
<td>30</td>
<td>138 hrs - Mother</td>
</tr>
<tr>
<td>Wendy</td>
<td>9</td>
<td></td>
<td></td>
<td>168</td>
<td>36.5</td>
<td>131.5 hrs - mother</td>
</tr>
<tr>
<td>Dayna</td>
<td>14</td>
<td></td>
<td></td>
<td>168</td>
<td>Nil</td>
<td>168 hrs - husband</td>
</tr>
<tr>
<td>No cases</td>
<td>9 (n=0)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thomas</td>
<td>3</td>
<td>10 (n=3)</td>
<td>Full-time Direct (5)</td>
<td>168 +</td>
<td>168</td>
<td>7-14 extra hrs – sister visits daily</td>
</tr>
<tr>
<td>Moira</td>
<td>6</td>
<td></td>
<td></td>
<td>168 +</td>
<td>42</td>
<td>126 hrs - husband</td>
</tr>
<tr>
<td>Joe</td>
<td>13</td>
<td></td>
<td></td>
<td>168 +</td>
<td>168</td>
<td>7-14 extra hrs - brother and sister in law</td>
</tr>
<tr>
<td><strong>11-13 (n=0)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note.* Shading has been used to visually separate SRS levels
4.3 Ways of Living with Care

4.3.1 Introduction and Definitions

All 14 people with brain injury in the study could be categorised as living in one of four ways, in the presence of care. These four ways were labelled: institutional living, living with family, living alone with high support and living alone with low support. A way of living described a person’s living situation (where they lived and with whom), their configuration of carers (paid versus unpaid carers, nature of the shifts and rosters used) and the level of care received (hours and intensity). The properties and dimensions of each way of living are presented in Table 4.2 (page 98), and further defined below.

4.3.2 Properties and Dimensions

Living situation. This term refers to the place where a person with brain injury lived, and the people with whom they shared their daily routines. Living situations ranged from an institution with multiple rules and routines, to an independent home.

Configuration of carers. This term refers to a loose grouping of individuals, paid and unpaid, family and non-family, who assumed responsibility for helping the person with brain injury. These configurations could be formal, such as a roster of paid staff working weekly shifts, or informal, characterised by unpaid family carers.

Level of care. This term refers to the amount and nature of direct and indirect care received. The level of care ranged from low (less than 30 hours per week) through to high (full-time, 24-hour care), direct (on-site, hands-on care) through to indirect (off-site care, involving prompting and support).

Most people with brain injury in the study lived with their family after leaving hospital (n = 12). Six were still living with family at the time of interview. Eight lived alone with support. Half of the sample had experienced two or more ways of living since their injury.
### Table 4.2 Properties and Dimensions of the Four Ways of Living

<table>
<thead>
<tr>
<th>Ways of living</th>
<th>Pseudonym of person with brain injury</th>
<th>Living situation</th>
<th>Configuration of carers</th>
<th>Hours of care (per week)</th>
<th>Level of supervision (SRS score /13) b</th>
<th>Cognitive Handicap (R-CHART score/100)c</th>
<th>Physical Handicap (R-CHART Score/100)c</th>
<th>Social Integration Handicap (R-CHART score/100)c</th>
<th>Independent Living Skills (SPRS score /24) d</th>
<th>Interpersonal Relationships (SPRS score /24) d</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Institutional Living</strong> a (n=0)</td>
<td>Nil at time of interview a</td>
<td>Nursing home</td>
<td>Nursing home staff and paid care</td>
<td>168</td>
<td>Assumed to be high: 8-10</td>
<td>Not measured</td>
<td>Not measured</td>
<td>Not measured</td>
<td>Not measured</td>
<td>Not measured</td>
</tr>
<tr>
<td><strong>Living with Family</strong> (n=6)</td>
<td>Moira, Gary, Angus, Wendy, Dora, Dayna</td>
<td>With spouse or parents</td>
<td>Family and paid care or family only</td>
<td>100-168</td>
<td>Low to high: 3-10</td>
<td>Moderate to high (18-66)</td>
<td>Wide range (4-100)</td>
<td>Wide range (21-100)</td>
<td>Wide range (4-19)</td>
<td>Wide range (7-18)</td>
</tr>
<tr>
<td><strong>Living Alone with High Support</strong> (n=4)</td>
<td>Gareth, Lara, Thomas, Joe</td>
<td>Alone in own home</td>
<td>Family and paid care or paid care only</td>
<td>84-168</td>
<td>Mod to high: 6-10</td>
<td>High (14-34)</td>
<td>Wide range (4-91)</td>
<td>Wide range (21-100)</td>
<td>Low (6-7)</td>
<td>Low to moderate (7-13)</td>
</tr>
<tr>
<td><strong>Living Alone with Low Support</strong> (n=4)</td>
<td>Sheila, Will, Keith, Paul</td>
<td>Alone in own home</td>
<td>Family and paid care or paid care only</td>
<td>13-28</td>
<td>Low: 1-2</td>
<td>Low (72-96)</td>
<td>Low (88-100)</td>
<td>Low to moderate (31-100)</td>
<td>Moderate to high (14-19)</td>
<td>Low to moderate (5-14)</td>
</tr>
</tbody>
</table>

**Notes.** Shading has been used to separate SRS, R-CHART and SPRS data. aAlthough no person with a brain injury was living in a nursing home at the time of interview, two participants had recently moved into their own home after 10 and 13 years in a nursing home. bSupervision Rating Scale scores: High 8-13; Moderate 4-7; Low 1-3. cRevised-Craig Handicap Assessment and Reporting Technique scores: High 0-33; Moderate 34-66; Low 67-100. dSydney Psychosocial Reintegration Scale scores: High 17-24 (no significant change); Moderate 9-16 (some change); Low 0-8 (major change).
4.3.3 Institutional Living

The first way of living, institutional living refers to people with brain injury whose permanent living situation was a nursing home. They received 24-hour nursing care. None of the 14 people with brain injury in this study were living in an institution at the time of interview; however, two had previously spent 10 and 13 years respectively in a nursing home before moving into their own home. They had only recently moved out. Paid carers had been employed to assist these two individuals, in addition to care being provided by nursing home staff.

No retrospective SRS scores were available to describe these two participants’ level of supervision when resident in a nursing home. However, because institutional living implies a need for 24-hour care, these two people with brain injury would have scored 10 or more on the SRS and been categorised as receiving ‘Full-Time Direct Supervision’. No retrospective R-CHART or SPRS scores were available, to determine their earlier level of handicap and integration during the period of institutional living. However, as a comparison, at the time of interview, one participant still had significant physical disabilities and challenging behaviour, and a high physical and cognitive handicap on the R-CHART. The other had mild physical disabilities, but a significant ongoing cognitive handicap as measured by the R-CHART at the time of interview.

With regard to autonomy, interview data suggest that this sub-group of participants had limited independence, and few opportunities for risk-taking. They had little influence over their daily routine, due to the many rules and regulations of the institution. This limited autonomy and lack of experience with day-to-day decision-making was even more evident when participants moved to a new way of living:

[when he moved into his own house]... he wanted to make a few decisions of his own...[but] he had no idea how to ...decide on meals, how to direct the running of his household (Gareth’s case manager).
Nonetheless, these two participants were consulted about major care decisions affecting their life. For example, when planning to move out of the nursing home, they were consulted extensively about where they wanted to live. Paid case managers took responsibility for seeking out such information, discussing alternative care and accommodation options, and negotiating with various organisations when decisions had to be made.

The textbox on the following page (see Case Study 1) illustrates the properties and dimensions of this first way of living, and the nature of care provided. Participants living in an institution required a high level of care and supervision, as measured by the SRS and the hours of care per day (24-hours a day or 168 hours a week). This way of living offered few opportunities for participants to test their independence, take risks, assert control, have autonomy or time alone. Strategies used by case managers and others to help participants cope with this restrictive way of living included managing conflict, supporting carers, and arranging respite or time-out for both the recipient and providers of care.
Case Study 1. Institutional Living

Gareth was a single 18-year old male who lived with his parents before and after the accident. His mother assumed the role of primary caregiver when he returned home from hospital. No funds were available at that time to buy paid care, although some government-funded HomeCare was provided. Within 12 months of leaving hospital, Gareth moved to a nursing home. The physical demands of care, combined with Gareth’s challenging behaviour, led his mother to give up her caring role after months of struggle. At this time, he had only two alternatives: to stay with his family or move to a nursing home.

Gareth argued incessantly with nursing staff and other residents. He was unpopular because he grabbed female nursing staff. A paid carer was employed to take him out once or twice a week for social and recreational activities. This paid carer provided respite for Gareth, the staff and other residents. Nursing staff tried to control and modify Gareth’s behaviour by setting rules. They restricted outings if he broke the rules. Paid carers also set rules when Gareth went out into the community. They admonished him for his offensive language and behaviour. These rules and interactions appeared to increase the conflict between Gareth and his carers.

Although nursing home staff were experienced at providing hands-on care, they appeared to have limited experience working with people like Gareth, who had challenging and sexually-disinhibited behaviour due to a brain injury. Gareth’s case manager spent much of her time managing conflict, mediating between Gareth, the nursing home staff and paid carers, and troubleshooting. The hours of paid care were slowly increased over the years. Paid care increased from one to five shifts per week. This extra paid care enabled Gareth to spend more time away from the institution, and engage in age-appropriate activities in the community.

After Gareth had spent nearly 10 years living in an institution, a new case manager was appointed. She became the catalyst for change. This person knew of alternative ways of living that had not yet been explored. She saw potential for other ways of living. After lengthy negotiations, Gareth’s insurance company reluctantly approved and paid for 24 hour care and rental accommodation in the community. Establishing a new way of living took Gareth’s case manager nearly two years. The planning stage involved harnessing resources such as funding, 24 hour paid care, and a wheelchair-accessible residence. Only once these resources had been obtained could the transition from institutional living occur, enabling Gareth to live alone with high support.

Gareth was 28 years of age and over 10 years post-injury when he left the nursing home.
4.3.4 Living with Family

The second way of living referred to people with brain injury who lived with their parents, or spouse and children. Although 12 participants lived with their family after leaving hospital, only six were still there at the time of interview. All received a high level of care or supervision (100 hours or more per week). This support was provided by a combination of family and paid carers (n=4), or family carers alone (n=2). In this study, this was the only way of living where participants received care solely from a family carer, with all paid care having ceased. A highly variable level of cognitive handicap was a feature of this group, as measured by the R-CHART (see Table 4.2, page 98). A variable level of independent living skills and interpersonal relationships were also characteristic of this group, as measured by the SPRS.

The level of autonomy afforded by family carers was limited. Most family carers were reluctant to let the person with brain injury spend time alone at home or go to the shops unsupervised. Family carers were concerned about physical safety, social judgement, the impact of challenging behaviour on other people in the community, and the possibility of abuse. People with brain injury such as Dayna described the consequences of constant surveillance and limited risk-taking, for her and her husband:

[My husband] doesn’t like me going [out] by myself...he’s restricted going places unless I go too (Dayna, person with brain injury).

Participants with brain injury mostly wanted more autonomy and opportunities for greater risk-taking. A consequence of close supervision combined with this desire for autonomy was that risk-taking sometimes took place without the knowledge of family carers. Participants with brain injury sometimes took low-level risks, performing activities alone, and taking opportunities to test out their independence. For example, Dora went to the shops unsupervised, while her husband was at work and unaware of his wife’s plans.

She got into the shopping centre, but couldn’t find the right door to go out...but she did eventually get home...which is a bit of a worry (Dora’s husband).
Generally, skill development and independence appeared to develop more slowly for these participants with brain injury than for those living alone. This difference possibly resulted from the high level of supervision provided by family carers. At the other end of the spectrum among those who lived with their family were participants who did not initiate or request independence, and needed encouragement to participate in most activities.

The group of participants who lived with their family made most of their own day-to-day decisions, such as how they spent their weekly allowance and how they spent their day. However, no-one living with their family made major decisions about the configuration of carers or level of care. As the following quote illustrates, it was typically a family carer or case manager who took responsibility for gathering information about care, appraising care alternatives and negotiating with service providers when such decisions had to be made:

_Question:_ So what did you do...phone the agency, and see if they could find somebody to fill in? _Answer:_ No, no. [my husband] just picked them (Dayna, person with brain injury).

The textbox on the following page (see Case Study 2) illustrates the properties of this second way of living. Participants who continued to live with their family received varying levels of support, and had varying levels of handicap and psychosocial reintegration. All received at least 100 hours of paid and/or unpaid care per week, with some receiving 168 hours a week, or 24 hour care. The amount of care and support received was not necessarily associated with the level of handicap or psychosocial reintegration.

Living with family typically offered limited opportunities for acquiring or testing independence, taking risks, asserting control, having autonomy or time alone. Skills also appeared to be acquired more slowly by those living with family, than by those with a similar level of disability who lived alone.
Case Study 2. Living with Family

Angus was age 11 at the time of his injury. He returned home to live with his mother after leaving hospital. She wanted to be his primary carer, and felt it was her role and responsibility. However, his mother was also happy to accept supplementary paid care, which enabled her to continue paid work. A combination of family and paid care was therefore arranged. Paid carers were employed to transport Angus to and from school, take him on social outings and help with personal care.

Some paid carers refused to work with Angus after their initial shift, because of his challenging behaviour. At least two paid carers lodged a Workers’ Compensation claim after receiving injuries inflicted by Angus. None of the initial paid carers remained beyond the first week. Angus remained at school for only a few weeks before being asked to leave. His behaviour was getting progressively worse, disrupting classes and causing major conflict.

Angus’ mother decided to reduce her paid work to fill the care gaps. This care arrangement was less stressful for Angus and his mother than ‘breaking in’ inexperienced carers. Paid carers were failing to turn up for work, and the agency had no more staff to send. Next, Angus’ mother advertised for, and employed, private carers instead of using an agency, which enabled carers to earn more money.

Only one paid carer remained at the time of interview. He took Angus out from time-to-time with his own friends and girlfriend. Angus had no friends of his own, only the carer. The carer was having difficulty taking time off for holidays because Angus had no reliable, alternate carers. He was working more shifts with Angus than he wanted to, in order to help ease the burden on family.

At the time of interview, Angus was age 19 and received the majority of care from his mother and one remaining carer.
4.3.5 Living Alone with High Support

The third way of living referred to people with brain injury who had progressed from living with their family or in an institution, to living alone with high support. Four participants in the sample lived in their own home and received a high level of care (see Table 4.2, page 98). Three people in this category received 24 hour paid care, and the fourth received 12 hours of paid care per day. A team of carers provided the necessary care, working 8 to 12 hour shifts on a live-out basis. No person with brain injury used the live-in model of paid care. In two of the four cases, family members provided drop-in support and coordinated paid carers, but rarely provided direct care. Family members appeared to make an active decision that they could not, or would not, live with the person with brain injury on a day-to-day basis:

_He used to come home and...see I’ve got a granny flat out there, and he’d say, “Can I live here?” And I say, “Joe, there’s no-one home to look after you”_ (Joe’s brother).

These people with brain injury had varying levels of physical handicap. All had a high level of cognitive handicap and experienced more difficulty with independent living skills than other sub-groups (see Table 4.2, page 98). This group scored poorly with regard to interpersonal relationships. The level of social integration handicap was more variable for this group than for other groups: low for three of the people with brain injury but high for one person.

Limited independence was another feature of this way of living, since all of these participants were supervised during waking hours. Three out of four participants received 168 hours of care per week, or 24-hour care. Most had improved their ability to eat, transfer, shower and go to the toilet, with coaching and encouragement since their discharge from hospital. They continued, however, to have difficulty with planning, memory, solving problems and making decisions. This cognitive handicap necessitated a high level of support and limited their opportunities for independence.
He was in no other way prepared for community living. He’d never dealt with that many carers before. He had very limited social skills (Gareth’s case manager).

He gets his weekly allowance...$200 to do the shopping and ...he goes and gets that out [from the bank] himself, with the carer (Joe’s sister-in-law).

One of the reasons for the high level of care was that participants were considered ‘at risk’ of injury or abuse when unsupervised. None travelled alone or went to social events unsupervised. All required the help of another person for transport and money management, and for physical assistance. Typically, these participants used a wheelchair for mobility and required significant levels of physical assistance when away from home. One participant was known to wander at night and was consequently locked into the house when he and his paid carer went to bed at night. Most could not go out spontaneously when they wanted to. Overall, there were few opportunities for risk-taking by this group, partly because they were supervised for the majority of the day:

...even with the telephone book, we can’t leave that out because he’ll just ring up everyone (Joe’s brother).

The textbox on the following page illustrates the properties of this third way of living (see Case Study 3). This case illustrates that time alone was something participants rarely experienced until their level of care was reduced, and some risk tolerated. This tolerance for risk is illustrated in the following quote, where Lara’s case manager reflects on their decision to reduce care hours:

The care agency make a lot of money out of her, and they feel she needs 24 hour care... she DOES need care...there’s no question of that but....she’s not going to have a...well she might have an [epileptic] fit but she’s not that vulnerable. She can get around. When she goes to bed at night, she’s basically safe...so out of a 24 hour day it leaves you with less than 12 hours [of care](Lara’s case manager).
Case Study 3. Living Alone with High Support

Lara was 43 years of age when she sustained a brain injury. Her mother assumed the role of primary carer when Lara returned home from hospital. At this time, Lara used a wheelchair, was totally amnesic and verbally aggressive. Her insurer funded 40 hours of paid care per week.

The physical demands of Lara’s care, combined with her challenging behaviour, placed a considerable strain on Lara’s mother and the mother-daughter relationship. The case manager spent much of her time engaged in conflict management. Within two years of leaving hospital, Lara indicated that she wanted to leave home. An Estate Manager at the Office of the Protective Commissioner became involved to manage Lara’s estate and oversee the transition to a new way of living. More generous compensation ensured that Lara had an option not initially available to Gareth (Case Study 1) living alone in her own home.

A private care agency was contracted to provide a team of paid carers. Each carer worked 12-hour shifts on a live-out basis, with one carer assuming the role of coordinator. After moving into her own home, Lara chose to reduce the frequency of contact with her mother, and at the time of interview had only limited telephone contact, much of which was initiated by a paid carer. Lara’s health and well-being were monitored by an Estate Manager, a court visitor who visited twice yearly, her paid carers, and the care agency director.

After about two years in her own home, Lara indicated dissatisfaction with the care agency and some of her carers, and wanted time alone. However, neither the configuration of carers nor the level of care changed. The care agency director and paid carers felt that Lara would be ‘at risk’ if unsupervised. To help make the decision about Lara’s level of care, an independent opinion was sought. A private health professional gathered information and views from the relevant stakeholders. This person reported that, while Lara would be at some risk if left alone at night, this risk was not high. After much debate, Lara’s care was reduced by 50%, from 24 hours to 12 hours each day. She was finally allowed to be alone, some five years post-injury.

At the time of interview, Lara was 49 years of age and six years post-injury. She continued to rely on a wheelchair, had severe amnesia and was verbally aggressive. She received 12 hours of paid care each day, but spent the night alone in her own home. There had been no negative consequences arising from this time alone.
A recurring problem for the majority of participants using paid care was the limited influence they and their families felt they had over major care decisions. For example, many were unhappy about the lack of experience of paid carers who came to work with them, or agencies that took weeks to discontinue unsatisfactory carers. This perception of a lack of influence over care decisions was reported across all ways of living where paid care was used, as the following quotes illustrate:

There was one carer I was unhappy about... I let [the agency] know that I wasn’t thrilled with her, and [that] I’d prefer someone else...and it took a long time...I’d say two to three months that she was still there...they didn’t get rid of her (Tom’s sister).

Carers still keep turning up ...weeks after the agency has been asked to cease their employment... the agency says that if the client does not complain, they should keep the carer on. Until the client complains...nothing changes. The agency says it’s expensive to recruit new carers for difficult clients like [him], and they avoid replacing as long as possible...they become too busy to advertise and select good staff (Gareth’s case manager).

In summary, those participants who lived alone in their own home were highly dependent on a team of paid carers, often supplemented by family visits. They had a high level of cognitive handicap which limited their ability to make decisions without support. They had few opportunities to spend time alone or take risks. Major decisions were made with support. Family carers and the person with brain injury were often frustrated by their lack of control and influence over major decisions, particularly decisions involving care agencies.

