UNIVERSITY OF WESTERN SYDNEY
School of Exercise and Health Sciences

Final Report

Care Decision-Making and Care Management after Traumatic Brain Injury

by
Annie McCluskey
February 2004

A project funded by the Motor Accidents Authority of NSW 2000-2002
Care Decision-Making and Care Management after Traumatic Brain Injury

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- The 51 participants who gave their time, and shared their experiences so openly and honestly. I hope their stories and concerns have been interpreted accurately in this report.

Annie McCluskey

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Preface

Interest in this study arose from my involvement as an occupational therapist with people who had sustained a traumatic brain injury. Initially I worked in the community for the Lidcombe Head Injury Service in Sydney, Australia, visiting people at home who had sustained a brain injury. In private practice, my work also involved home visiting and writing medicolegal reports about the current and future needs of people with brain injury. Later, I would be required to defend these opinions in court as an expert witness.

Over the years, I noticed a marked difference in the nature and level of care received by people with brain injury, according to their circumstances. Regardless of compensation received, the nature of care did not always match the level of disability, nor the perceived needs of individuals. Furthermore, despite the recommendations of health and legal professionals prior to compensation that some individuals should employ a ‘live-in house couple’ to provide 24-hour care, I had never met a person with brain injury who used this configuration. There was a mismatch between recommendations and the reality of care in the community. These inconsistencies and questions led to the current research project being conducted.

This research, involving 14 people with brain injury and another 37 people associated with their care management, reveals a number of different expectations and beliefs about long-term care across stakeholder groups. Health professionals view the benefits and risks of care, particularly paid care, differently from people with brain injury and their families. Some professionals – particularly those with years of experience – and experienced family carers, are able to tolerate and share a higher level of risk than others. This tolerance is a positive characteristic, resulting in reduced levels of care, reduced cost, and most importantly, greater autonomy for a person with brain injury.

Completion of this study coincides with the development of guidelines for assessing the care needs of people with brain injury (a work in progress), and publication of competency standards for attendant carers¹. The Motor Accidents Authority of NSW has commissioned these important projects. I hope that those two projects and the current study will help to better inform health professionals, insurers and service providers who make recommendations about future care. I also hope that these same individuals and organisations will view the needs of people with brain injury and their families differently as a result of reading this report.

Annie McCluskey
February 2004

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EXECUTIVE SUMMARY

The Research Problem

No studies to date have investigated how people with brain injury and their families make decisions about and manage care, which families do and do not use paid care, or the factors that influence care management after compensation has been awarded. Such information would be useful for a number of groups including: family carers; health professionals who assist family carers; legal professionals preparing claims for future care; judges making judgements; and policy makers involved in the compulsory third party system.

Aims of the Study

In relation to a sample of people with severe traumatic brain injury, this study aimed to explore and describe:

(i) The processes of care decision-making and care management;
(ii) Factors that influenced care decisions and care management;
(iii) Care outcomes.

Study Methods

The research method was qualitative, involving face-to-face interviews with 51 people between January 1999 and April 2001 in New South Wales (NSW), Australia. Grounded theory methods were used for data collection and analysis, the latter process continuing until 2003. The chief investigator conducted all interviews.

(a) Measures: Four instruments were used to collect information from people with brain injury in the study about their level of handicap, psychosocial reintegration and the level of care and supervision received. This information allowed comparisons to be made between participants. The four instruments or measures used were: The Revised Craig Handicap Assessment and Reporting Technique (R-CHART); the Sydney Psychosocial Reintegration Scale (SPRS); the Supervision Rating Scale (SRS); and total hours of care and supervision (paid and unpaid).

(b) The sample and setting: The purposive sample of 51 participants comprised 14 people with a traumatic brain injury and 37 ‘others’, enabling triangulation of data collection to occur. The ‘other’ participants included family members (n=12), paid carers (n=14), directors of care agencies (n=4), case managers (n=6) and one estate manager from the NSW Office of the Protective Commissioner (n=1). These participants either provided or coordinated care. The study was conducted in the community, in metropolitan and rural Australia.

(c) Eligibility criteria: To be included in the study, people with brain injury were required to meet the following criteria: (i) be able to communicate responses to an interviewer verbally or in writing without a carer being present; (ii) be receiving paid care or domestic help, or have received these services within the previous six months;
(iii) have received compensation, or be likely to have settled their compensation claim by the end of 2001 when data collection concluded; and (iv) be 16 years of age or more at the time of interview.

(d) Characteristics of people with brain injury: There were eight men and six women with brain injury in the sample. Seven lived in metropolitan Sydney, and seven in country NSW. The average age at interview was 36.5 years (median 38; range 19 to 56 years). The average time post-injury at interview was 9.9 years (median 8.7; range 2.5 to 37 years).