4.3.6 Living Alone with Low Support

The fourth way of living referred to people with brain injury who had progressed to living alone with low support. Three participants lived on their own with paid care and family care. A fourth person had recently begun sharing with her defacto partner, after effectively living alone in a variety of temporary residences for nearly 10 years.
This group received the lowest level of care and support of all groups in the study (see Table 4.2, page 98). Although classified as ‘Independent’ on the SRS, they still received a considerable amount of support each week (up to 30 hours). Support was typically provided by a configuration of family and paid carers, or paid carers only.

With regard to level of handicap, participants in this group were noted to have a low physical, mobility and cognitive handicap, a moderate social integration handicap, variable levels of occupational handicap, and a moderate level of independent living skills (see Table 4.2, page 98). This was the highest functioning group in the study. Participants went to the shops or to visit friends when they wished without an escort. They did their own day-to-day banking and cooking.

*The amount of care has got less, which is good. I’m doing more stuff by myself. Instead of them doing...things for me...I can do all these thing* (Will, person with brain injury).

*Now [I live alone] there’s no answering to anyone...I get out when I want to* (Keith, person with brain injury).

Unlike other participants who lived in a nursing home or with their family, these participants were encouraged to take low-level risks. Family members, case managers and paid carers had learned to accept that low-level risk taking was necessary if these participants were to live away from their family, assume greater independence and reduce their level of support.

Greater involvement in decision-making was another characteristic of this way of living. These participants went out whenever they wanted and spent money on a day-to-day basis without asking for advice. However, the scope of decisions was limited to minor matters. Like other participants with brain injury in the sample, they usually made major decisions with support, including choosing new carers or planning a holiday:

There were occasions, however, when participants made a decision that they later regretted. For example, Paul described how he befriended a woman in his local neighbourhood. After several weeks, he allowed this person to help him with his banking when she went shopping. Unfortunately, this person withdrew $40,000 over several weeks using Paul’s keycard before the fraud was discovered, and his money was never recovered or repaid. Although there were other examples of poor decision-making by these participants, the incidence of negative outcomes was low.

The textbox on the following page illustrates the properties of this fourth way of living (see Case Study 4). Several participants noticed improved social behaviour when the person with brain injury moved into their own home, and support was reduced. It was as if a series of stressors associated with family living had been removed, enabling the person with brain injury to gain better control over their emotions, behaviour and actions.

*It has been the best thing that could possibly have happened. It’s very different to living with him. It’s much better. The pressure is off. The behavioural problems...just stopped STRAIGHT away* (Will’s wife).

In this case, Will had previously required close supervision for outings, but began to make more of his own decisions, go out alone and take risks when he and his wife separated. He rose to the challenge when living independently. Other peoples’ expectations of him also changed. Participants in this final group enjoyed increased independence which, in turn, provided greater opportunities for risk-taking. They had high levels of physical and cognitive independence relative to the other groups. Involvement in decision-making was highest in this group, with many minor day-to-day decisions being made autonomously. However, major decisions were still made with the support of another person or persons.
Case Study 4. Living Alone with Low Support

Keith was aged 14 at the time of his injury. His mother assumed the role of primary carer when Keith returned home from hospital. At this time, he was very physically disabled and used an electric wheelchair. He also displayed very challenging and aggressive behaviour. No funds were available to buy paid care, only government-funded HomeCare.

Like Gareth (Case Study 1) and Lara (Case Study 2), the physical demands of Keith’s care, combined with his challenging behaviour placed a great strain on his mother and the mother-son relationship. His case manager spent much of her time engaged in conflict management. Within two years of leaving hospital, Keith asked the case manager to arrange alternative accommodation. He wanted to leave home. He moved into respite care temporarily while awaiting an alternative place to live.

After much planning and negotiation, Keith moved to cluster accommodation for young people with a physical disability, where the residents shared paid care. Keith had his own room, and enjoyed living away from home. However, after only a few months, he was asked to leave the accommodation because of his challenging behaviour and poor temper control. He had driven his electric wheelchair into a carer in a rage.

Once again, Keith returned home to live with his mother and stepfather. Once again, he received a small amount of government-funded HomeCare, and his mother became the primary carer. After months of conflict, Keith moved out again, this time to a transitional living unit. While there, he developed new skills such as budgeting and shopping, but was physically unable to cook for himself. The case manager negotiated for increased community care, and found wheelchair-accessible accommodation to rent. Months later, Keith moved into his own home with a team of paid carers. The agency director and Keith’s case manager provided support to staff, and monitored satisfaction with care.

At the time of interview, Keith was 27 years of age and 13 years post-injury. He continued to rely on an electric wheelchair for mobility, and required a mobile hoist for transfers in the home. However, his behaviour was much more controlled and predictable, and he rarely lost his temper. Remarkably, Keith received only four hours of paid care each day, and spent most of the day and all night alone. There had been no negative consequences arising from his time alone.
4.4 Chapter Summary

This chapter has presented key characteristics of the 14 participants with brain injury, and four different ways of living. Analysis of R-CHART, SPRS, and SRS, as well as hours of care and supervision, allowed similarities, differences and patterns to be identified across participants. Although there were exceptions, most participants with brain injury were physically able and independently mobile, but had difficulty with psychosocial functioning. A range of levels of cognitive independence and occupational functioning was identified. A range of levels of care and supervision was also evident.

Using SRS data, four participants with brain injury were categorised as ‘Independent’, three as requiring ‘Part-Time Supervision’, four as requiring ‘Full-Time Indirect Supervision’, and three as requiring ‘Full-Time Direct Supervision’. Eight people with brain injury – more than half of the sample – received 24-hour care, seven days a week. There were clearly three groups: those receiving less than 30 hours a week (or 2 to 4 hours per day), those receiving between 84 and 105 hours a week (12 to 15 hours per day), and those receiving 168 hours a week (24 hours per day). The number of paid carers employed per household ranged from none to seven. Three people with brain injury had no family member involved in their care or day-to-day management. They relied entirely on paid carers.

A way of living referred to a participants’ living situation (where participants lived and with whom), their configuration of carers (paid versus unpaid carers, nature of the shifts and rosters used), and the level of care received (hours and intensity). These three components were inter-related. For example, the configuration of carers was linked to where a person lived and the availability of carers.

A preferred way of living was identified by participants as one that minimised direct care and maximised autonomy. Living alone with low support was the preferred way of living for the majority of people with brain injury. Unexpectedly, living alone was also the preferred way of living for some married participants, and others with significant physical limitations. Defining characteristics of this group that lived alone included a low level of physical and cognitive handicap as...
measured by the R-CHART, and a moderate to high level of independent living skills as measured by the SPRS. The absence of carers for extended periods of the day placed new demands on these participants who were required to perform household and community living skills. They enjoyed greater privacy and time alone.

A less desirable way of living was identified as one where the living situation, configuration or carers, and/or the level of care received were problematic in some way. Institutional living was identified as the least desirable way of living, because of the absence of risk tolerance, opportunities for autonomy, time alone and privacy. Defining characteristics of this sub-group were difficult to obtain retrospectively but almost certainly included a high level of cognitive handicap as measured by the R-CHART, and a low level of independent living skills as measured by the SPRS.

Chapters 5 and 6 will describe the processes, care decision-making and care maintenance, and strategies used to achieve and maintain a preferred way of living, as well as negative cases where this did not occur.
CHAPTER FIVE
THE PROCESS OF CARE DECISION-MAKING

5.1 Introduction

In Chapter 4, the context of care was presented. Characteristics of the sample and the four ways of living were described, including the location where care was provided, various configurations and levels of care. Challenges and problems could arise in any or all of these areas. Data analysis revealed that participants collectively engaged in two closely related processes, in order to optimise care within a preferred way of living. These processes were CARE DECISION-MAKING and CARE MAINTENANCE. Both had a number of sub-processes and strategies.

CARE DECISION-MAKING involved an appraisal of the living situation, configuration of carers and level of care, and determining whether change was necessary. Decision-making began when a person with brain injury was preparing to leave hospital, ceased when the decision had been enacted, and could recommence at any time when another problem arose. Care problems threatened the stability of the way of living. For example, when a long-standing paid carer resigned and left a gap, this event could trigger the decision-making process and a review of care. Such problems were recognised and addressed by an identified decision-maker.

5.2 The Decision-Makers

The identified decision-maker was typically a family carer or health professional, such as a private case manager or estate manager from the OPC. These individuals recognised and took responsibility for resolving major care problems and overseeing the process of CARE DECISION-MAKING. Often the identified decision-maker changed over time; for example, when a family carer and the person with brain injury decided to live separately. Sometimes the decision-making process was shared. In none of the 14 cases was the person with brain injury the identified or primary decision-maker, although their role changed over time from being passive initially to being more active. Their involvement in decision-making was dependent in part on the expectations of others, and the focus of a decision.
### 5.3 The Focus of Care-Related Decisions

The 10 most common care-related decisions, presented in Table 5.1 below, focussed primarily on the living situation, configuration of carers, level of care and supervision.

**Table 5.1** The 10 Most Common Care-Related Decisions and Stage Post-Discharge

<table>
<thead>
<tr>
<th>Focus of Decision and Care Problem</th>
<th>Decision</th>
<th>Stage Post-Discharge</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>‘Should he/she return home to live with the family?’</td>
<td>◆</td>
</tr>
<tr>
<td><strong>Living Situation</strong></td>
<td>‘Should he/she leave the family home/nursing home and live alone with paid care?’</td>
<td>◆ ◆ ◆</td>
</tr>
<tr>
<td></td>
<td>‘Should he/she use paid care? If so, how much?’</td>
<td>◆</td>
</tr>
<tr>
<td><strong>Configuration of Carers</strong></td>
<td>‘Is he/she at risk of abuse from that paid carer or family member?’</td>
<td>◆ ◆ ◆</td>
</tr>
<tr>
<td></td>
<td>‘Can we recruit self-employed paid carers privately for him/her?’</td>
<td>◆</td>
</tr>
<tr>
<td><strong>Level of Care and Supervision</strong></td>
<td>‘Should he/she use more or less paid care?’</td>
<td>◆</td>
</tr>
<tr>
<td></td>
<td>‘How can he/she/we reduce the cost of 24-hour care?’</td>
<td>◆</td>
</tr>
<tr>
<td></td>
<td>‘Can he/she be left unsupervised overnight?’</td>
<td>◆</td>
</tr>
<tr>
<td><strong>Other Related Issues</strong></td>
<td>‘Should his/her compensation funds be co-supervised by the next-of-kin, or managed externally by the OPC?’</td>
<td>◆</td>
</tr>
<tr>
<td></td>
<td>‘Should I suggest/arrange a sex worker to meet his sexual health needs?’</td>
<td>◆</td>
</tr>
</tbody>
</table>

*Note:* ◆Before and immediately after leaving hospital. ◆◆Up to two years after leaving hospital. ◆◆◆Two or more years after leaving hospital. ◆OPC = Office of the Protective Commissioner.
Decisions were also categorised temporally. They were categorised as occurring ‘early’ (before or immediately after leaving hospital), in the ‘intermediate’ stage post-injury (up to two years after leaving hospital), or ‘later’ (two or more years after leaving hospital). In the early and intermediate stages, the two most common decisions focussed on the living situation and configuration of carers. In the later stage, the focus of care decisions was on the level of care, and other problems such as the supervision of finances and sexual health needs post-injury.

Whether the decision focussed on changing the living situation, employing paid carers or decreasing the level of care, the process was remarkably similar. CARE DECISION-MAKING involved ‘Gathering Information’, ‘Appraising Alternatives’, then ‘Enacting a Decision’. Making the decision occurred implicitly and marked a transition from preparation to implementation. The process and associated strategies are summarised below in Figure 5.1.

<table>
<thead>
<tr>
<th>Sub-processes</th>
<th>Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gathering Information</td>
<td>Consulting Experts</td>
</tr>
<tr>
<td></td>
<td>Managing Barriers</td>
</tr>
<tr>
<td>Appraising Alternatives</td>
<td>Anticipating Benefits</td>
</tr>
<tr>
<td></td>
<td>Weighing Up Risks</td>
</tr>
<tr>
<td></td>
<td>Remaining Open</td>
</tr>
<tr>
<td>Enacting a Decision</td>
<td>Obtaining Resources</td>
</tr>
<tr>
<td></td>
<td>Building Skills</td>
</tr>
<tr>
<td></td>
<td>Adjusting Expectations</td>
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</tbody>
</table>

Figure 5.1 The Process of Care Decision-Making
5.4 Gathering Information

The first sub-process of CARE DECISION-MAKING involved Gathering Information about alternatives. Gathering Information from multiple sources helped to ensure that decision-makers had alternatives to consider. The primary strategies used to ensure that adequate information was available for decision-making were consulting experts and managing barriers.

5.4.1 Consulting Experts

This was one of two key strategies used as part of the sub-process, Gathering Information. Experts possessed special skills, knowledge and experience relevant to the decision. By consulting experts, primary decision-makers ensured that accurate and up-to-date information was available about alternatives. This strategy involved seeking verbal and/or written opinions from experts through case conferences, personal consultations, formal assessments and reports. The identified decision-maker also consulted specialist manuals written by local and international experts, to source information about such matters as employing paid carers privately.

Health professionals arranged meetings with care agency directors. The purpose of these meetings was to exchange information: [The hospital social worker] brought in a couple of agencies ... for me to meet, [and] we chose from those. Later, in the community professionals were invited to meet and form a ‘think-tank’ of experts. The aim of these meetings was to generate a list of alternative care and living arrangements and decision pre-requisites. These meetings were similar to, but less structured than family conferences. For example, Angus’ mother consulted experts of her own volition when making post-compensation decisions about her son’s future:

> Last year when we were...trying to... see what it would be like if he was going to move out on his own [I] called in a psychologist...[and] a case manager. And then we sat around and talked about ...how things were going to be... “What would you need [in place] to be able to do this?” (Angus’ mother).
Consultation with an experienced case manager was a common strategy used by family carers. At all stages, case managers were considered a valuable source of information and a service connector: they have connections to a lot of different things...like Community Options or Centrelink and things that maybe I don’t know enough about. Families continued to use private case managers for this reason after compensation.

Consultation with an estate manager from the OPC and/or Public Guardian (OPG) commenced later, around the time of compensation and continued thereafter for most families. Experts at the OPC or OPG had a breadth or experience in long-term financial and care planning. They provided accurate information to people with brain injury and their family about the long-term cost of paid care, and what was possible with available funds.

Commissioning an expert report was another way in which decision-makers gathered information. Estate managers at the OPC and OPG frequently requested such reports. They wanted objective, unbiased opinions about alternatives. These independent experts in turn gathered information on functional abilities of the person with brain injury from multiple sources. They documented the findings in a report and made recommendations about the best alternative. These reports guided decision-makers at the OPC and OPG. Both Joe and Keith participated in assessments of this kind when experts were collecting information to plan for their future:

[the court visitor]... said “I would like him to be fully assessed by a transitional living unit, with the view of looking at the practicality and the viability of setting him up in his own home in the community” (Joe’s Estate Manager at the OPC).

Two factors limited information gathered from experts. Cost was the first limiting factor. People with brain injury and their family objected to expensive consultants, particularly when they knew and had to pay a consultant’s fees. A conflict of interest was the second limiting factor. Care agencies were seen to have a conflict of interest when advising on the level of care required by clients of their service. This conflict
of interest biased their opinions about the best care alternative. Biased information was treated cautiously by decision-makers, and sometimes even ignored:

She’s being case managed by that [care] service, and the service is saying “Yes she does [need 12 hours of care a day]”. They’re not in a position to determine hours and needs…There’s an inherent problem in that (Case manager to Gareth discussing one of her other clients).

All participants in the study were potential informants. However, noticeably absent from the list of experts consulted were other families and people with brain injury. Despite the potential benefits, these experienced users of care services were not consulted. Whether this was from choice or lack of information is not known. Paid carers were consulted occasionally, particularly when decisions were made about the configuration of carers. Other informants outside the study included insurer representatives and solicitors.

In summary, when making a decision about care and how to best improve the way of living, decision-makers consulted experts. Strategies used included meetings with and commissioning reports from experts. The aim was to gather reliable and up-to-date information about alternatives. Experts generated a list of possible courses of action and decision pre-requisites. However, reliable information about alternatives was conditional on the expert being free from bias and a conflict of interest. Care agency directors were generally not considered a reliable source for this reason. Experienced case managers were a regular source of reliable and practical information. In none of the cases in this study were other family carers or people with brain injury consulted for advice or information about alternatives.

When decision-makers used experts effectively, they achieved two outcomes that would later help them make better decisions. First, complex information was synthesised into a digestible form. Second, a list of short and long-term alternatives was generated for appraisal.
5.4.2 Managing Barriers

Another strategy used by participants when Gathering Information about care alternatives was managing barriers. This strategy was used to ensure that decision-makers obtained information in a timely manner. Barriers to information could be internal or external. Attitudes and personal biases of decision-makers acted as an internal barrier to information. For example, family carers preferred to ask professionals for information on their terms when they needed it. They resisted unsolicited information from professionals about their relative’s way of living:

*You really don’t want to hear what people have to tell you...Even though they’re well-meaning, [and] they’re not TELLING you - they’re [only] suggesting...I didn’t really want people to be telling me what I should be doing with my son* (Angus’ mother).

Decision-makers tried to consciously manage these attitudinal barriers to information. They were careful not to disenfranchise people that might later be needed: *I thought it could do more damage for later on for Gary [if I rejected the case manager’s advice]...so I had to sit back and let them do [their] bit.*

Another barrier to information presented in the form of gatekeepers. Insurance company representatives and health professionals were perceived to be gatekeepers. They could withhold information about alternatives and effectively become an external barrier. Some family decision-makers considered insurance companies to be slow-moving, obstructive and a source of much frustration in the early days. Families often waited weeks for information and approval by insurer representatives. They were reliant on this information to advance their decision-making. Such external barriers were managed by recruiting allies and bypassing gatekeepers. In the following example, Moira’s husband describes both strategies:

*The main opposition was trying to get some sense out of the insurance company...information on...would they extend our old house, or work something out about accommodation so we could get her home from hospital. [So I] got our Member of Parliament to write a letter, and then all of a sudden things happened very quickly. He really got things moving. Once it got on the desk of the head compensation department or manager...things sort of happened overnight* (Moira’s husband).
In summary, decision-makers identified, reflected on and managed barriers to information. Family decision-makers recognised that they were not always receptive to information from professionals. They acknowledged that such attitudes were unhelpful, and consciously tried to overcome them. Decision-makers also encountered external barriers. They strategically recruited influential allies to help. Information that had previously been blocked or withheld by gatekeepers became available when decision-makers recruited an ally, or simply bypassed the gatekeeper. Armed with information on care alternatives, the decision-making process could then move forward. Alternatives were then appraised.

5.5 Appraising Alternatives

The second sub-process of CARE DECISION-MAKING was Appraising Alternatives. Once information had been gathered and care alternatives identified, decision-makers engaged in the process of appraisal. They considered the advantages and disadvantages of alternatives in the short and long-term. They continued to gather information concurrently, staying open to new alternatives that arose.

Alternatives were appraised in terms of benefits and risks. Ideally, an alternative would benefit the person with brain injury and significant others, and improve on their way of living: [I’d like] for him to live on his own... have a nice apartment - be around young people - nightclubs and that. Alternatives also had potential risks: I don’t have female [carers] here. He’s very sexually inappropriate and I don’t want to put him in a position where he’s going to hurt someone. The bottom line was that benefits had to outweigh risks. Strategies used during the appraisal process included anticipating benefits, weighing-up risks and remaining open.

5.5.1 Anticipating Benefits

The first strategy used during appraisal was anticipating benefits to the person with brain injury and others of choosing an alternative. This strategy helped to ensure that decision-makers considered benefits and advantages to individual participants and the collective. The greater the benefits, the more likely an alternative would be selected.
A benefit was a gain or improvement in one domain such as reduced cost of care or improved family relationships. Benefits to people with brain injury included reduced long-term cost, better value for money, increased satisfaction with services, greater privacy and time alone. Benefits to family members included less responsibility and day-to-day care work, reduced violence and aggression, less anxiety and more personal freedom: I’m really looking forward to having my own space again. Mutual benefits for the collective included reduced conflict and stress, improved relationships, and greater care stability: we didn’t think we could really lose. We would just try it.

Decision-makers imagined the short and long-term benefits of each alternative on the way of living. They looked further down the track, when parents and siblings would no longer be able to provide care: I thought ‘If I’m not here, and they don’t make allowances for future care, who’s going to do it?’. They wondered what arrangements would be the least complicated, the best value for money, the most long-lasting. For example, Gary’s parents were asked by their solicitor to consider the long-term benefits to Gary and his siblings of involving the OPC for financial management: He said ‘Who’s gonna be looking after him when you go? The way he put it [the OPC] takes the pressure off his brother... if Gary wanted to have his own house. Alternatives were viewed differently when decision-makers looked further than one or two years ahead.

Family carers reported that some health professionals described benefits of alternatives that never materialised and were unrealistic. For example, health professionals believed that families would benefit from and want to use paid care when the person with brain injury left hospital. The benefits of paid care were said to be many. Paid carers would be experienced, know how to manage challenging behaviour and help with rehabilitation. They would provide respite for family members and act as a buffer:

_We were told that all the carers would have experience with people with head injuries. If Will’s behaviour was bad, then they would take the brunt... so that...the children and I didn’t have to be subjected to it. We could remove ourselves (Will’s wife)._
On the contrary, almost half of the family decision-makers felt that the benefits of family care outweighed the benefits of paid care: *I thought we’d be better off on our own...without paid carers*. These decision-makers believed there would be fewer people to coordinate, adjust to and negotiate with. They anticipated greater flexibility of routines and privacy in the home without paid care. Their appraisal of carer alternatives was clearly different from that of health professionals. However, health professionals promoted the advantages of paid care so well that most family carers accepted. Of the 10 family carers who were able to consider paid care as an alternative, eight accepted. Only two family carers declined because the benefits were not perceived to be great.

*We were offered...a carer for Dayna...to get her back in the role of housework and washing and stuff like that, but...the carer couldn’t look after the baby as well...And for all the messing around...it wasn’t worth it* (Dayna’s husband).

In summary, decision-makers imagined, discussed and anticipated the short and longer-term benefits of each alternative. They were encouraged to look ahead. Health professionals and family carers in this study held different assumptions about the benefits of care alternatives particularly paid care. In the early days, opinions of professionals strongly influenced the choices that family carers made.

### 5.5.2 Weighing-Up Risks

The second strategy used during the appraisal of alternatives was *weighing-up risks* to the person with brain injury and others of choosing a course of action. A risk was a negative consequence resulting from a decision to either take or not take action. The process involved recognising then articulating concerns about the consequences of action or inaction.

Risks to the person with brain injury included ill-health and injury: *her sexual behaviour [was] quite disturbing... she would sleep at anybody’s place... loss of companionship, financial debt, insufficient money to fund a preferred way of living: money is running out very quickly, and abuse: there’d be hangers-on...he’d be too vulnerable.* Risks to the family unit and the care collective included physical...
assault, violence and aggression: *he grabbed our son’s arm and bit it*, ongoing conflict and stress, irretrievable relationship breakdown, and care instability: *If I didn’t live here he would be here by himself. because nobody turned up.*

When weighing-up risks, decision-makers carefully considered and articulated what aspects of an alternative most concerned them, such as the characteristics of a living situation: *I knew he needed to be central...not to be in a dangerous area. I knew he needed not to be near any housing commission...any high risk areas.* These characteristics included level of risk and the nature of any negative consequences.

There were high and low level risks. For example, serious injury and financial debt were high-level risks associated with living alone and reduced care levels. Choosing to leave a person with brain injury alone overnight was categorised as a high-level risk, whereas one to two hours alone was a low-level risk. The greater the level of risk, the less likely an alternative would be selected.

Not all participants were able to articulate exactly what they were concerned about. Some participants objected to an alternative on principle, such as letting a person with brain injury spend time alone or conduct an activity without supervision. *[He] doesn’t like me going [out] by myself, in case something happens.* This general concern for the injured person’s welfare caused some family members to withhold their approval for a course of action.

Decision-makers consulted and negotiated with other participants when there was a difference of opinion about acceptable risk. Priorities differed. Some participants had a high tolerance for risk, whereas others had a low tolerance. These differences could lead to conflict. Agreement had to be negotiated by decision-makers:

*You might have one side of the family saying “We don’t want you to spend any of the money”. Equally, there could be another side of the family where they believe: “Let him spend it now...we don’t know how long he’s going to live...a few years is better than no time in the community”* (Joe’s Estate Manager at the OPC).
When a case manager and the person with brain injury were willing to accept risk but a family carer was not, this blocked a possible alternative. *She’d have her goals: ‘I want to do the dinners, and I want…’ Quite reasonable… not over the top.*  *[But her husband] he’d say ‘No, no, you can’t do that’.* Similarly, if a case manager or care agency director were concerned about the level of risk, this could sway a family carer’s decision. Mutual risk tolerance was necessary for a course of action to be pursued.

Individual tolerance for risk associated with an alternative appeared to be influenced by experience. For example, estate managers at the OPC, case managers and family carers with several years of experience as a care decision-maker had the highest tolerance for risk when appraising care alternatives. They considered some level of risk necessary if a person with brain injury was to develop autonomy and improve their quality of life. As alternatives became fewer due to limited finance, decision-makers also began to tolerate greater risk: *Financially we just couldn’t cope if I didn’t work…it was really difficult. I used to have to leave him there for long periods.* Limited finance not only increased family decision-makers tolerance for risk. This condition also increased the risk tolerance of service providers and health professionals for care alternatives:

> *At the moment here with the budget so bad, if we get a 24-hour person [into the transitional living unit] we really have to think about it [the level of paid care]. Some service people say “Oh they need 24-hour care”. But …most people don’t need it while they sleep. So…we have to say “What is everyone prepared to take here?”*  (Dayna’s case manager).

The level of risk tolerated did not appear to be related to participants’ level of disability after brain injury. That is, decision-makers did not seem to weigh-up the risks any differently if a person had significant versus minimal disabilities. As an example, Keith has significant physical disabilities and was unable to get himself in or out of bed unassisted at night. Yet he was alone from 8pm to 8am each day. In his case, no money was available to purchase additional paid care. The potential negative consequences for Keith of being alone at night were considered less of a concern than the consequences of him returning to shared family living.
In summary, the risks of a given course of action were carefully considered, articulated and negotiated by decision-makers in order to reach consensus. Level of risk and negative consequences were perceived differently by participants, as were benefits. The experiences of participants, and availability of finance influenced the way in which they considered risks. The level of disability of a person with brain injury did not appear to substantially influence the perception of risk. Rather it came down to comparing one risk with another, and one negative consequence with another. Mutual risk tolerance between the person with brain injury, primary decision-makers and case managers was a necessary condition for a course of action to be pursued and a decision enacted.

5.5.3 Remaining Open

The third and final strategy used during the appraisal of alternatives was remaining open. This strategy referred to participants staying open to new and unorthodox alternatives as they emerged, and was evident throughout the process of decision-making. Participants tried to ensure that an alternative was not excluded. This strategy also helped to ensure that the best way of living was achieved. The more experienced the identified decision-makers were, the more open-minded they tended to be in seeking, respecting and accepting alternative opinions.

*Remaining open* involved a readiness to listen and allocate time for discussion. Giving a new alternative a hearing was important. An example of an unorthodox alternative that paid carers had to consider regularly in their work was being asked to find a local escort agency or sex worker for their client. Most paid carers had no such prior experience, were relatively young and anxious about the ethics of pursuing this course of action. They were aware it was illegal. Despite the barriers, they stayed focussed on the clients’ needs:

*She was upset that no mother should have to organise her son’s sex life. I can understand that [but] I don’t think it’s really fair to be asked to do that...I don’t know whether I think it’s right or wrong. I wouldn’t feel comfortable with it because I’ve never been to [an escort agency]....I’d be scared to go into one....if I was to take him in there for the first time ...I’d want someone with me* (Angus’ paid carer).
When a paid carer was unsure about the appropriateness of an alternative, they voiced their concerns and ambivalence to a trusted person:

_He was turning 18 and he’d never made love…said it was something he…needed to do. He told me there was a…sexual surrogate agency [that] took care of people with disabilities. So his mum and I [talked about it] (Gary’s paid carer)._  

When decision-makers had selected a preferred alternative and were close to enacting a decision, they were less inclined to consider new alternatives. This resistance was not unexpected, given the time and energy expended on the decision-making process. For example, when Joe was preparing to move out of a nursing home, he identified an alternative living situation just as his new home was being purchased. He announced that he wanted to live with and marry his girlfriend. Joe’s case manager and family were initially anxious about this alternative, as they had spent two years setting up a suitable home for him. However, they were able to remain open to this new alternative, and took his request on board:

_The implications …were huge. We’d just settled on the property … exchanged contracts about a week before…So I then talked to the carer. I said “We need to set up a meeting with Joe and Mary”. At that meeting, we talked about “Do they want to get married?”. And they quite strongly said “Yes, they did want to”. We also felt that before we went any further, we needed to have just one overnight stay (Joe’s case manager)._  

Joe’s support circle listened and encouraged him with his new relationship. They recognised that, while suitable accommodation was difficult to find, close relationships following brain injury were rare, and therefore important to nurture.

In summary, _remaining open_ involved a willingness to consider new, often unorthodox alternatives during the appraisal process. This strategy helped to avoid alternatives being rejected or prematurely excluded. At this point, participants had gathered information and appraised alternatives, and were ready to choose a course of action. The act of making a decision was a brief event, which did not involve any
strategies or sub-processes, and was therefore implicit in the decision-making process. They were then ready to plan for and enact their decision.

5.6 Enacting a Decision

The third sub-process of CARE DECISION-MAKING was Enacting a Decision. Once an alternative had been selected and a decision made, preparations began for implementation. This sub-process was important for ensuring that necessary resources were identified, obtained, and retained on an ongoing basis. Furthermore, this sub-process prepared the person with brain injury for change, both in terms of skill and attitude. Strategies used when Enacting a Decision included obtaining resources, building skills and adjusting expectations.

5.6.1 Obtaining Resources

When Enacting a Decision, participants used strategies that helped in obtaining resources. They had to identify, negotiate for and retain essential resources. A resource was a source of support or aid. Human resources included paid carers, care agencies, family members, case managers and estate managers. Physical resources included accommodation, transport and money. Without these resources, a decision could not be successfully enacted.

When planning a change in the way of living, participants identified through experience what resources they would need, and in what order. They knew that people with brain injury usually needed a care package including paid care, support from brain injury services and the health system, case management, accommodation, and sufficient funds to finance ongoing care:

[I said] “Look, how about let’s go for [a] case manager first and the case manager would be in the best position to give advice in terms of purchasing the property... making recommendations about renovations...[and] care arrangements”. So in fact the first task in the plan is ...the engagement of a case manager (Joe’s Estate Manager at the OPC).
A decision to move out of a nursing home could only be implemented if the cost of 24-hour care was met on an ongoing basis, and a supply of reliable paid carers located. Like a jigsaw, all the pieces needed to be in place. A total care package was required if the move was to be successful: stable, affordable accommodation plus a stable, affordable configuration of carers.

Finding the necessary resources was a challenge: there is a lack of alternative accommodation options for people who have a brain injury. Physical resources such as accommodation were difficult to find for a person with challenging behaviour or using a wheelchair. A pre-requisite for buying a wheelchair-accessible home was money: it can only come about when you’ve got the lump sum. Information about services and the locality, gathered in the earlier stages of decision-making, was used at this time.

Recruitment and retention of paid carers were major barriers to enacting a decision. Family decision-makers lamented the fact that they could afford but could not find or keep capable and experienced staff: In terms of shopping around, it is limited. [The] geographical location affects the availability. These barriers were even greater in rural areas: There are only so many carers in a remote country town. Care agencies endeavoured to meet the need but resorted to filling care gaps with inexperienced staff. As one family carer lamented, care agencies will just take anyone, and inexperienced carers did not last if they turned up at all:

I’m paying all this money…the insurance company was paying all this money. And what for? The agency doesn’t send people out. There’s no-one. If I didn’t live here he would be here by himself…because nobody turned up. It was like everyday was a battle (Angus’s mother).

The family member above had used about eight care agencies over the years in her quest to find and keep paid care staff. Similar problems were encountered with each new agency. As a consequence, three families in the study employed their own carers to help eliminate care agency fees, increase carers’ salary and retain good staff.
Negotiating for resources involved seeking approval and funding from gatekeepers before a decision could be enacted. Once again, decision-makers encountered gatekeepers in the form of insurer representatives, solicitors, estate managers at the OPC and other family members. Approval from an insurance company to trial community living could take months, especially if a court hearing was needed to secure funding.

In summary, obtaining a package of resources was essential for the enactment of a decision. Resources had to be identified, located then approved by gatekeepers following negotiation by decision makers. Furthermore, resources had to be retained in the longer term. Availability of appropriate paid carers was a recurring barrier to successful implementation of care decisions.

5.6.2 Building Skills

The second strategy, building skills was also important for successfully Enacting a Decision. This strategy refers to the identification, progressive development and testing of skills. Skills included catching a bus, preparing meals, making coffee, feeding [the] dog, or directing the running of [a] household. These skills would be necessary if a new way of living was to be successful. Once a decision had been made to change the way of living, the person with brain injury had to acquire these new skills, particularly if they would be living alone. The aim was to increase the likelihood of success in the new living situation. Skills were built up slowly by setting goals, establishing routines and testing performance.

Setting goals, or an end-point towards which efforts could be directed, helped to identify necessary skills. The person setting goals initially was either the person with brain injury, a family member, paid carer or case manager. Ideally, goals were shared and agreed upon by participants, particularly the person with brain injury. Common goals included having a nice apartment or house of their own, being around young people, and being left alone for a while.

The goals of a person with brain injury did not always match those of their family or case manager. This mismatch caused relationship conflict and frustration, and
limited skill development. For example, Dora wanted to start increasing her activity level by cooking the family meals: ‘I want to do the dinners ... just let me start DOING some things’. Her husband’s response was discouraging: ‘No, no...you can’t do that. I did them all on the weekend. They’re all frozen’. In other instances, carers or case managers set goals such as increased mobility and weight loss, or engagement in leisure activities that did not interest the person with brain injury. Such goals did not reach fruition:

She [previously] had a case manager coming in from the care company... who also happened to be an OT and rubbed Lara [up] the wrong way... she was encouraging more independence, and that was moving Lara outside of her comfort zone... [this] got under Lara’s skin and she verbalised it (Lara’s case manager).

Establishing routines helped to structure the lives and activities of people with brain injury. Routines gave purpose to their lives, helped to improve day-to-day skills and performance through repeated practice, and often improved autonomy as a consequence. For example, Will was reluctant to go outdoors after leaving hospital. Therefore, activities inside the home were introduced gradually, starting with some basic routine activity... some structured daily routine. Gradually Will started doing more for himself at home, such as cooking meals. After several months, he began going out into the community with paid carers. Two years later, he moved into his own home with minimal support, and began taking public transport alone.

People with brain injury recognised that they needed routine to enhance their performance. Changes in carers, activities and routines challenged their memory and made them more reliant on others:

...when I started learning to do things she showed me how to make the formula for my daughter’s milk - next day she stood with me while I made it, to make sure I could do it- did the same again the following day, then the next day I got up and I made it myself. I had to get in a routine of doing it before she gets up because I don’t like interruptions. So I started setting the alarm (Dora, person with brain injury).
Testing abilities and performance was another strategy used when building skills. Family carers, paid carers and case managers tested the skill and ability of a person with a brain injury before or while reducing care. This strategy involved standing back, observing from a distance, and eventually leaving the person unsupervised for several hours at a time. During this time, performance and safety were monitored. For example, family carers telephoned the person with brain injury at intervals, to check on their well being and to minimise risk:

*I’ll leave here at 9am and he’ll stay in the house by himself until I get home at 1pm...we’re doing that more now...he was the one who wanted to do it...he didn’t want any carers. I thought it was a good way for him to see what it’s going to be like if he doesn’t have carers* (Angus’ mother).

Testing performance and skills was also achieved through more formal assessments. Psychologists and occupational therapists conducted independent assessments to help determine skills, abilities and care needs. Sometimes a period in a transitional living unit was arranged for the same reason: [he] went to the transitional [living] unit before he went into his house, to see...what he could do, and what he couldn’t.

In summary, building skills was one of three strategies used by participants when Enacting a Decision. Building skills was achieved by setting goals, identifying necessary skills for living, establishing routines, and testing performance and skills. Skills were developed gradually over time, thereby helping to minimise risk and maximise the likelihood of success.

5.6.3 Adjusting Expectations

The third strategy used by participants when Enacting a Decision was adjusting expectations. Participants held expectations and assumptions about the new way of living. If expectations were not or could not be met, post-decision adjustments had to be made. A cognitive shift was required. Furthermore, expectations changed over time with the benefit of experience, and were notably different for family carers compared to professionals.
The majority of participants shared the following expectations. First, they expected that living with family would be better for the person with brain injury than living in an institution, or living alone. Second, they expected that paid care would relieve the stress on family carers, as well as establishing a precedent for future care. The third expectation was that attempts to reduce care would place the person with brain injury at increased risk, which in turn would lead to negative outcomes. It was by enacting many care-related decisions over time that participants’ collective expectations and beliefs were challenged, and needed to be adjusted.

The first expectation was that living with family would enhance recovery more than any other living situation. However, family carers and people with brain injury soon realised that living together was not what they had expected. Family relationships and roles had changed. Instead of contributing to the progress and rehabilitation of the person with brain injury, some families found themselves focussing on their own survival:

_He tried to put an axe through my daughter’s car…our son tried to take it off him and he pelted a piece of wood at me, and cut my face open._
(Paul’s wife).

As a result of these negative experiences, many family carers adjusted their expectations of family life after brain injury. Paul’s wife began to gather information about alternative living situations: _I just decided that he couldn’t live here like that._ She moved immediately into another phase of care decision-making. Others curtailed their own life, and that of their children, in order to accommodate the needs of the person with brain injury while others found ways to share care responsibilities.

When a change was made, such as the person with brain injury moving out into his or her own home, the expectation was that this new way of living would be better for everyone concerned. This expectation was usually met if adequate preparations had been made:
It has been the best thing that could possibly have happened. It’s very different to living with him. It’s much better. The pressure is off. The behavioural problems ...just stopped STRAIGHT away...[Now] the kids probably go over once a week. Sometimes when I’m feeling a bit grumpy about it, I think “Remember what it was like when we were living together?”.. and I feel much better (Will’s wife).

The second expectation held collectively by participants was that paid care would relieve the stress on family carers. Health professionals strongly encouraged the use of paid care when a person with brain injury left hospital, as the following quote illustrates:

I don’t think it was really even an option ...not to have the carers there. I don’t think [the] brain injury ...team would ever have allowed that to happen (Will’s case manager).

However, half of the family carers found themselves engaging in more care maintenance, and feeling more stressed when paid carers were present than when they were absent. The supply of carers promised by the agency either did not materialise or could not be maintained: The care thing fell apart, so everything else fell apart...if you haven’t got carers that are experienced... forget it. Family carers found themselves providing support and training to staff instead of the agency, or they performed the carer’s role themselves. This was not what had been expected when enacting a decision and making a change to the way of living:

[A client’s] husband rang me one day and said “What’s the point of having a waking night shift”? When my wife ran out of the house in a rage at night, I was the one who had to get up and run for my wife... the paid carer was still fast asleep” (Joe’s Estate Manager at the OPC).
Furthermore, the presence of paid carers in the household, all day everyday was *like an invasion*, and impinged on family life. Some families, particularly those with children, felt they would have been better off with much less or no paid care at all. They felt their expectations had been raised unrealistically:

*It actually turned out to be nothing like [the agency director had promised]...None of them [paid carers] had experience working with anyone with a head injury, and they were all frightened of Will. So I ended being the one that took the brunt of it for them. I was flying by the seat of my pants and trying to reassure them... It was a bit of a nightmare for the first six months...I definitely felt that we would have been better off on our own but everyone was against that* (Will’s wife).

Although this experience was relatively common, two family carers did not share this negative experience of paid care. These family carers were very satisfied with the paid care provided. Their expectations had been met. In another five cases, the family did not use paid care in the early days. Two had declined, and three had not been offered paid care.

Health and legal professionals also encouraged the use of paid care because it established a precedent. This would be important later on, they said, when future care needs and costs were being calculated for compensation: *If they said ‘no’ [to paid care], the insurance company would hold that against their claim.*

The third commonly held expectation was that reducing care would increase risk and lead to negative outcomes for the person with brain injury. This expectation was partly true. In many instances, the person with brain injury *would* be placed at greater risk of ill-health and injury, financial problems or abuse when unsupervised than if they continued to receive 24-hour care.

*If he goes out of the house, he wouldn’t think to look left and right before he crossed the street. He’d just go straight across the street. He’s got no sense as far as that’s concerned. He really cannot be trusted on his own. That is more the reason why he needs 24-hour care than the physical care. He really can’t be trusted* (Thomas’ sister).
However, what changed over time with the benefit of experience, and the reality of care costs, was participants’ attitude to risk. Their expectation that 24-hour care would be needed indefinitely changed. After a few years, many participants were willing to gradually increase risk in order to reduce care costs or allow the person with brain injury more time alone. They did this by testing performance and abilities, and building skills:

*The role of the carers has always been seen to keep her insular in her own little environment…but she’s safe to be on her own …she’s not that vulnerable. …. When she goes to bed at night, she’s basically safe…she could get out of the house if it suddenly got on fire… she doesn’t need someone hovering around 24 hours a day* (Lara’s case manager).

Instead of being perceived negatively, risk was accepted as something to be managed. An expectation of a risk-free existence was incompatible with reduced care and being alone. Therefore, risk management strategies became part of ongoing care management. This change in expectations and increased risk tolerance occurred over time with experience, knowledge of care costs and the limitations of the person’s estate.

*The family and the clients would have waited for years for the settlement or the award to come through, only to find that with that amount of money, you can do nothing. You don’t have enough for care. You don’t have enough to buy the house - or you buy the house and you don’t have the care part. The first thing people think of is cutting the case management service…which …compared to the cost of care, it is really a drop in the ocean….a few hundred dollars …Even if its a dwindling estate, really its not going to make a difference… There is only one way to rescue a dwindling estate and that is you massively cut that paid care* (Estate Manager at the OPC).

In summary, *adjusting expectations* was one of three strategies used in the process of enacting care-related decisions. A cognitive shift was typically required in beliefs and expectations. Participants altered their expectations of life after brain injury, particularly staying together as a family, the role of care agencies and paid carers, and the place of risk in rehabilitation. They made adjustments because many of their expectations were not or could not be met.
5.7 Chapter Summary

CARE DECISION-MAKING involved Gathering Information about alternative ways of living, Appraising Alternatives, making and then Enacting a Decision.

Gathering Information about alternative ways of living involved consulting experts, or resources prepared by experts. Barriers to information such as gatekeepers, or attitudes and personal biases had to be managed. Appraising Alternatives involved considering the risks and benefits of each alternative, and staying open to new alternatives as they arose. Ultimately, benefits had to outweigh risks. Enacting a Decision involved preparing for and then implementing a decision once it had been made. Human and physical resources had to be identified, obtained and retained. People with brain injury were also prepared for the impending change. Skills for living were built over time to help increase the likelihood of success. Finally, decision-makers and people with brain injury compared the new way of living with earlier expectations, and made cognitive adjustments when these expectations were not, or could not, be met.

Chapter 6 presents CARE MAINTENANCE, an equally important process, which contributed to the care management cycle by maintaining a way of living. This process served an important preventative role.
6.1 Introduction

In this study, which aimed to explore the processes and conditions that surround care decision-making and care management after brain injury, a second important process, CARE MAINTENANCE was identified. Constant comparison of the data revealed that this process began when a person left hospital and continued indefinitely in all 14 cases. Unlike CARE DECISION-MAKING which was intermittent, the process of CARE MAINTENANCE continued for many years as concerned individuals helped the person with brain injury attain a preferred way of living. Family carers, and paid case managers in particular, actively monitored the way of living, provided conflict management and carer support. Their aim was to prevent minor problems from developing into major ones. This preventative role partly explained the continuous nature of care maintenance work. The person responsible was typically a family member or case manager assigned to the household. This person moved back and forth between care decision-making and maintenance.

CARE MAINTENANCE involved three sub-processes, Monitoring the quality of care and the way of living, Managing Conflict, and Supporting Carers, and six strategies (see Figure 6.1).

<table>
<thead>
<tr>
<th>Sub-Processes</th>
<th>Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monitoring</td>
<td>Checking Others</td>
</tr>
<tr>
<td></td>
<td>Looking For Signs</td>
</tr>
<tr>
<td>Managing Conflict</td>
<td>Eliminating Triggers</td>
</tr>
<tr>
<td></td>
<td>Mediating</td>
</tr>
<tr>
<td>Supporting Carers</td>
<td>Being There</td>
</tr>
<tr>
<td></td>
<td>Sharing Responsibility</td>
</tr>
</tbody>
</table>

Figure 6.1 The Process of Care Maintenance
6.2 Monitoring

The first sub-process of CARE MAINTENANCE involved Monitoring the performance of carers, the person with brain injury and the way of living to ensure arrangements were the best under the circumstance. Once a new way of living had been established, paid case managers, family carers and others felt a responsibility to engage in quality control. They wanted to check that carers were fulfilling expectations, and that the person with brain injury was safe and healthy particularly if they lived alone. Monitoring helped to prevent minor problems from developing into major ones. Strategies used for Monitoring included checking the performance of members of the care team (checking others) and observing the health and well-being of the person with brain injury (looking for signs).

6.2.1 Checking Others

The first strategy for Monitoring a way of living involved checking others. This strategy refers to overt and covert methods of ensuring that members of the care team were performing their expected role. Participants expected others to be honest, reliable, and protect the interests of the person with brain injury although carer roles were not explicitly described and rarely documented.

Overt methods of checking others included making telephone calls and home visits, asking questions, viewing documentation and records. The day-to-day performance of carers, both paid and unpaid, was closely scrutinised by others, in addition to the performance of estate managers at the OPC, case managers and care agencies. In the following example, a family carer approached the OPC for assistance, having previously tried to check up on a paid carer independently. The family was concerned about carers arriving late and leaving shifts early, leaving the person with brain injury unsupervised for periods of time:

> When this family asked the agency for a statement so they can check against the hours, they [the care agency] said “No, no, we can’t give you a statement”. I thought “This is rather odd?” And so [the family] came to us and said “Can we have a statement?”. I said “Of course you can have a statement!” That’s the only way that we could find out whether the hours claimed are the hours worked (Joe’s Estate Manager at the OPC).
Covert methods included reading communication books kept by paid carers, dropping in unexpectedly and cross checking stories. These strategies were typically used when family carers distrusted someone on the care team. Inconsistent stories between paid carers and the person with brain injury caused family carers to become suspicious and engage in further covert checking:

*I used to come home and that carer would ...write these terrible things in the book. And then I would say to Angus “Well, how did your day go with [the carer] today?” And he would tell me something completely different...and Angus doesn’t lie. He’s lost that ability (Angus’ mother).*

Not everyone engaged in monitoring and checking to the same degree. Although multiple paid carers working in a household tended to improve accountability (because carers monitored each other’s work), the accountability of care agencies arose time and time again as a major concern. Agencies were expected to check the performance of staff, but rarely did so. This responsibility fell instead to case managers, family carers and estate managers at the OPC.

*Often we’ve got carers saying “Well it’s my first day at work. I have no induction. I’m only a backpacker”. Very, very common...There is no way that you can check who’s trained, who’s not...I do have many, many criticisms about [care agencies] but one is really the quality of the carers...when [the care] is not value for money, you don’t know where to turn (Joe’s Estate Manager at the OPC).*

An ongoing dilemma was what to do when the performance of an individual team member was unsatisfactory. In country areas particularly, there was little to be gained by terminating the work of an unsatisfactory paid carer or agency, since there were few alternatives. The best strategy appeared to be informing these individuals and organisations that their performance was being checked.

Another covert method of *checking others* was listening to comments about working relationships; for example, reports of uncharacteristic temper outbursts by the person with brain injury, reluctance to spend time with, or complaints about a carer. In the following example, a paid carer was suspected of emotional blackmail and intimidation, because of comments made by Keith to his care agency director:
He used to say he felt intimidated by [the paid carer]...She was [sort of saying] “You need me. You’d be lost without me. I can really say what I like to you”...That was the impression I was getting (Keith’s care agency director).

In summary, the strategy checking others involved overt and covert methods of monitoring the performance of other team members. Activities included telephone calls, home visits, reading communication books, checking timesheets, and cross checking verbal accounts of an event. The purpose was to ensure that individuals and organisations met expectations, expectations which were often implicit.

6.2.2 Looking for Signs

The second strategy for Monitoring a way of living involved looking for signs. Family carers, paid carers, case managers and others actively watched the person with brain injury for visible signs of deteriorating health or risk-taking behaviour that might endanger their health. These observers used their knowledge of the person and their experience to distinguish between important and unimportant signs. They noticed, processed and interpreted this information. This strategy was closely associated with, but separate from, the strategy of checking others.

Physical signs such as an unkempt appearance or weight loss suggested deteriorating personal hygiene or ill-health. Food stains on clothing, wet clothing due to incontinence, or unclean living conditions were noticed particularly if these signs were atypical. Management of incontinence was a health concern for several people with brain injury. One paid carer spoke of her concern for Moira and the lack of attention paid to toilet hygiene by Moira’s husband. The paid carer in the instance was monitoring the performance of a family carer by looking for signs of neglect:

She will wet herself, and then he [her husband] won’t change her. Just when I’m going, [I’ll say] “I’ll change her” and [he says] “No. You go off. You go”. And I think to myself “Well it’s going to go on all night, anyway isn’t it?” Because when you come back in the morning - she wears an overnight pad - the pad is so full, it drops on the floor (Moira’s paid carer).
When a person with brain injury lived alone or reduced their level of care, case managers and others looked for signs that informed them about the person’s subsequent health and wellbeing. For example, when Paul began living alone, there were concerns about the management of his diabetes. His diet and insulin-taking were irregular, and needed to be carefully watched. The signs were not encouraging. His ex-wife found Paul in a hypo everyday when she visited. This was a visible sign that Paul was not eating adequately and required closer supervision of his diet and medications.

Participants tried to interpret signs cautiously before asking questions or taking action. Misinterpreting signs could lead to unfair accusations and conflict. For example, when a paid carer noticed bruises on Joe’s body, she waited before discussing her concerns with the case manager. Bruises were not uncommon as Joe had poor balance and often knocked into furniture. However, when combined with conflict between Joe and his family carers, these visible signs prompted the carer to enquire further. This was another example of a paid carer monitoring the performance of family carers:

> When I noticed bruising on him...I didn’t know if it was him falling over and bruising himself, or was it physical abuse. Because when he does get tired, he does fall over. But he had [also] been scared to come out of his bedroom for some time. [So] I queried them...[and his] sister in law...told me that Joe went to smack [the baby], and she tripped him over and started laying the boot into him. So I realised ... it was from physical abuse (Joe’s paid carer).

Agency directors and family carers recognised signs of altered care relationships, such as frequent calls to the agency or complaints from a client or paid carer. When an otherwise stable care relationship deteriorated, paid carers were at increased risk of resigning. Urgent preventative action was required. Typically, this preventative action involved reducing the number of hours spent together by the paid carer and person with brain injury. Carers learned to recognise signs that they were spending too much time working with one client:
I see him angry at me, and swearing saying “You’re an f---ing this...”, “You smell” or just excuses to pick a fight with you. Or instead of “Can I have a drink”, its “I WANT a drink!”. Or [he] hits you for no reason (Angus’ paid carer).

These anti-social behaviours suggested to experienced carers that they and the person with brain injury needed time away from one another, or that the carer needed a permanent change: The agency manager’s really good. She recognises it. She said to me a couple of times “I can see that you’re stressed” (Joe’s paid carer).

In summary, participants looked for visible signs of an altered health status, unsafe or anti-social behaviour in the person with brain injury. They looked for, processed and carefully interpreted such information before taking action. They used their prior experience and knowledge. This cautious monitoring helped prevent misinterpretation of signs and unfair accusations.

### 6.3 Managing Conflict

The second sub-process of CARE MAINTENANCE was **Managing Conflict**. Conflict was defined as antagonism, opposition or discord between a person with brain injury and another person or persons – typically a paid carer or family member. Conflict could be managed and reduced but rarely resolved and was continuously present in most households: Everyday there was a fight. Participants used two main conflict management strategies to avoid relationship breakdown and help maintain the stability of care: eliminating triggers and mediating.

#### 6.3.1 Eliminating Triggers

The first strategy used by participants when **Managing Conflict** was eliminating triggers. This strategy refers to the identification, anticipation and avoidance of any factors known to trigger conflict. A trigger could be a person, activity or event. Family members, case managers and paid carers learned to recognise and avoid triggers that caused the person with brain injury to become angry, aggressive or embroiled in an argument.
Triggers had to be identified before they could be eliminated. This goal was achieved by reflecting on situations where conflict had arisen, and identifying the antecedents or preceding events. Professional case managers and psychologists taught paid carers and family members how to identify triggers:

*I would say [to the paid carers] “OK. Talk about what happened. What were the triggers? Why do you think it happened? Let’s try to work this one out, so it doesn’t happen again”* (Gareth’s case manager).

Once identified, strategies for elimination were proposed. Typically conflict was triggered by environmental factors, such as noisy children: *He couldn’t stand noise. He couldn’t stand ... for the kids to have anyone around – their friends.* In this example, the noise problem could be minimised by scheduling visits from children’s friends when the person with brain injury was out. Less desirable strategies included placing the children in day-care, and asking their friends to cease visiting the house.

The presence of an attractive female carer during personal care sessions was identified as another factor that triggered sexual harassment and conflict. Strategies that were used to eliminate this trigger included asking female carers to wear more conservative clothing, approaching the person with brain injury from their paralysed side, and rostering male carers on to the morning shifts. Modifying the environment typically helped to eliminate conflict.

In summary, care managers and paid carers primarily relied on environmental modification to eliminate triggers and avert conflict between a person with brain injury and others. Variables such as the timing of outings and visits, care rosters and the manual handling techniques used could all be modified and manipulated. Eliminating triggers was a basic behaviour modification technique. Professional case managers spent a considerable amount of time teaching paid carers and family members how to use this strategy in order to optimise the way of living.
6.3.2 Mediating

The second strategy for Managing Conflict was termed mediating. This was a strategy that professional case managers and family carers used to keep care relationships intact and limit the number of carer resignations. Mediating involved listening to the parties involved, negotiating rules, limits and boundaries. Regular mediation was provided in person and by telephone.

Listening to both sides of an argument was the first step to mediation. People with brain injury complained that paid carers and care agencies did not listen to or respect their wishes: *I don’t get on with them...they’re too bossy...they tell me what I should be doing.* In such instances, a third person stepped in. They listened to both parties, then negotiated a compromise:

*I’ll go around there and Gareth will say “I hate that so and so. She did this to me” or “She did that to me..”. And then I hear the carer’s side of the story (Gareth’s case manager).*

Negotiating rules, limits and boundaries was the next step. Dayna’s husband acted as a mediator between his wife and paid carers on a daily basis. He tried, unsuccessfully, to establish rules for paid carers to follow during times of conflict:

*I said “When you ... have a go back, that fires her up and gets her to say more things”. [The paid carer said] “I’m not going to take it ... she shouldn’t say...” I said ‘Well...you’ve got to be more understanding. Just don’t come back [to the topic] ...talk nicely about something else and get her mind off whatever it is” (Dayna’s husband).*

Rules were also negotiated for people with brain injury to follow instead of firing paid carers impulsively during an argument. Family carers and case managers knew that by getting rid of a carer in this way, the person with brain injury was creating a major care gap. The care agency would have trouble getting anyone to replace that carer. Agency directors and case managers reached an agreement that only the agency could terminate employment. The person with brain injury had to contact the agency by telephone to discuss proposed terminations, allowing an opportunity for mediation.
In summary, case managers, family carers and agency directors engaged in mediation by listening to and negotiating rules, limits and boundaries with the parties in conflict. These strategies helped to maintain the stability of a care configuration. Without regular conflict management and mediation, the way of living was seriously threatened.

6.4 Supporting Carers

The third sub-process of CARE MAINTENANCE was Supporting Carers. There was universal acceptance that carers needed emotional and practical support to sustain them through challenging times. The majority of participants, most notably case managers and, to a lesser extent, care agency directors, tried to help carers in some way. Family carers also offered advice and support to paid carers, who in turn supported other paid carers. Strategies used included being on-call to debrief carers (being there), and sharing responsibility for care-related tasks.

6.4.1 Being There

The first strategy for Supporting Carers was being there. This strategy referred to the allocation of work time and attention focussed specifically on carers’ needs (both family and paid carers). Care agency directors and case managers had not only to promise support to carers, they had to be there when needed. They had to anticipate needs and be available by telephone or to visit carers at such times.

Paid carers needed advice on such matters as managing challenging behaviour, health and safety issues. Sometimes they needed mediation by a third party. In the following example, a paid carer reported having regular telephone consultations and meetings with her supervisor and client to help manage challenging behaviour:

When I’m with Gareth I would speak to [agency director] maybe two or three times a day...[And] we have regular team meetings for Gareth. Depending on the urgency, it could be every fortnight (Gareth’s paid carer).
However, only one or two care agencies had established procedures to ensure that time was allocated for supporting carers. Agency directors were perceived to be too busy to give staff or clients the attention they needed: *The first month ...everything’s going fine ... but it doesn’t last*. Paid carers said repeatedly that agency directors had little or no time for staff or clients: *Their workload is so full, because they have so many new referrals, they forget about that client for 12 months*. Several agency directors genuinely believed they supported their staff. They asked carers to call them at any time. However, paid carers had a different perception of their employers’ availability.

> With the first agency…I just felt like there was no help for me. If I wanted to talk to the boss, she was never there... if I ever needed to talk to her about something that wasn’t going right with the client or whatever, I just didn’t feel like I had any help from her (Joe’s paid carer).

> Carers don’t know who they should officially go to when they have a problem or need advice or help, or to debrief. They feel left out in the cold...(Gareth’s case manager).

Paid carers confided in other paid carers as an alternative to their supervisors, in spite of concerns about breaching confidentiality. They shared concerns with their own family and with other carers, partly because little employer support was available:

> I said to the other carer “I really shouldn’t be discussing this with you, cause it’s breaching confidentiality. I’m sure [the family] wouldn’t like to hear some of the things I’m saying today to you, but it’s good to talk to someone about it” (Moira’s paid carer).

There were several consequences of agency directors being unable to support and maintain regular contact with staff. First, when they did eventually meet up with carers and the client, agency directors were often unfairly critical. They identified failings in the carers’ performance. They made paid carers feel awful. Carers felt judged by their employers, rather than supported when a face-to-face review or family meeting occurred.
“Why haven’t we done this? We should have been doing this” [They come in and tell] you what mistakes you’ve been making... it’s just dreadful...You feel like you’re defending yourself. I left those last two meetings feeling really anxious (Gary’s paid carer).

Paid carers felt their employer would disapprove of their behaviour or consider them incompetent if they reported all the incidents that occurred in a week. If they were considered incompetent, this could place their employment in jeopardy. One experienced case manager recognised this association. She noted that paid carers feel...as if they will be seen not to be coping and lose their job if they ask for help or complain. Therefore, a second consequence of limited support being available was under reporting of work-related incidents that put the safety of the paid carer and client at risk:

He grabbed the steering wheel and when I tried to wrestle it out of his hands...he punched me in the face...It freaked me out. [But] I didn’t write an accident report because...I didn’t want anyone to think I was going badly (Gary’s paid carer).

On the contrary, support provided by case managers was mostly helpful and available when needed. However, not all families had or wanted access to a paid case manager. When employed, family and paid carers used these professionals regularly for information and advice:

I had an extremely good case manager...she was fabulous...She gave information without...as you know there’s a way to tell people and there’s a way to tell people. And you’ve either got it or you haven’t. And she was very good...she helped me a lot...They were the ones that would ring up once a week. Or I would ring them when I was having problems (Angus’ mother).

In summary, paid carers wanted access to agency directors and other professionals who provided unconditional, non-judgemental support and were available on-call. In the current study, support for paid carers in particular was typically insufficient to meet their needs, resulting in carer anxiety and lack of confidence. Limited support
for carers contributed to sub-optimal care maintenance because carers were distracted and could not perform at their best, and the way of living was unstable.

6.4.2  Sharing Responsibility

The second strategy for Supporting Carers involved professionals, family carers and others sharing responsibility for management of care problems. This was an active strategy that helped carers to cope in challenging situations until day-to-day problems were resolved. Care problems, such as a paid carer not turning up for a shift, were a threat to the stability of a way of living, the safety and well-being of the person with brain injury. The strategy of sharing responsibility held a care problem temporarily at bay, and deferred a crisis. Participants shared care problems by temporarily shifting the carer role to another person, or relocating the person with brain injury.

Family carers shared care problems, both emotionally and in real terms with family, friends and case managers. Other family members were brought in to share care responsibilities. They took the person with brain injury out for the day, or came to stay in the house for a while to help with care: I had a sister who was doing some shift work so she’d go out and stay with him for a while. Sometimes, friends and family temporarily arranged alternative accommodation or provided respite for the person with brain injury in a crisis:

There was a lot of bad language and anger...in the...family home...Her mother was in a very bad state so ...she came here, away from it...she stayed with me for about three months (A family friend of Sheila’s who later became her paid carer).

Family carers recognised that they had to adopt strategies to cope with the challenges and stress of living with the person with brain injury. One such strategy was sharing responsibility for care. Family carers arranged for the person to stay in respite accommodation or return to the rehabilitation hospital for a few days to give the family a break:’...he was backwards and forwards there a little while - for probably two or three months’. However, temporary accommodation usually had to be booked in advance by a case manager, and was not always available at short notice.
Several families lived with physical aggression and domestic violence. In order to temporarily break this cycle and give family members a break, a residential respite service or transitional living unit (TLU) was used. For example, Paul was backwards and forwards for probably 2 or 3 months to the TLU. On one occasion, he was also taken to the local psychiatric hospital:

*(One day he thought) our daughter had been on the phone too long...he pelted the baked dinner everywhere – half burned himself. Our son tried to help...*(but) he just put his hands on his shoulders and he grabbed our son’s arm and bit it ...So I rang the case manager. It was Saturday night. She said “I can’t do anything. Ring the police”. So the police came and took him (Paul’s ex-wife).

Attempts to cope by temporarily transferring responsibility were not always supported by others. In the above situation, Paul’s mother was critical of the daughter-in-law’s action, discharged Paul from hospital, and took him home to stay. However, Paul’s mother only coped with him for a day. She brought him back the next day. Thus the ‘problem’, physical aggression and conflict, returned to Paul’s wife within 24 hours.

In summary, sharing responsibility for care and care problems was one strategy for Supporting Carers. This strategy involved active and practical help from family and friends, and temporarily relocating the person with brain injury. Alternative accommodation provided a much-needed break and respite for the family and person with brain injury.

### 6.5 Chapter Summary

The process of CARE MAINTENANCE involved Monitoring the way of living, Managing Conflict within care relationships and Supporting Carers. Monitoring involved checking the quality of work and performance of care team members, and looking for any signs that might suggest deteriorating health and well being of the person with brain injury. Managing conflict involved eliminating triggers that were known to lead to arguments and relationship breakdown, and mediating between the person with brain injury, paid carers, family carers and others. Supporting carers
involved professionals and care agency directors being there when they were needed, and willingness by others to share responsibility for care problems. These six strategies helped to avert care crises and prevent minor care problems from developing into major ones. However, in the absence of effective strategies, the way of living had to be reviewed and participants moved back to the process of care decision-making. Less often, other conditions such as carer ill-health or a chronic relationship problem prompted a review of care arrangements. However, this shift was not triggered by a failure of the care maintenance process.

This chapter has described CARE MAINTENANCE while the previous chapter discussed CARE DECISION-MAKING. Together, these closely related processes helped to optimise care for a person with brain injury, within a preferred way of living. Chapter 7 presents an integrated model of long-term care management following brain injury, with illustrative case studies.
CHAPTER SEVEN
A GROUNDED THEORY OF CARE MANAGEMENT

7.1 Introduction

The aim of this study was to explore the processes and conditions surrounding care decision-making and care management after brain injury. The previous two chapters described two closely related processes, CARE DECISION-MAKING and CARE MAINTENANCE, that were necessary for optimisation of care within a preferred way of living.

In Chapter 7, a condensed interpretation of data will be presented, summarising the content of Chapters 4, 5 and 6. In the tradition of grounded theory, a storyline will be used. Two case studies illustrate the processes, strategies, influencing conditions and the key consequence of optimising care. The first case study illustrates a more autonomous way of living resulting from organised and consistent care management. The second illustrates a less favourable, less autonomous way of living resulting from limited care management. Key processes and strategies are shown in lower case. The central process and core category of the study is shown in BOLD UPPER CASE.

7.2 The Storyline

CARE DECISION-MAKING begins before a person with brain injury leaves hospital. Important decisions need to be made about the future way of living, as many of these people with brain injury will need 24-hour care. By default or personal choice, family members assume the role of primary decision-maker at this time, regardless of their pre-injury relationship with the injured person. Early CARE DECISION-MAKING is also shared with members of the rehabilitation team.

Decision-makers start by Gathering Information about alternatives, particularly the living situation. Family members consult experts such as health professionals, directors of care agencies and insurer representatives in order to obtain information. These experts meet with and offer advice to family decision-makers. These experts provide information about care alternatives and make recommendations about the possible and recommended ways of living. These experts typically advise that
recovery will be enhanced if the person with brain injury lives in a familiar environment with their family, and if paid carers are used. However, if no close family member is available as the primary live-in carer, or if the injured person is very impaired, experts are likely to suggest nursing home placement. The limited alternatives are appraised by family decision-makers. They consider the benefits and risks of each alternative, to the person with brain injury and the family as a whole. A spouse or parent will usually live with the person with brain injury and become their primary carer. Most will receive some insurer-funded care if a third party insurer has accepted liability.

Implementing the preferred way of living and **Enacting a Decision** involves obtaining **resources**. These resources typically include a private case manager, a care agency, a team of paid carers, accessible housing and specialist disability equipment. Insurer approval and funding are required. Furthermore, skills such as mobility and transfer skills need to be developed prior to hospital discharge, as well as learning how to manage challenging behaviour. Both carers and the person with brain injury require additional skills. Performance of these skills is tested and refined in hospital and at home.

When the person with brain injury returns home, participants hold expectations about the contribution of the living situation and configuration of carers to recovery. They reflect on and learn to **adjust their expectations** as experience increases. They recognise that staying together as a family may or may not be possible because of the brain injury. Some family carers recognise that the presence of paid carers has increased rather than decreased their work. This was not what had been expected. Some learn to accept risk, recognising that a risk-free existence is unrealistic if care is to be reduced and autonomy increased.

The process of **CARE MAINTENANCE** begins at this time and will continue indefinitely. Although **CARE DECISION-MAKING** has been the focus up to this point, priorities change. **CARE MAINTENANCE** involves **Monitoring** the way of living, **Managing Conflict**, and **Supporting Carers**. **Monitoring** the way of living, the quality of care and performance of carers is part of maintaining a stable way of living. Some ways of living require more **Monitoring** than others. Everyone in the
team, except the person with brain injury monitors the performance of others. Paid carers monitor the work of other paid carers and of family carers. Case managers do likewise. Family carers monitor the work of paid carers. Everyone checks the wellbeing of the person with brain injury. They *look for physical signs* or changes in behaviour that might indicate a problem.

**Managing Conflict** consumes a large part of most family carers’ time. Challenging behaviour of the person with brain injury means that conflict is never far away. Case managers and family carers learn to recognise conditions that will trigger conflict. They try to *eliminate these triggers*. They also act as a mediator when conflict arises in the home.

**Supporting Carers** is the role of a case manager in most instances. They regularly contact, visit and liaise with family, paid carers and care agencies to help with problem solving. Others such as siblings, friends and respite service providers also try to *share responsibility* for care. Family carers provide much of the necessary support to paid carers, because they work closely together in the home. Paid carers may not be as experienced as the care agency promised. Consequently, many do not cope well with the demands of the job. Care agency directors may not be available to support staff when they most need help. Paid carers will often leave during or after their first shift.

In roughly half the cases, the living situation, configuration of carers and level of care will stabilise, and minimal CARE MAINTENANCE will be required. However, the constancy of CARE MAINTENANCE work becomes too great for some family carers. Alternatively, the person with brain injury may prefer a different way of living. At this time, CARE DECISION-MAKING begins again, shared by the family carer and case manager.

The process of CARE DECISION-MAKING proceeds as before. The identified decision-maker engages in **Gathering Information** about possible ways of living for the person with brain injury, such as living alone with paid support or moving into a nursing home. Information is needed about the implications and long-term cost of each alternative. This information can be obtained from experts such as estate
managers at the OPC. An independent medicolegal assessment may be requested, to objectively assess abilities and needs. New barriers to information have to be overcome, such as a slow or obstructive insurance company, and an ally such as a local Member of Parliament may be recruited for this purpose.

The benefits and risks of each new alternative are appraised but this time in more depth. Benefits to the person with brain injury and their family need to outweigh the risks. Tolerance for risk increases with experience and with each episode of CARE DECISION-MAKING. After a period of living together as a family and experiencing the associated stresses of this way of living, many participants have an increased and mutual risk tolerance. The person with brain injury and family may recognise that they need to live apart. Shared living may have failed or the person with brain injury may be ready for more autonomy. A decision is made to find a new home for the person with brain injury and purchase more paid care to replace family care. Decision-makers try to remain open to any alternatives that will optimise the way of living. They consider leaving the person with brain injury alone at home for short periods. Such a risk would have been unthinkable at the time of hospital discharge.

Before and while enacting these decisions, resources need to be obtained. A new home needs to be bought or rented. Skills such as budgeting and cooking need to be developed, to increase the chance of success. Goals are set and routines established. Money is a key resource at this stage if the person with brain injury moves into his or her own home with paid care. In order to contain long-term costs and find satisfactory staff, decision-makers may recruit carers privately and choose to bypass the care agency. The family decision-maker will shortly cease being the primary on-site care provider, but remain involved in Monitoring care. CARE MAINTENANCE work will require renewed vigilance as the person with brain injury moves into his or her own home, but will reduce later.

While Enacting a Decision, the person with brain injury and their family reflect on the outcome and adjust expectations again. Often the way of living and outcomes of decision-making are better than expected. The person with brain injury enjoys autonomy and privacy for the first time in years. They take control of their daily routine and make small but independent day-to-day decisions. They are given
permission once again to learn from their mistakes and enjoy the dignity of risk. Relationships with family often improve. The person with brain injury wants and hopes for more. They want friends, intimacy, more control over their life and less supervision. Family carers and case managers, now more experienced, agree with these goals and the cycle continues.

This storyline has described the processes and strategies that participants engage in when making care-related decisions. The storyline reveals a core category or social process, **OPTIMISING CARE WITHIN A PREFERRED WAY OF LIVING**. The processes of CARE DECISION-MAKING and CARE MAINTENANCE, and the associated strategies are concerned with establishing and then maintaining the best possible living situation, configuration of carers and level of care. Improvement in one or all of the properties of a way of living, and moving forward becomes the focus of participants’ endeavours. The storyline also reveals two necessary conditions for **OPTIMISING CARE WITHIN A PREFERRED WAY OF LIVING**: a ‘care’ manager and mutual risk tolerance. The presence of a care manager contributes to the success of the process and the resulting way of living. As time passes, risk tolerance increases. When this tolerance for risk is mutual, decisions will be made that lead to a reduction in the level of care, support low-level risk taking and lead to a more satisfying and autonomous way of living. The model is represented visually in Figure 7.1.

Two cases from the study will be used to illustrate the core process of **OPTIMISING CARE WITHIN A PREFERRED WAY OF LIVING** and the cycle of CARE DECISION-MAKING and MAINTENANCE. The first case illustrates a successful transition from living with family to living alone. The second ‘negative’ or least optimal case illustrates a way of living and the consequences for a person with brain injury when the process of optimising care and the necessary conditions were limited.
Basic Social Problem:
The Need for Ongoing Care following Brain Injury

Figure 7.1 The Basic Social Process and Core Category: Optimising Care within a Preferred Way of Living

Chapter 7.  A Grounded Theory of Care Management
7.3 Case Example 1: Will

Will returned home after many months in hospital to live with his wife and children. He was still in post-traumatic amnesia when he left hospital, having refused to remain there after a weekend at home. An emergency planning meeting was called to plan for his imminent discharge. At this time, Will was unable to control his temper. He was verbally and physically aggressive. Will walked around the house with an aid but needed carer assistance outdoors. He also needed help with personal care.

In the early phase of CARE DECISION-MAKING there was no doubt that Will would return home to live with his family. No alternative living situation was proposed or appraised. The brain injury unit strongly recommended 40 hours of paid care each week, and Will’s wife agreed. Paid carers would help by supervising Will during the day while his wife attended to the children. A variety of physical and human resources were obtained; a house was rented without steps and with a separate room for Will. A care agency was introduced. The agency advised that they had been established for many years, and agreed to supply a team of experienced paid carers.

However, skills would need to be developed. Carers therefore received training in behaviour management and assisted mobility from staff of the brain injury unit. Then Will went home. At this point, CARE MAINTENANCE began. The process was shared between Will’s wife and a private case manager. Care maintenance consumed much of their day. His wife spent much of her time supporting and debriefing paid carers. None were experienced in brain injury as the care agency had promised. All of the paid carers were distressed by their contact with Will. Although the care agency was in regular contact by phone, it was the family carer who mostly supported the paid carers. She was on-site in the house when a crisis arose. By the end of the first week, only one of the five paid carers remained. The others were too afraid to stay, or had been told by Will to leave and not come back. When she needed advice, Will’s wife called the case manager. Other family
members, particularly siblings helped with weekend care. This sharing of responsibility for Will’s care gave his wife some much-needed respite.

Will’s wife spent many hours managing conflict and mediating between her husband, the paid carers and children. Between them, the care team (his wife, case manager, paid carers and agency director) identified that Will was unable to tolerate the company of male carers, particularly when engaging in personal care. Male carers were discontinued. Noise from the children and school friends also caused agitation and triggered temper outbursts therefore, the children were placed in daycare for part of the week. School friends were also asked not to visit when Will was at home. After a year, weekend respite care was arranged for Will. By this time, he was harassing and verbally abusing one of their teenage children. Temporary respite care at weekends allowed his wife and children some precious family time free from conflict and abuse.

Eventually it became clear that an alternative way of living had to be found. The family could no longer tolerate the conflict, abuse and stress of living with Will. His wife hoped that, several months later, a new way of living could be set up with money from his compensation. In the meantime they would live together, use weekend respite care and plan for the future. Another phase of CARE DECISION-MAKING began.

In the second phase of CARE DECISION-MAKING, Will’s wife as primary decision-maker began gathering information about alternatives. The case manager located information about employing paid carers privately, because Will’s wife felt that she already performed most of the agency’s work. The agency had served its purpose and was now an unnecessary expense. The case manager located resource manuals through the Internet about employing paid attendant carers privately, and arranging workers compensation insurance for home-based employees.

Benefits and risks of each alternative were appraised. By employing staff privately and eliminating the agency fee, paid carers would each receive an extra $5 per hour or $40 per day in their pay packet. This might help to attract and retain staff; this was identified as a benefit. However, Will’s wife was concerned about his
vulnerability when living alone. There would be increased potential for paid carers to take financial advantage of Will when he lived alone; this was identified as a risk. She would, therefore, have to screen new staff carefully. His wife also thought that involving the OPC for financial management and major decisions would be of benefit to Will. There would be other identified risks if he lived alone, particularly when he was unsupervised at night. For example, he may forget to lock up, or befriend someone, invite him or her home and find them untrustworthy. Risks to family health and family relationships were compared with the benefits of living separately. Following appraisal of these alternatives, Will agreed albeit reluctantly that he would move into a separate house close to the family and receive several hours of paid care per day.

Enacting the decision and building skills took more than 12 months. A skills-training program was developed by the occupational therapist and implemented by his wife and paid carers. Will learned to cook while living with his wife. He still lacked confidence in his mobility and would not go out alone except by taxi. He always went with an escort. Will finally agreed to travel alone unexpectedly one day, when no paid carer could be found and there was a gap in care. This event became a test. He rose to the challenge, travelled alone by train and enjoyed his new-found independence. Thereafter, he travelled alone and paid care ceased during outings.

Obtaining resources from the insurance company was difficult. Following settlement of his compensation claim, a period of several weeks lapsed before money was available to purchase paid care. Will started spending more time unsupervised because he could not afford to pay for care. His skills and confidence improved during this time. As a consequence, much less paid care was required at the end of the year than they had initially planned. He finally moved into his own home with six hours of paid care a week. His wife provided a similar number of hours of off-site monitoring. Thereafter, his wife and the OPC conducted CARE MAINTENANCE.

When reflecting on the changed way of living, both Will and his wife were effusive. Almost every aspect of their lives had improved as a result of living apart. The
outcomes were better than they could have hoped for. They adjusted their expectations and plans for the future, and felt that anything was possible. Will resumed an active role as a parent after more than two years. He saw his wife and children daily, and the children stayed overnight at his new home from time to time. The children enjoyed his company and respected their father again. Will negotiated public transport alone, cooked independently, and had a few new friends of his own. He was even planning a holiday with one of his new friends.

Privacy, time alone and autonomy were important outcomes when describing his new way of living. Will said he enjoyed spending time alone, listening to music and “doing nothing” if he wished. He reported some negative outcomes as a result of less supervision. For example, he accidentally ran up a telephone bill of $3000, due to extended Internet use. His wife helped him to negotiate repayments with the telephone company and the OPC, as Will still was verbally aggressive when negotiating with these agencies. Although he still became angry, his behaviour had changed dramatically as a result of living apart from the family.

Another outcome of this way of living and successful care management was that CARE MAINTENANCE had decreased. Formal case management and carer support decreased as paid care decreased. Will and his wife received phone calls and visits several times a year from a private case manager but did not feel a need for more frequent support. They also had contact with staff from the OPC, who monitored Will’s physical, emotional and financial wellbeing.

In conclusion, Will initially left hospital with 24-hour care and lived with his family. When this way of living was unsuccessful, he still required considerable care maintenance, and moved into his own home. When living alone, he required a lower level of CARE MAINTENANCE than anticipated. As the identified decision-maker, primary carer and ‘care manager’, his wife had helped to optimise his care within the preferred way of living. Less than three years post injury, the level of care had dropped from 168 hours to 13 hours of care a week, shared between his wife and a paid carer. Both Will and his wife had learned to tolerate increased risk. This mutual risk tolerance, also shared by the private case manager and the estate manager at the OPC, resulted in less care, greater skill development, increased autonomy, and improved social relationships. A successful way of living had been
achieved for Will and his family. There was still considerable potential and opportunity for further improvement in Will’s lifestyle.

7.4 Case Example 2: Moira

The next case study illustrates how another person’s preferred way of living had not yet been achieved when compared with other participants in the study. Moira returned home to live with her husband after a long stay in hospital. Her husband spent over 12 months visiting her at weekends in Sydney, before Moira was transferred to the local country hospital. She had severe amnesia, temper outbursts and limited communication. Moira was very physically dependent, needing a hoist for transfers, and was incontinent at the time of leaving hospital.

The initial phase of CARE DECISION-MAKING was not easy for Moira’s husband. When gathering information for discharge planning, he was reliant on the knowledge and experience of hospital professionals. They initially advised him that nursing home placement would be best for him and his wife. However, when appraising the alternatives, nursing home placement was not one that Moira’s husband was willing to consider. He wanted his wife to come home. He could not, and would not, think about a nursing home as an alternative. There was no further discussion of institutional living; Moira would go home to live with her husband. Hospital staff and a local care agency proposed 40 hours of paid care each week, and Moira’s husband agreed. He would benefit by having someone to supervise Moira during the day while he returned to part-time work, or spent time on their property.

When preparing to enact these decisions, a variety of physical and human resources were required. The family home had to be modified for wheelchair access. Moira’s husband had to gather more information. He consulted experts, including an occupational therapist, a builder and their insurance company. He identified that modifications would require approval and funding from the insurance company. He waited for approval. This was not forthcoming. Finally, in frustration, he recruited the assistance of a local Member of Parliament. The insurer granted approval and funding for the modifications within a few days. Recruiting an ally to manage financial gatekeepers paid off for Moira and her husband.
The local care agency employed two experienced paid carers. Both received training in behaviour management, assisted mobility and safe hoist transfers from staff at the local hospital. This skill building was essential for the health and safety of the carers, including Moira’s husband. Finally, Moira went home, and the process of CARE MAINTENANCE began. The two paid carers monitored the quality of care and checked on Moira’s wellbeing. They monitored each other’s performance and that of Moira’s husband. They checked for signs of ill-health. The paid carers were concerned about Moira’s diet, her weight, continence management and mental health. They worried that Moira’s husband was neglecting her.

There was limited support for carers. No-one from the agency visited, assuming that the carers would phone if a need arose. The paid carers debriefed occasionally with each other outside of work hours, although this was not known by the agency. No case manager was involved, nor was the OPC. Moira’s husband felt he did not need emotional or practical support other than that already provided. Managing conflict was left up to the paid carers, although this was much less of a problem with Moira than in other cases. Misunderstandings arose from time to time, because of Moira’s poor verbal communication skills. Members of the public, in shops and cafes could not understand her requests or responses. Moira became frustrated and verbally aggressive in these situations. Paid carers learned to intervene early in social interactions and act as an interpreter. They tried to eliminate potential triggers.

When reflecting on his wife’s way of living one-year later, Moira’s husband did not feel any need to adjust his expectations. He was satisfied with the care arrangements and trusted the paid carers. They were capable and caring. He felt lucky to have them. He left most decisions about Moira’s day-to-day care to the paid carers, including Moira’s attendance at medical appointments. However, he acknowledged that he did not really know much about the paid carers, as he left home when they arrived. He also had no contact with the agency, but interpreted this as meaning that the carers were doing well. Moira was unable to reflect much on the outcomes or her way of living due to memory loss and perseveration. She stated that her carers were good to her and treated her well. It was unclear if her expectations had been met. However, interviews with her husband and a paid carer revealed that Moira
had little autonomy, few opportunities for choice or risk-taking, and spent no time alone except in bed at night.

When reflecting one year later, the paid carer who had been interviewed was disappointed and critical of Moira’s way of living. Her personal expectations of Moira’s recovery had not been met. She felt that Moira was deprived, emotionally and physically, because her husband provided only the most basic of care. The paid carer observed that Moira and her husband had little physical contact except during care activities, but felt that this may reflect their pre-injury relationship. The carer felt that Moira needed more affection, social interaction, outings, and attention to personal hygiene, which she personally tried to provide. However, the paid carer was beginning to show signs of burnout. She expected Moira’s husband to place his wife in a nursing home in the coming years and recognised that she, as the paid carer, would have little influence over this decision.

In conclusion, Moira had moved home from hospital to live with her husband and received 24-hour care. Her way of living remained unchanged 12 months later. Although it was still less than three years post-injury, no-one was actively monitoring Moira’s way of living to explore how the living situation, configuration of carers or level of care might be improved, and more autonomy achieved. Paid carers were engaged in CARE MAINTENANCE and the way of living was stable; however, no other person with an interest in Moira’s welfare, such as a case manager, was visiting regularly to support or monitor carers, encourage skill building, or look for signs of improvement. No-one was seeking opportunities for increased autonomy, social participation or low-level risk taking. There was potential to further improve Moira’s way of living.

7.5 Chapter Summary

A grounded theory of care management has been presented, explaining change over time in the preferred ways of living and patterns of care after brain injury. These changes were related to the extent of CARE MAINTENANCE and DECISION-MAKING. A person with brain injury, such as Will who required extensive CARE
MAINTENANCE, caused his wife and case manager to re-engage in decision-making sooner rather than later. Change and review became necessary early. When the process of CARE MAINTENANCE became too arduous to sustain, decision-making began again. On the contrary, Moira required much less day-to-day CARE MAINTENANCE by her husband. He did not need to engage in CARE DECISION-MAKING soon after hospital discharge, as Will’s wife had. Moira’s way of living was stable, and could be maintained relatively easily; however, her level of autonomy was low relative to that of Will.

These two case studies were selected to illustrate variations in the process of OPTIMISING CARE WITHIN A PREFERRED WAY OF LIVING. Will was ‘high maintenance’ and moved out of the family home within a short time. His wife acted as the identified case manager and decision-maker. Mutual risk tolerance was evident. The outcomes were reduced care, reduced cost, reduced CARE MAINTENANCE by his wife, and increased autonomy for Will. On the contrary, Moira was relatively ‘low maintenance’, although she still required 24-hour care.

The following chapter will discuss study findings in the context of existing literature, consider implications of the findings and make recommendations for policy, practice and future research.
CHAPTER EIGHT: DISCUSSION AND CONCLUSIONS

8.1 Introduction

The consequences of a severe traumatic brain injury are substantial, both socially and financially, for the person affected, their family and society as a whole. Despite the financial impact of brain injury and the high cost of care for many people, allocation of compensation for care in Australia remains inconsistent across professionals, judges and cases. Decisions about future care are based on expert opinion rather than on factual information and research evidence. Furthermore, decisions about service provision vary unduly, and inequities exist between people with and without compensation, those living in city and country areas, and those with and without family carers.

This study sought to redress gaps in knowledge about care decision-making and care management following brain injury. Given the lack of knowledge and research in this field of study, a grounded theory methodology was used. The study aim was to explore the processes and conditions that surround care decision-making and care management. Research questions focussed on the models of care preferred and used by people with brain injury, and the processes and conditions that influence care decision-making and care management. A substantive theory was developed which explains how and why care decisions are made and how care is managed.

This discussion chapter begins with a brief review of the study sample. Second, ways of living and models of care preferred by people with brain injury are compared with current literature and the opinions of experts. Third, the processes of care decision-making and care maintenance, associated strategies and conditions are discussed within the context of existing literature. Fourth, the impact that mutual risk tolerance and the presence of a care manager have on the autonomy of a person with brain injury are explored. Finally, implications are drawn for practice, policy, education and research.
8.2 The Study Sample

With a mean age of 26.5 years at the time of their brain injury, participants were generally representative of people with brain injury in Australia who receive rehabilitation and follow-up (Olver et al., 1996; Tooth et al., 2001). Males with brain injury were somewhat under-represented (57%) compared with the 65% to 80% reported in other Australian studies (Olver et al., 1996; Tooth et al., 2001). Although the intention was to recruit both men and women with brain injury, more women were recruited than is typically seen in other studies. The primary implication of this imbalance is a corresponding increase in the number of male spouse carers in the study sample.

The four sets of data from the R-CHART, SPRS, SRS and hours of care were interrelated, revealing three distinct sub-groups of people with brain injury. Participants in the high functioning group had a low cognitive and physical handicap, a moderate to high level of performance in independent living skills, and received between two and four hours of care each day. It is this high functioning group, and the processes and conditions surrounding their care management that are of greatest interest because of the participants’ improved functional status and reduced care costs.

By all accounts, these four participants in the high functioning group were not significantly different to others in the study at the time of hospital discharge. All four were reported to have challenging behaviour, and social and cognitive disabilities for some time after leaving hospital. Yet in this high functioning group, care levels decreased relatively quickly in the first three to five years. They were forced by circumstances, such as the absence of paid care, not by the absence of disability, to develop new skills and become more autonomous. Regardless of the trigger for change, a tolerance for risk by these participants and their associates was a condition that distinguished this group from others. I will return to the topic of mutual risk tolerance later in the chapter.
8.3 Preferred Ways of Living and Models of Care

One of the questions posed at the beginning of this study was which models of care were most preferred by people with brain injury. While it has been possible to report on the models used and those not used, it was difficult to identify a preferred model because choices were so limited. Nonetheless, findings reveal that unpaid family care was the predominant model in the early days when most participants lived with their family. A much smaller proportion of care, roughly one quarter of all hours was typically provided by paid carers and directed by an agency. When shared living became unsustainable, as occurred in more than half of the cases, the person with brain injury moved out to live in their own home. Most continued to employ paid carers on a live-out basis, managed by a family carer, paid professional, or an agency.

Although there was no universally preferred way of living, the majority of people with brain injury wanted more personal control, freedom from rules and routines, privacy and time alone without supervision. These were not far-fetched dreams or unrealistic goals. Like other people with disabilities, these participants wanted nothing more than the preservation of their basic human rights (Moore et al., 2000). They wanted an ordinary life, with some choice in how they lived.

8.3.1 Limited Choice, Limited Preferences. People with brain injury in this study and their families needed greater choice, more options and more flexibility in the way they lived. The alternatives were too few and too restrictive. Initially, there were only two real alternatives: living with family or institutional living, although these alternatives increased over time as professionals and family carers became more informed and gained experience. This finding, that people with brain injury had limited options particularly if they wanted to live more autonomously is consistent with other recent reports (Bowen, 2003; Brain Injury Association of NSW et al., 2002; Physical Disability Council of NSW, 2003; Walsh et al., 2002). Compensation increased their care and living options to some degree, but participants still faced two problems: limited information about the options, and limited services. Either they did not know what was possible, could not access services or both.
First, family carers were reliant on information provided by ‘expert’ professionals in the early days because they themselves were new to care decision-making. Yet these experts knew little themselves about alternative ways of living. Family carers needed better information. Professionals working in this field need to become more vigilant about checking that they themselves, and family members in turn, are aware of a wider range of options. Moore and colleagues (2000) have previously suggested that professionals may wish to organise a ‘showcase’ of potential living options for their clients, including written materials, a photo montage or video footage. Examples and stories from this current study would provide a good starting point for such a showcase.

The second problem that remained unaffected by compensation was the lack of experienced paid carers and quality care services. Society, including health and legal professionals, assumes that compensation gives people with brain injury greater choice in how they live because they can buy paid care. Unfortunately, the paid model of care was not the panacea everyone assumed it to be.

8.3.2 Paid Care was Intrusive, Inflexible and did not suit every family. A combined model of paid and unpaid care predominated in the early days post-injury. This model was consistently recommended as ‘usual practice’ by health professionals during the initial stage of care decision-making. However, this was not what all families wanted or preferred. Some participants found paid care intrusive. Consistent with other users of paid care (Charles, 1986), study participants often wanted more time alone as a family. Yet professional decision-makers did not appear to recognise the importance of privacy to families and individuals. The second reason that a paid model of care was not always successful was because paid carers were typically inexperienced, some were unreliable and arrangements were inflexible. This inflexibility of formal paid care (for example, inflexible hours, tasks and roles) has long been a complaint of people with disabilities who depend on agency carers (Batavia et al., 1991; Mattson Prince et al., 1995; Physical Disability Council of NSW, 2003). The third reason why families were not always enthusiastic about paid care was because they spent much of their time in those difficult early days supporting staff, when the employing agency was being paid to train and support carers.
This myriad of problems with agency carers has not previously been reported in Australia, although the findings will be no surprise to anyone working in the field. The findings have ramifications for agency accountability, as well as health professionals who routinely recommend a set amount of paid care. Greater flexibility is needed, in addition to a better system of quality control by commercial care agencies. Although the latter has previously been recommended (Bloom & Associates, 1996), the current accreditation system for care agencies in NSW is voluntary and appears to have had little impact on the quality of service provision.

8.3.3 Consumer-Directed Care was not used by participants. The paid, consumer-directed model of care has the potential to offer people with disabilities more flexibility, accountability, control and autonomy as well as better value for money. It is the model most preferred by people with physical disabilities (Batavia et al., 1991; Beatty et al., 1998; Mattson Prince et al., 1995; Vasey, 2000) over family care, care managed by professionals and care managed by an agency. Yet no-one with brain injury in the current study directed or managed their own carers, not even the four participants in the high functioning group. Most were not even aware of the option, nor were their family carers.

There appeared to be a general lack of awareness about the consumer-directed model, which may be appropriate for some people with brain injury who have a low cognitive handicap and are able to direct their carers. Clearly, specialised training is necessary if this model is to be successful, such as training provided by Paraquad on recruiting and managing paid carers (Paraplegic and Quadriplegic Association of NSW, 2003). Other sources of information about consumer-directed care include manuals such as ‘The Personal Assistant Employer’s Handbook’ (West of England Centre for Integrated Living, 1998), the ‘Personal Assistance Services User Manual’ (Washington Coalition of Citizens with disABILITIES (WCCD), 1997), and ‘The Rough Guide to Managing Personal Assistants’ (Vasey, 2000). These manuals include chapters on: advertising and recruitment; staff management and training; back-up arrangements; employment law; budgeting and salary rates.

8.3.4 An off-site ‘Family-Directed’ Model of Care worked well for Couples who Lived Separately. Although not previously reported, a ‘family-directed’ model of paid care was used in several cases, particularly when a person with brain injury
separated from their spouse and children. In the case of couples, this model had the advantage of maintaining relationships without the stress of living together. A spouse lived off-site and managed the paid carers’ salaries, working conditions, hours of work and duties in conjunction with the person with brain injury. The spouse also provided daily support and prompting.

Wood and Yurdakul (1997), in their follow-up study of 131 adults with brain injury, reported that separations occurred twice as often as divorces, and suggested that it was the physical distance that separating spouses needed to relieve stress and help them cope. Furthermore, some spouses in that study said they planned to continue to support their partner on a live-out basis, so long as they did not have to live in the same house. The current study confirms the observations of Wood and Yurdakul and provides important contextual information on events and issues that lead up to this major decision.

In the case of couples, a family-directed model of care offers spouse carers in particular a contingency plan when living together becomes intolerable. A decision to live separately can then be made with less guilt in the knowledge that shared living has been tried. Living separately need not signal the end of family relationships. To protect important social relationships, this family-directed model of care should be considered earlier by professionals and families as a real alternative to the person living with their family.

Two important Australian studies (Perlesz et al., 2000 and Ponsford et al., 2003) have reported that some families cope well despite their initial traumatic experience. These researchers concluded by calling on professionals to develop models of long-term care and support that help to alleviate some of the sources of stress on relatives. The current study responds to this call. Whether this family directed model of care with separate living arrangements continues in the longer-term (if for example, a spouse remarries) is unknown. For this reason, the ability to buy private care management should continue to be considered in compensation.

8.3.5 Institutional Living was the Least Preferred Way of Living. Institutional living is the model of care least preferred by young people with disabilities.
(Moseley, 2003; Nosek, 1990; Vasey, 2000). Nonetheless, two study participants spent 10 and 13 years respectively in a nursing home. They did so because no-one had been able to secure funding for 24-hour care, which would enable them to live in their own home; that is, until a proactive and persistent case manager appeared. A way of living that had previously been considered ‘a dream’— to live alone in their own home —then became possible. However, people with brain injury were reliant on the skills, knowledge and persistence of their respective case managers to establish a more autonomous way of living outside a nursing home and separate from their family. Compensation made little or no difference to the calibre or outcomes of care management. Instead, it was the nature of the professional that made the difference. Therefore, another key finding of this study was that ways of living were very much dependent on the level of interest, experience and knowledge of individual professionals, particularly case managers.

Consistent with the literature, the present study found that institutional living offered participants little autonomy compared to other ways of living. Limited autonomy and personal freedom in nursing homes have previously been reported as concerns by other young Australians, who feel “restricted and frustrated by the inflexible routine, rules and lack of choices” (Clough, 2003, p. 1). In extreme cases of desperation, young people with disabilities such as 34-year old David Rivlin from Michigan have sought (and gained) legal permission to commit suicide because the quality of their life in a nursing home was so low (Kennedy, 1995; Longmore, 1990). Such decisions are being made in the absence of real or perceived alternatives to institutional living.

Living situations that provide opportunities for autonomy, control and independence have been identified as important by people with brain injury (McColl et al., 1998). In the current study, participants who lived alone enjoyed more personal control, increased privacy, flexibility and freedom from rules and routines. These were desirable characteristics of any new living situation, and often recognised only in hindsight. When a participant moved from a restrictive living situation such as a nursing home to one that provided more autonomy, they quickly recognised the difference.
For the two people with brain injury in the present study who had moved out of a nursing home, the decision-making process was slow. A professional was needed who would persist, harness resources and enact the necessary decisions. Moving out took approximately two years of planning and preparation. This time period is consistent with the experiences of other young people moving out of nursing homes around Australia. For example, one 40-year old woman recently moved into her own home after 16 years in a nursing home, but only after years of planning and organising by multiple service providers (Moseley, 2003). Clearly, persistence and patience are needed (in addition to adequate funding).

8.3.6 Importance of the Living Situation. Participants conceptualised their preferred way of living according to the place and people with whom they lived. When a decision was being made about a new way of living, it was the place and people living there that were the primary focus. For example, when a person with brain injury was preparing to leave hospital, the care decision-makers first considered where the person would live, and if they could return home to live with their family or not. Once these factors had been considered, attention could turn to the providers of care, and the configuration of carers. In many ways, the configuration of carers was secondary to, and fitted around, the living situation.

This study finding highlights the importance of physical place and people in defining a preferred way of living. Implications include a need to ask people with brain injury ‘where’ they would (and would not) like to live. A response to this type of question may help professional decision-makers and case managers eliminate particular living situations from a list of options.

8.3.7 Living Alone was Achievable, Desirable and Realistic. Another key finding was that more than half of the participants with brain injury lived alone at the time of interview. Upon leaving hospital, most returned to live with their families (n=12, 85.7%), and only one person lived alone with 24-hour support. A far greater proportion of the sample (n=8, 57%) lived alone at the time of interview, on average 10 years post-injury, compared to their initial discharge destination. Other international studies, although not directly comparable because of sampling differences, have reported a lower proportion of participants living alone at similar

Living alone after a severe traumatic brain injury was a remarkable achievement, considering that all participants needed 24-hour care at the time of hospital discharge. The encouraging message for people with brain injury is that more autonomous living is possible and can be achieved, often many years post-injury. Living alone is not an impossible dream. This finding, that roughly half the sample eventually lived alone, also concurs with the observations of Brzuzny and Corrigan (1996). These researchers noted that people with brain injury were more likely to live alone when they approached or were entering their 30s, and were a greater number of years post-injury.

Of those living alone, most wanted to live separately from their family after months or years of conflict. Living separately immediately after hospital discharge may be an arrangement worth considering if it helps to maintain important social relationships. Therefore, if health professionals in a hospital setting expect shared family living to be challenging or to fail, then living with family should be avoided.

8.3.8 Live-In Paid Care was not used by Participants. Study findings challenge the views of professionals who state that a ‘paid live-in housekeeper’ (Foster v. Prospect County Council, 1999, para.124) or house couple should be employed to replace family carers when a person has high care needs. The present study did not identify anyone with a brain injury who employed live-in carers (nor was any such person available for involvement in the study, over the three years that interviews were conducted). The following quote, from a care agency director, highlights the reasons why live-in carers are not recommended or used.

_You need to have a number of carers looking after them. You can’t have live-in carers for some of these people with the behaviours they have…but also their physical limitations you need more than one carer. And I send these reports to these solicitors and they just go absolutely berserk at how much it actually adds up to based on an hourly rate. They don’t understand that you can’t have live-in support…you couldn’t even have 2 people live-in. The hours are too long…the days are too long…it just doesn’t work_ (Case 6, Care Agency Director)
Participants in this study who needed 24-hour care and did not live with their families employed a team of six or seven live-out paid carers, all sharing a weekly roster. This configuration was preferred to live-in carers. It is estimated by this author that live-in care currently costs about AUD $100,000 total per year for two live-in carers on a salary. Yet study participants were paying much more, between AUD $250,000 and AUD $300,000 for 24-hour paid care on a live-out basis. These much higher total costs were incurred because live-out care was charged on a casual hourly rate by agencies, for six or seven staff, instead of employing staff on a salary.

These high salary costs are clearly not sustainable, as Bloom and Associates (1996) warned some years ago, when reviewing the cost of paid care for a similar group of people with brain and spinal cord injury. The hourly rate of pay for casual staff did not make economic sense to families in the current study, although casual staff were easier to employ initially. None of the 14 paid carers in the study was employed on an annual salary, although some had been with the same agency and the same client for years. The challenge now is encouraging care agencies, who run their businesses for profit, to change their policies and procedures.

8.4 Level of Care

Two key findings emerge from this study related to changes in the level of care. First, some participants with brain injury required less care over time, while others required more. Both groups are of interest because of implications for funding and service provision. Second, the Supervision Rating Scale (SRS), a measure of level of care and supervision, was insensitive when applied to participants with low support needs.

8.4.1 Changes in the Level of Care. Where care hours were reduced significantly, there was acceptance of and mutual tolerance for risk. This acceptance was accompanied by a major change in the way of living, orchestrated by the primary decision-maker and ‘care’ manager. Other factors that contributed to a reduction in care were lack of staff and a desire for more time alone. A reduction in care was considered desirable because of the increased opportunity for time alone, privacy
and autonomy. Just as important, particularly for those needing 24-hour care, was the reduction in care costs. Surprisingly, the high cost of care in itself was not a primary trigger for change.

A large reduction in the level of care, from 24 to 12 hours per day, occurred in one case after an independent care review. While this case presents another example of mutual risk tolerance, there was no gradual decrease in care hours to help the transition. Instead, the hours were reduced by half. A preferable strategy, and one used often by family carers, would be to gradually increase the time spent alone, between one carer leaving and the next one arriving, beginning with a period of one to two hours. This gradual decrease in the level of care would allow living skills and safety to be tested.

Where care hours were increased significantly, this change had implications for funding and service provision. Such an increase occurred primarily when participants left the family home or a nursing home to live alone. Prior to compensation, when insurance companies were meeting care costs, the hours of paid care rarely exceeded 40-hours a week. However, after compensation, three participants received 24-hour paid care for the first time. The assumption prior to compensation was that living alone with 24-hour paid care would be unsustainable for these individuals, in the absence of their family. This assumption was wrong.

8.4.2 Measurement of the Level of Care. The level of care was measured in this study in two ways, using the SRS and by calculating actual hours of care and supervision. Scores on the SRS were compared with hours of care received. The SRS was able to correctly classify participants requiring a high level of care (Levels 3 to 5), but not those requiring lower levels of care (Levels 1 and 2). Participants who received some care but were alone for much of the day and overnight, such as Lara and Keith, were misclassified on the SRS. The insensitivity of the SRS has recently been identified when SRS scores were compared with those from a new scale, the Care and Needs Scale (Tate, in press). When scores for this new scale were compared with those from the SRS, 61% of people with brain injury classified as ‘independent’ on the SRS were not, in fact, independent. More than half of this
large group (57%) needed care intermittently (35%), at least once a week (14%), or every few days (8%).

Therefore, observations in the current study about limitations of the SRS are consistent with and support the work of Tate. The Care and Needs Scale is reported to be superior to the SRS in discriminating between people with brain injury who are truly independent of others, and those who need intermittent care or prompting. The new measure, once published and validated, will more effectively measure differences in care needs and changes in care levels over time than the SRS, and will be suitable for both clinical and research purposes.

8.5 The Process of Care Decision-Making

One of the questions posed at the beginning of this study was about processes and strategies used to make care-related decisions. Participants engaged in a three-step process of care decision-making. The process was intermittent, triggered by an event or care problem, and used to achieve the best possible living situation, configuration of carers, level of care and, ultimately, greater autonomy for a person with brain injury.

The process of care decision-making in this context was consistent with the steps and criteria described by Janis and Mann (1977), and included seeking and gathering information, appraising alternatives for risks and benefits, then enacting a decision. However, one major difference was that participants finished each step prematurely, with implications for quality. For example, participants did not conduct a second round of searching for new information when looking for ideas and alternatives. Nor did they re-examine the benefits and risks, the positive and negative consequences of each alternative.

This self-limiting behaviour is consistent with Simon’s concept of ‘bounded rationality’ (Simon, 1976) where problems and the decision-making process are simplified in times of stress to compensate for information overload. Rather than seeking the best possible solution, decision-makers simplify choices and look for a course of action that is ‘good enough’. They set boundaries on the time, effort and
resources to be invested in a decision, and may not be aware that they have overlooked alternatives. Similarly, in another study of women’s decision-making during a personal health crisis, Reaby (1996) found that participants limited their search for, and processing of information, when in a state of extreme stress, anxiety and cognitive overload.

8.5.1 Gathering Information. In the present study, family carers experienced stress and cognitive overload and had little time to follow up on information after long days at the hospital. They consulted and relied on information provided by professionals. Carers who did seek information independently in the early days were rare. However, family carers had a reasonably long period of time to make decisions during hospitalisation. They spent many months thinking about the time when their relative would leave hospital. This time could be used more productively, to enhance the quality of early care decisions and coach family carers for future decision-making.

8.5.2 Assisted Decision-Making. Assisted decision-making is a specialised process that may benefit family carers and people with brain injury. A number of assisted decision-making strategies were described earlier in Chapter 2, including informal decision-analysis (Owens et al., 1987), the use of decision-making aids (Lewis et al., 1999) and manuals that present the benefits and risks of different lifestyle alternatives (Brain Injury Association of NSW, 1998). Despite the cost of developing and publishing these resources, none appear to have been used by participants in this study. Health professionals would benefit from acquainting themselves with and using some of these resources in practice. These resources and strategies have the potential to help people with brain injury and their family to participate more fully in care decision-making and to be better informed about alternatives, particularly in the early stages post-injury.

8.5.3 Consulting Experts. Another finding of this study was that, while most spouses and parents talked to other carers in hospital, none talked to more experienced carers or people with brain injury in the community. Information about alternative ways of living, possible consequences, risk and benefits should be presented by experienced family carers and people with brain injury and not just by
professionals. Family carers need to know that living alone is an achievable goal. They need hope for the future. This hope is more likely to come from people with first-hand experience who are the ‘real’ experts on care management.

As family carers and health professionals gained experience of care decision-making in the community and became more willing to tolerate risk, their information gathering abilities increased. They spent more time seeking information, looking for alternatives and consulted more widely than before. For example, over time family carers used case managers more as a source of information. With the benefit of experience, decision-makers also recognised that some expert sources were more expensive or biased than others, or had a conflict of interest, such as care agencies. They learned to treat these sources with caution. These changes in skill and knowledge over time are consistent with other experienced decision-makers (Janis & Mann, 1977). As the topic and focus of decisions becomes more familiar, the process becomes less stressful and more of the criteria for quality decision-making become evident. The outcome of these decisions is likely to be superior with the benefit of experience and knowledge.

8.5.4 The Role of People with Brain Injury. The focus of this study, and of care decisions, was the person with brain injury. Despite their centrality to the process, one of the most striking observations in this study was their limited involvement in care decision-making. Although they often triggered the care decision-making process, participants with brain injury relied consistently on family carers to assume the role of primary decision-maker. Furthermore, in four of the 14 cases there was a shift in primary decision-maker role from family to professionals following a breakdown in parent-child relationships.

This limited involvement of people with brain injury reflects the complexity of decision-making. Some participants had difficulty retaining an idea, formulating a plan with steps, and engaging in problem-solving. Difficulty with decision-making and problem-solving is consistent with a very severe brain injury (Mateer & Sohlberg, 2003; Sloan & Ponsford, 1995; Stuss, Winocur, & Robertson, 1999). These difficulties are recognised by the courts and typically result in a recommendation that substitute decision-making be instituted (Foster v Prospect
County Council, 1999; Jones v Bradley, 2003; Joyce v Geelan, 2001). This need for help with decision-making, whether shared, assisted or substituted, continued for all participants regardless of time post-injury.

All participants with brain injury, including those in the high functioning group, engaged in shared or assisted decision-making some of the time, particularly for financial decision-making and management. This finding suggests a hierarchy of decisions, with financial management at the top. Financial management is a highly complex skill, particularly when it involves managing a lump sum from compensation. The need for assistance with financial decisions is consistent with the use of the OPC by the majority of participants. Nonetheless, even when the OPC was involved, family carers still engaged in shared or assisted decision-making.

8.5.5 The Role of Family Carers and Case Managers. One important difference between this and other studies was the relatively small number of family carers who acted as primary carer and decision-maker at the time of interview. Consistent with previous studies (Man, 2002; Nabors et al., 2002; Ponsford et al., 2003), a female family member was typically the primary carer at the time of hospital discharge (n=10, 71.4%); however, this proportion had dropped to 42.8% (n=6) by the time of interview. The four family members who ceased being primary carer and decision-maker were mothers, and in three cases the person with brain injury had initiated this change. When this change occurred, the role shifted from a family member to a paid professional, typically a case manager. The involvement of private case managers as primary care decision-maker in five of the 14 cases (35.7%) is an important finding, with implications for compensation settlement, funding and provision of services.

8.5.6 The Role of Estate Managers at the OPC. In addition to using private case management services, most people with brain injury in the study were linked to the OPC and, to a lesser extent, to the Office of the Public Guardian (OPG). Most financial, and some personal decisions, were supervised by an estate manager at the OPC, often in conjunction with a family carer. This arrangement was typically determined at the time of compensation. Involvement of the OPC in long-term care
decision-making is well established in Australia. In addition to monitoring a person’s quality of life, the OPC describes its role as that of ‘substitute’ decision-making in financial matters, for people with decision-making disabilities (OPC, undated). However, estate managers at the OPC, referred to in the present study, engaged more in shared or assisted financial decision-making, than substitute decision-making. They always tried to involve the person with brain injury to some degree in major decision-making for example, by inviting them to meetings with family members and/or health professionals.

The majority of participants agreed with the need for external safeguards such as the OPC to monitor their finances and well-being. However, consistent with previous reviews of the OPC (Brain Injury Association of NSW, 2000), several people complained about the process of fund management and what felt like excessive gatekeeping. They lamented the number of barriers to be overcome when accessing funds through the OPC for example, when buying Christmas presents or going on holiday.

At the crux of these complaints about the OPC was loss of freedom to spend money at will. The very reason for shared or assisted decision-making following brain injury — to curb impulsive spending — was also what angered people with brain injury and their families. Nonetheless, in one instance where a participant had ‘avoided’ management of his finances by the OPC, serious financial consequences resulted. He lost thousands of dollars when a new ‘friend’ accessed his bank account. This participant was also being pursued by debt collectors at the time of interview after purchasing an expensive home computer that he could not afford. Clearly the gatekeeping and monitoring role of the OPC is important in preventing impulsive spending, financial abuse and major debts.

In short, there are serious potential consequences for some people with brain injury if the OPC is not involved in financial decision-making. The majority of participants recognised a need for this service. This finding, that participants mostly wanted involvement of the OPC, needs to be shared with health and legal professionals who advise people with brain injury on such matters when they receive compensation. Hospital-based professionals, in particular, need a greater
understanding of the potential negative consequences of bypassing the OPC, since they do not have contact with the person after they leave hospital.

Another finding was that staff at the OPC had unique experience and knowledge to share with professionals and family carers. In particular, they had experience of different models of care that involved economising and cutting back on care costs. Cost containment strategies included by-passing care agencies, encouraging self-employment of paid carers and changing the pay conditions of paid carers. As a result of their broad community experience, these professionals also appeared to have a higher tolerance for risk than other professionals, an attribute that others could learn.

8.6 The Process of Care Maintenance

A primary aim of this study was to examine the processes and strategies used during care decision-making. However, it was care maintenance, not care decision-making, that emerged as the important process for maintaining a stable way of living, averting care crises and generally optimising care.

8.6.1 Preventative Strategies. Paid support and maintenance are recognised as important facets of community care, enabling people with disabilities to remain at home (Donnelly, Kelly, Stewart, & Armstrong, 1995). In the current study, care maintenance was used to prevent minor problems from becoming major ones. This preventative aim, and associated tasks and strategies, are consistent with family caregiving work described by Bowers (1987) and Corcoran (1994). Strategies such as monitoring a person’s health status and questioning the person about symptoms and medications are part of the work performed by family carers (Bowers, 1987). These strategies are similar to monitoring, checking others, and looking for signs in the present study.

In another study by Corcoran (1994), spouse carers of people with Alzheimer’s disease consulted their general practitioner regularly for advice, aimed to provide good nutrition, and kept the older person active throughout the day. In that study,
family carers used these strategies to help minimise existing health problems, prevent new ones from developing, and reduce the risk of physical injury to the cognitively impaired older person.

8.6.2 Roles and Responsibilities of Paid Carers. The present study highlights some of the unique roles and responsibilities of paid carers in terms of their day-to-day work. Unlike most family members, paid carers did not live with and did not have an extended relationship with the person with brain injury prior to employment. Yet they still monitored the quality of care, engaged in negotiation, mediation and conflict management, and supported other carers. The roles of attendant, protector, friend, coach and negotiator have previously been attributed to paid carers who work with this unique population (McCluskey, 2000), along with a number of associated strategies, skills and knowledge. Furthermore, the recently developed ‘Brain Injury Specific Support Worker Competencies’ (Motor Accidents Authority of NSW, 2003) state that paid carers working in this field are expected to be able to manage “relationship issues …emotional crises…cognitive impulsivity…and situations which pose a risk” (p. 12). The current study extends what is known about the knowledge, skills and attitudes required by paid carers by adding conflict management, mediation and counselling skills to the list.

Unfortunately, employing agencies were not always meeting their responsibilities to staff or the client. Recognising this problem, the Motor Accidents Authority of NSW has recently produced a consensus document on staff competencies which also outlines the responsibilities of an employing care agency.

Service providers are responsible for ensuring the skills of staff employed as support workers are assessed on initial employment, appropriate training is provided and their ongoing performance is regularly re-assessed (Motor Accidents Authority of NSW, 2003, p. 8).

Whether this document is having, or will have, any impact on the care industry remains to be seen.

8.6.3 The Importance of Maintaining Social Relationships. Consistent with the theory of symbolic interactionism (Blumer, 1969), maintaining social relationships...
was an important part of care maintenance work, as indicated by strategies such as managing conflict and mediating between the person with brain injury and others, supporting carers and being there to counsel, advise and assist carers. Because relationship breakdown was common after brain injury, participants engaged in troubleshooting to help maintain important family relationships.

McColl and colleagues (1998) suggested that healthy relationships are an important part of successful community integration after brain injury. They also suggested that ongoing conflict between a person with brain injury and their family may need to be resolved before future plans can be pursued. This suggestion, that family conflict may limit community integration and an individual’s personal development, is consistent with findings of the current study. Until relationships were resolved (typically by living separately), the person’s way of living remained problematic.

### 8.7 Conditions that Influenced Care Optimisation

Another question posed at the beginning of this study related to conditions that influenced care decision-making and care management. Two conditions, mutual risk tolerance and the presence of a ‘care’ manager, positively influenced these processes and resulted in optimal care within a preferred way of living. When these conditions were absent, neither care nor the way of living was optimised.

#### 8.7.1 Mutual Risk Tolerance

People with brain injury who achieved the most autonomous way of living were those who took risks. Risks could be large or small, and were physical, emotional, financial, sexual and social in nature. The presence of risk distinguished these individuals from others. To take risks, they needed people in their network who accepted, tolerated and even encouraged risks. Differences in outcome were not related to level of disability. Participants with brain injury in the high functioning group, like other participants, had significant cognitive and behavioural problems at the time of their hospital post-discharge, based on family and professionals’ reports.
8.7.1.1 Overcoming Risk Aversion. Risk aversion is a natural response from family
carers and professionals when working with people who have sustained their
injuries engaging in, or as the result of, another person’s risk-taking behaviour. A
natural tendency is to protect the person from further risk. Furthermore, risk
aversion is intrinsic within our health and welfare system, partly because of fear of
litigation. However, in a study of health professionals working with at-risk elders
in a hospital setting, different thresholds for risk tolerance were reported depending
on professional socialisation, level of education and experience, fear of liability and
concern for cost containment (Clemens & Hayes, 1997). In that study, a concern
for safety was more important to some professionals than a concern for their client’s
autonomy.

Risk aversion can be managed by gradual, planned risk-taking. Risk should not
occur by chance or opportunity, as occurred in this study. Durgin (2000) has
previously identified a number of strategies that professionals and families can use
to increase risk-taking. These strategies include: setting measurable goals,
identifying barriers and concerns, determining the number of simulated and field
trials required for graduated risk-taking, implementing, then evaluating a program
where standby or distant supervision might be all that is needed. Unfortunately the
examples provided by Durgin were very basic, such as using a baby doll to practice
bathing a young child (although this strategy does reflect common rehabilitation
practice). However, the current study offers an array of interesting and creative
ways of introducing graduated risk.

Participants with brain injury in the current study needed an opportunity to develop
skills through practice, and to learn from their mistakes. They needed time alone to
test their skills without close supervision. Rehabilitation professionals are familiar
with these tensions, however, the current study indicates that risk aversion can be
overcome.

8.7.1.2 Education about Risk Management. Education about pro-active risk
management is clearly needed for less experienced professionals, paid carers and
care agency directors, particularly those with limited community experience.
Education might include the concept of risk tolerance, the various types of risk,
minor versus major risks, and the properties and dimensions of risks as identified through this research. Examples are required from experienced participants such as family carers and people with brain injury to illustrate how risk can be gradually increased, how they test and monitor skills and gradually increase safety. Professionals and others are likely to be particularly interested in a hierarchy of risks, ways of introducing checks and balances such as daily phone calls, visits and the like. Professionals can also consider using informal decision-analysis or decision aids when engaged in group decision-making about risks and risk management. However, the biggest challenge will be changing attitudes to risk.

8.7.1.3 *The Risk Management Team*. An important finding of this study was the apparent shared responsibility for risk management by three or more people. This group typically included a person with brain injury, a family carer, agency manager or paid carer. Between them the group planned, shared and assumed responsibility for increasing risk and decreasing care. Alone, professionals found such decisions difficult because of risk aversion and concern about their duty of care. Alone, family carers were limited by the system, which was often unable to provide the necessary back-up and support during the transition period. Alone, the person with brain injury was also held back by others who were averse to risk. However, together a shared tolerance for risk enabled the person with brain injury to move forward.

This risk management team was group decision-making at its best. Information was gathered systematically, alternatives were carefully appraised on more than one occasion for risks and benefits, contingencies were planned, and considerable time was taken over enactment of a decision. Concurrently, there was reflection on the outcomes and an adjustment of expectations. This study contributes important new knowledge about the features of successful risk-taking, risk minimisation and risk management in relation to people with brain injury.

8.7.1.4 *Risk equalled Time Alone without Supervision*. In an earlier study by McColl and colleagues (1998), people with brain injury identified staff supervision as a hindrance to independent living and community integration. Living independently was associated with freedom from supervision. In the current study,
several participants wanted time alone without supervision, and permission to take risks, consistent with the findings of McColl et al., (1998). Too much supervision can undermine a person’s desire for more autonomy, and take away opportunities for low-level risk-taking that other citizens’ enjoy. This balance of autonomy and interdependence versus safety and risk is precarious but important for optimising care within a person’s preferred way of living.

8.7.1.5 A Provisional Hierarchy of Risks. Finally, a provisional hierarchy of risks for people with a severe brain injury, based on the current study, places financial risk at the top, with sexual risk second. This hierarchy may or may not be similar for people with bipolar disorder, people with dementia, or intellectual disabilities, since all face challenges because of impaired judgement due to cognitive and behavioural problems, and difficult with decision-making. This is a fruitful area for future research.

In summary, mutual risk tolerance was one of two conditions necessary for care optimisation within a preferred way of living. Some individuals already had a high tolerance for risk, while others gained experience and an increased tolerance over several years. The single Estate Manager from the OPC who was interviewed appeared to have a particularly high tolerance for risk because of her broad experience over many years. When a person with brain injury engaged in graduated risk-taking, this was generally negotiated by and with the care team, which collectively shared the responsibility.

8.7.2 ‘Care’ Management versus Case Management.

Participants in the current study engaged in care decision-making and care maintenance, a process collectively referred to as ‘care’ management. No Australian literature was identified that referred specifically to ‘care’ managers in relation to people with brain injury. In other contexts, ‘care’ managers are health professionals who support the rights and interests of a person with disability, who assist new carers with their role transition, and generally position themselves as a source of support (Moore et al., 2000).
In Australia, the concept of a ‘case’ manager remains dominant, with care management as a sub-component of this work. A case manager is a health professional who coordinates and manages care as part of their overall role. They engage in “planning and organizing day to day activities” (Curry v ACI Operations, 2001), “oversee and coordinate…maintenance programs and...ensure that everything possible is done to maximise…quality of life, independence and assimilation into the community” (Fitzgerald v Dansey, 2001).

The current study provides a range of examples of care decision-making and care maintenance work conducted by case managers. Such examples will be informative for medicolegal professionals who wish to make recommendations about future care based on research data.

8.7.2.1 People with Brain Injury needed Face-To-Face Visits. Long-term case management, although common during rehabilitation, has only recently been added into compensation claims as a head of damages. Unlike the United States, there are no graduate certificates or textbooks on case management or care management in Australia (Weed, 1999), nor is there universal acceptance in this country of the need for long-term case management. Variations in opinion about the need for long-term case management lead to inconsistencies in judgements when compensation is being determined.

For example, in one recent case, a judge approved two hours of case management a month for life (Aoun v. GIO, 2001) in addition to a daily paid care and regular fund management, while another judge rejected case management outright on the basis that “…once the plaintiff’s…care was set up…the need for supervision…would become…nominal and capable of being monitored…by telephone calls rather than visits” (Fitzgerald v. Dansey, 2001, para 72). The assumption of this latter judge was that care maintenance, including monitoring of care, could be done by telephone. This assumption was wrong. All participants with brain injury needed regular visits to monitor their health and wellbeing, and to check on care relationships.
Health and legal professionals in Australia face a major challenge convincing judges of the need for long-term case management. The present study will go some way to correcting this misinformation, by providing empirical data on the importance and need for long-term case management following brain injury.

8.8 **Increased Autonomy: The Consequence of Successful Care Management**

The last major finding of this study was the increased opportunity for autonomy and self-rule as a consequence of effective care decision-making and management, and tolerance for risk. Increased autonomy was the desired consequence of optimising care within a preferred way of living. Autonomy literally means ‘self-rule’, from the Greek ‘auto’ for self and ‘nomos’ for rule (Dworkin, 1988, p.12). In this context, autonomy referred to control over plans, actions and routines, opportunities to perform activities alone, to enjoy privacy and freedom from constant supervision.

Participants who lived alone with low support enjoyed autonomy and freedom from the influence of family, paid carers and professionals for part of their week. One participant compared shopping alone for the first time with how it must feel getting out of jail. On the contrary, participants who lived alone with 24-hour care or in a nursing home had less control and self-rule over their daily routine. They had little privacy and no time alone without supervision.

8.8.1 *Autonomy Defined.* Autonomy is a widely used term that has several meanings. When used by adults, particularly teenagers and adolescents, autonomy has come to mean the right to privacy, and to control one’s own decisions, routines and finances. Traditionally, autonomy in this context has referred to freedom from the influence of parents and has been synonymous with financial independence and living independently (Fasick, 1984; Irwin & Vaughan, 1988). However, in recent years many adolescents have continued to live in the family home while studying and remaining financially dependent on their parents. As a consequence, the meaning of autonomy has changed. Autonomy for many adults now means the right to have private space in the home, to make independent decisions and to come
and go at will (Fasick, 1984; Irwin & Vaughan, 1988). This meaning is consistent with what people with brain injury and their families were seeking.

8.8.2 Enhancing Autonomy Competency. The concept of autonomy competency has come to mean the development of skills for directing and controlling one’s life (Meyers, 1989). These skills include the ability to be self-referential (to recognise one’s response to a situation), self-directing (to direct one’s own life), self-defining (to know oneself), self-discovering (to be introspective and reflective), and having a self-portrait (or a self-concept). Development of these skills and autonomy competency require a person to reflect on what they value and care about in life, and to pursue these ideals as they reflect on and carry out their life plan. This psychological independence can lead to self-realisation, where a person takes control of their life, chooses among options what life to live and what risks to take (Cardol et al., 2002). By implication, this means that professionals and family carers need to take a step back.

Individuals with cognitive impairment will typically have a restricted ability to think about, direct and control their own life plans. Most of the participants with brain injury in the study needed help to plan and direct their life. Several were unable to plan five years ahead when asked what they might be doing then. However, autonomy competency can be enhanced with coaching and practice. One or two ‘care’ managers in the present study did actively encourage and try to develop autonomy competency. One participant provided information to the person with brain injury about buying a new home, guided her through the stage of collecting information from newspapers and real estate agents, helped her identify risks and benefits and then assisted her to make and enact a decision. This was an example of shared decision-making and empowerment, helping the person with brain injury to plan and take control of her own future.

8.8.3 Autonomy: More Important than Independence. The over-emphasis on independence as a primary goal of rehabilitation has been discussed recently in allied health literature (Cardol et al., 2002). The primary goal in most rehabilitation units is to acquire independent mobility and living skills, since these skills will facilitate discharge from hospital. Consequently, most outcome measures focus on
quantifying independence (and an equivalent number focus on the negative domain of dependence). ‘Independence’ has almost become synonymous with improved quality of life.

However, most individuals in society are not independent but interdependent. We rely on others for emotional support, social interaction and practical assistance. People with a disability are no different. Although they may have limited social contact and few friends, people with brain injury contribute much in the way of social interaction, humour, and intellectual discussion to their family, paid carers and others. Reciprocity and interdependence between people with disabilities and their carers have been identified as important outcomes of caregiving (Grenot-Scheyer, Staub, Peck, & Schwartz, 1998; McCluskey, 2000; Rosenblum, 1998; Russell, 1994; Wilson, Morse, & Penrod, 1998). Care involves an exchange. One person gives care and assistance, while the other receives it. There are many positive outcomes of relationships between paid carers and their clients, such as reciprocity and interdependence.

Therefore, a recommendation of this study is that the primary goal of brain injury rehabilitation, of professionals in the community and family carers might be better described as striving for autonomy and interdependence, than for independence. There is a need to help professionals better understand and aim for these concepts through their interventions. One strategy for increasing understanding is to introduce outcome measures that reflect the concepts of autonomy and interdependence instead of dependence or independence. The Community Integration Measure (CIM) is an example of a client-centred measure that reflects these concepts (McColl et al., 2001). Following a research project in Canada, the concepts of autonomy and interdependence were identified as components of successful community integration by people with brain injury and included in the CIM (McColl et al., 1998). Community integration encompassed nine categories, such as having close and diffuse relationships, living in a place that encourages autonomy and not having to ask permission before doing something. The introduction and routine use of the CIM in community-based rehabilitation programs may help to focus attention more on these important client-centred outcomes.
8.9 Limitations of the Study

This study was designed to explore, interpret, describe and develop a substantive theory that would help to explain care decision-making and care management after brain injury. These goals have been achieved, with a necessarily limited sample. The resulting theory of care management provides a practical framework to guide professionals, family carers and service providers in the field. The theory is ready for further testing and development beyond the state of NSW, and Australia, and perhaps with other disability groups. Consistent with grounded theory principles, no claims are made about the generalisability of findings.

Although a number of methods were used to check the fit of the emerging theory, it was not possible to truly reach the point of ‘saturation’, a goal of grounded theorists (Glaser & Strauss, 1967; Dey, 1999). Saturation implies that new concepts are not appearing in subsequent interviews, and new participants either confirm or add to the density of a theory but not new concepts (Murphy et al., 1998). In the current study, data collection ceased after two years and recruitment of the fourteenth case for pragmatic reasons. First, the study sample was already large for a qualitative study, with 51 participants. Second, there were few new recruitment opportunities. Third, analysis was already proving very challenging because of the many different voices coming through in the data (people with brain injury, family carers, paid carers and so forth), and the different ways of living. For the same reasons, only one interview was conducted with the majority of participants.

Nonetheless, a core category was identified that: explained variations in behaviour; identified similarities and differences across and between cases; accounted for the majority of cases; and described a social problem and a process for managing that problem. These are desirable features of a substantive grounded theory (Creswell, 1998; Dey, 1999).

Another limitation of the study was that no data were available on participants’ levels of disability, handicap or functioning at the time they left hospital. However, a substantial amount of quantitative data was collected and analysed to enable a comparison of participant characteristics to be made at the time of interview.
Initial concerns about the nature and limitations of data collected from people with brain injury were unwarranted, because these participants’ stories were so poignant. By posting out a background demographics data collection sheet (see Appendix B-3), and reviewing this prior to interview, the potential problems of forgetfulness, amnesia and perseveration could be easily managed. If a participant could not recall their care arrangements or level of care received, this information could be found on the written information sheet, thereby removing the need to include a third party in the interview.

Finally, noticeably absent from the study were Australians from different cultures and non-English speaking backgrounds, and people of Aboriginal and Torres Strait Islander descent. This absence was one of the reasons why Western or Anglo-Saxon pseudonyms were chosen for the participants with brain injury. It is anticipated that people from other cultures will have different understandings of brain injury, the rehabilitation process and long-term care, and, like the current sample, different responses to risk.

Before proceeding to study conclusions, the implications of findings for practice and policy, education, and future research will be presented.

8.10 Implications for Practice and Policy

The findings of this study have implications for the practice of health and legal professionals, for industry and for policy.

(a) Health professionals, particularly those who consider themselves experts in brain injury rehabilitation, need to become better informed about the ways of living with care after brain injury beyond living with family. These professionals in turn will be better able to inform family carers and people with brain injury about the options. The current research provides examples of different ways of living that could potentially form a ‘showcase’ of care and accommodation options, such as that proposed by Moore and colleagues (2000).
(b) Health professionals could greatly improve the quality of initial care decision-making with families in hospital if decision aids were used. Decision-aids could be used in conjunction with a showcase of options, with information repeated and presented in different ways. Family carers spend many weeks, often months, in hospital visiting the person with brain injury. Some of this time could be used exploring different ways of living, beyond the person living with their family or moving to an institution. If these strategies were introduced, they would require formal evaluation to determine effectiveness and the impact on family carers. Another clear message from this study was the need to involve people with brain injury more at all levels of decision-making, in an assisted or shared manner.

(c) Health professionals could and should invite family carers and people with brain injury to act as consultants to other families, particularly during the initial phase of care decision-making. These people have a wealth of experience and knowledge to share, but are not currently being used as a resource. A brief report on the study findings in the Brain Injury Association of NSW newsletter may help to stimulate letters from consumers, generate a list of ‘volunteers’ and start a dialogue based on experiences. Once again, if such strategies were introduced, the process and outcomes would require formal evaluation to determine the impact on family carers, their ongoing training and support needs, and the effectiveness of using family carers in this new role.

(d) More consideration should be given to people with brain injury living alone when they leave hospital, with a greater proportion of care being provided on a paid basis when funding permits. Such an arrangement, with family visiting and living nearby, will help to limit family conflict and stressful relationship breakdowns, which was so common in this study. Instead of family carers providing three quarters of their relative’s care, and paid carers providing one quarter, this configuration should be reversed. If a person with brain injury can be supported to live separately from their family, with 24-hour paid care around the time of hospital discharge, this arrangement may prove to be a good investment in the longer term for insurance companies and society. Such an arrangement may reduce family conflict and keep more families together. Currently, this way of living and providing care is the exception rather than the rule.
(e) Health and legal professionals need to recognise and respect the need of families for privacy and time alone after months in hospital. In some cases, placing paid carers in a household may do more harm than good, if they become another source of stress to family carers and people with brain injury. Although paid care can help families a great deal, the majority of paid carers in this study were inexperienced, afraid of the person with brain injury and required a large amount of support to function in their role.

(f) No-one in the study used live-in care, even those people with brain injury who received 24-hour paid care. The significance of this finding is that live-in carers and house couples should not be recommended routinely by health and legal professionals as the best way for people with brain injury to live. Live-out care should be recommended in preference, so that compensation funding matches the reality of long-term care costs.

(g) In several cases, families quickly exhausted all the possible care agencies and potential carers because of challenging behaviour, inexperienced staff and lack of agency support. Thus, even if more funds had been provided for paid care, these families would not have been able to locate the necessary personnel to meet the need for 24-hour care. There is, therefore, a problem meeting the need for paid care services. This need appeared to be greater in rural areas, where there is a limited supply of local workers.

(h) For care agencies, the main message coming from care users and family carers in this study was an urgent need for better quality control, accountability and value for money. There were many complaints about care agencies. Legislation may be required to force agencies to change their employment practices and employ more staff on fixed-term contracts or permanently, instead of on an ongoing casual basis in order to reduce costs if nothing else.

While a system of voluntary accreditation of care agencies operates in NSW, this does not appear to have improved the quality of care services since 1996, when similar problems were reported (Bloom & Associates, 1996). There are no signs
that the industry is planning to engage in self-regulation. Perhaps a lesson can be learned from the area of vocational rehabilitation and injury management, where providers must be accredited by a government body such as WorkCover in order to operate. Accreditation requires the provider to comply with guidelines on documentation and report writing, staff training, costing, and more recently, guidelines on evidence-based practice (Workcover Authority of NSW, 2003).

(i) A further implication for health professionals is a need to keep young (and older) people with brain injury out of institutions. Young people with brain injury were still being placed inappropriately in institutions because other ways of living offered too many challenges and risks. Once a person with brain injury moved into an institution, opportunities to move out were rare. Those who wanted to live alone in the community were dependent on the level of interest, experience, knowledge and persistence of individual case managers. Furthermore, a move from nursing home to the community required extensive planning and harnessing of resources over a period of two to three years.

(j) The current study identified a clear need for ongoing case management, for professionals who will manage long-term care as part of their role, and who will coordinate care decision-making when required. This person or persons could be a professional or family carer. In the absence of a case manager, people with brain injury remained at home in conflict with their parents, or in nursing homes for many years, unaware of possible alternatives. This finding has implications for compensation settlements, and is reflected in a small number of recent court cases. However, this need is not reflected consistently in cases reported from the NSW Supreme Court.

(k) Participants’ experiences of working with the Office of the Protective Commissioner (OPC) were generally positive. The OPC performs an important role in preventing major financial mismanagement and potential abuse, and should continue to be recommended in appropriate cases. Financial management was the highest level skill that people with brain injury sought help with. All participants with brain injury in the sample received help with money management and financial planning. Furthermore, the Estate Manager from the OPC who was interviewed had
valuable experience managing long-term care. Although some Estate Managers will be more experienced than others, these professionals should be consulted more for advice on care alternatives, particularly self-employment and consumer-direction of paid carers.

(l) This study highlights a need to accept, and even welcome risk as a precursor to increased autonomy and a better way of living. Graduated risk needs to be integrated into rehabilitation on an ongoing basis. A recent discussion paper has already addressed this issue (Durgin, 2000), suggesting ways of structuring support for at-risk individuals who want more autonomy. However, as with the use of decision aids, this type of intervention does not appear to have been implemented, nor evaluated for effectiveness.

(m) Professionals and family carers may find the concept of risk easier to manage if decisions about risk-taking are made collectively. The current study highlights the importance of a shared responsibility for risk, which has the potential to relieve some of anxiety facing professionals about their duty of care.

(n) Autonomy and interdependence, not just independence, are concepts that need greater consideration by health professionals. To this end, autonomy and interdependence should be reflected in outcome measures used by community-based professionals. One such measure is the Community Integration Measure or CIM (McColl et al., 2001). It would be beneficial to people with brain injury if such a measure was used more in practice, as the measure may help to focus clinicians’ attention more on autonomy as a desirable outcome. Furthermore, use of measures like the CIM as a research tool, and presentation of outcome data will encourage professionals to reflect on how they prioritise their time with clients, in terms of intervention.

(o) The Care and Needs Scale (CANS) once published and validated (Tate, in press) will more effectively measure differences in care needs, and changes in care levels over time than the SRS. This new measure will be suitable for both clinical and research purposes.
8.11 Implications for Education

Implications for education are closely related to practice. For example, changes in behaviour and practice, such as the introduction of decision aids and risk management programs to rehabilitation units will necessarily involve education and will not explicitly be discussed here.

First, the study identified specialised skills, attitudes and knowledge required by case managers who provide long-term care management as part of their service repertoire. As a first step, publication of current findings and the experiences of case managers who work in brain injury rehabilitation will help to inform practice, for example through the Case Management Society of Australia newsletter and website. While there are specialised graduate courses and certificates in life care planning and case management in the United States that focus on determining the needs of severely injured clients, Australia does not offer anything similar for professionals. It is likely that ‘care’ management will continue to be a sub-component of the work of traditional case managers in this country.

The second major implication of this study for education is the need to share findings with those who make important decisions about long-term care and compensation. This group includes legal professionals, insurance personnel, and health professionals who write medicolegal reports that include recommendations for future care. Discussions have also commenced between myself and policy writers in Australia (Walsh et al., 2002; Walsh, 2003) relating to preferred ways of living for people with long-term care needs, in the event that the Australia compensation system changes (as is expected in the near future).

8.12 Implications for Future Research

There are many possible areas for future research that have arisen during the study. The most obvious need is to test and further develop the theory with a similar population in another state or country. The related concepts of mutual risk tolerance and autonomy could also be tested quantitatively using a predictive model. Professionals (and the courts) would benefit from knowing who is likely to
achieve early increased autonomy and reduced levels of care, and who is not.
Further development and evaluation of a hierarchy of risks, and a graduated risk
management program for people with brain injury would be a valuable contribution
to community-based rehabilitation and research.

8.13 Conclusions

This study used grounded theory methodology to explore care decision-making and
care management after brain injury. The study was guided by three questions,
which enquired about (i) preferred models of care, (ii) the processes and strategies
involved, and (iii) the conditions influencing care decision-making and care
management.

Study findings highlight the need for models of care that acknowledge the need for,
and provide opportunities for increased risk and autonomy. Participants often took
many years to find their preferred way of living with care, through repeated
episodes of care decision-making and crises. The process of optimising care was
difficult for all concerned. The current study suggests a number of ways to
minimise these difficulties through improved education and practice, and by
consulting experienced family carers and people with brain injury as the experts
during early care decision-making. Ways of involving the affected person with
brain injury in care decision-making should also be a priority for professionals,
regardless of the person’s level of cognitive impairment.

The failure of compensation to meet the cost of care, particularly 24-hour paid care
was reported many times in this study. This underfunding of long-term care (and
case management) was compounded by agencies that used an expensive model of
care costing and provided inexperienced carers. There is an urgent need for better
regulation of, and accountability by, the paid care industry in Australia. Without
some form of government legislation or industry self-regulation, these problems
will continue to the detriment of people with severe disabilities.
Increased autonomy was a desired outcome for participants with brain injury in this study. While not everyone will want to live alone, living separately from family often proved to be the most stable way of living, with increased autonomy as an unexpected outcome.

Living alone and spending time alone were, however, also associated with increased risk. Unfortunately, most professionals are socialised to limit risk. Family carers are also understandably protective of relatives who may have sustained their injuries engaging in risk-taking behaviour. A series of strategies and processes are suggested for professionals and family carers to use, in order to gradually increase risk, share responsibility for risk management and establish a safety net for the person with brain injury.

If four very severely injured people were able to live alone and enjoy greater personal control, autonomy and privacy, with more flexible but less intrusive care, this way of living should be the goal for all people with brain injury. I leave the reader with a quote from Lara, who was still hoping for more autonomy:

* Can you imagine being stuck with someone who you really don’t like...for 12 hours a day...ALL day, every day? You’d go mad...*(Lara, Case 2).

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Appendices


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Appendices Page 231