Key Findings

Findings are presented in the following order: (i) the process of care management; (ii) factors that influenced care decisions and care management; and (iii) the nature of care decisions and outcomes.

(a) The Process of Care Management: When a person with brain injury left, or was preparing to leave hospital, it became apparent that 24-hour care was needed. This need for a high level of care and support was an ongoing concern requiring planning and management. The shared aim of the care management ‘team’ was to optimise the way of living for the injured person through effective care management.

(i) 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 had to be made about the future way of living, including where and with whom the person with brain injury would live, and who would provide daily support. Care decision-making involved gathering information about possible ways of living, appraising each alternative in terms of the likely risks and benefits, then implementing or enacting a decision.

- **Gathering information** involved consulting experts, and referring to printed manuals and resources prepared by organisations such as the local care agencies. Barriers to information, such as gatekeepers at the insurance company and personal biases about types of care and carers also had to be overcome.

- **Appraising alternatives** involved considering potential risks and benefits of each care configuration and living situation, and staying open to new alternatives as they arose. Ultimately, benefits had to outweigh risks for the person with brain injury and their family.

- **Enacting a decision** involved preparing for and then implementing care decisions once they had been made. Human and physical resources had to be identified, obtained and retained. A home had to be obtained and modified in many cases, and a team of paid carers employed. People with brain injury were also prepared for the impending change. Skills for living were developed over time to help increase the likelihood of success. Finally, decision-makers and people with brain injury compared the new way of living with their prior expectations, and made mental adjustments when these expectations were not, or could not be met.
(ii) Care maintenance began after a person with brain injury had been discharged from hospital and continued indefinitely whether that person returned to the family home, an institution or their own home. Care maintenance involved monitoring quality, managing conflict, and providing carer support.

- **Monitoring** involved checking the quality of work and the performance of care team members, and keeping a watchful eye on the health and well-being of a person with brain injury. Everyone, including paid carers engaged in monitoring of family carers, care agency directors and other paid carers.

- **Managing conflict** involved recognising and eliminating triggers that were known to lead to arguments and relationship breakdown, and mediating between the person with brain injury and others. This was one of the most time consuming roles of paid case managers and family carers.

- **Supporting carers** involved a willingness to share responsibility for care problems, and support those who provided direct care and support. Commercial care agencies typically promised to provide support to employees in their challenging new role as a paid carer, but rarely did so. Most of this work subsequently fell on the shoulders of family carers, who orientated, educated, counselled and generally supported paid carers. Several families chose to by-pass care agencies and employ staff privately because of their dissatisfaction with the quality and cost of agency services.

When used, these care maintenance strategies helped to avert care crises and prevent minor care problems from developing into major ones. When these strategies were not used, a care crisis arose and change soon became necessary. However, there were also times when change was necessary, even desirable. At such times, family carers and others engaged again in care decision-making in order to optimise care and the way of living, and the care management cycle continued.

**Factors that Influenced Care:** First, the presence of a care manager contributed to the success of care management and positively influenced care outcomes. The person responsible was typically a paid case manager but could also be a committed family carer. This person often changed over time, as circumstances and care arrangements changed.

Mutual risk tolerance was the second factor that positively influenced care outcomes. When tolerance for risk was mutual, decisions were made that led to low-level risk taking, reduced care and a more satisfying and autonomous way of living. Some health professionals – particularly those with several years of experience in the field – and experienced family carers were able to tolerate a higher level of risk than others. This tolerance was a positive characteristic, resulting in greater autonomy for the person with brain injury.

Without a committed case manager and mutual risk tolerance, two of the participants would have been unable to leave their nursing home after 10 and 13 years respectively. Without these two conditions being present, several people with brain injury and their families would have remained in a cycle of conflict, stress and crisis.
(c) The Nature of Care Decisions and Outcomes: The most common decisions focussed on a person’s living situation, their configuration of carers, and the level of care and support received. The outcomes of these decisions are presented below. Other decisions focussed on financial management and sexual health needs.

(i) Living situation: At the time of hospital discharge, 12 of the 14 participants with brain injury returned to live with their family, one went to a nursing home, and one lived alone (with 24-hour care). At the time of interview, 6 continued to live with their family but 8 had moved to their own home and lived alone with support.

(ii) Configuration of carers: All except one person with brain injury had the potential to buy paid care. However, at the time of hospital discharge when care needs were at their greatest, family members provided 75% of the care on an unpaid basis. Health professionals, at least in this sample, rarely recommended more than 40 hours of paid care a week, even when funds were available.

None of the people with brain injury used live-in paid care. Instead, those who needed a high level of paid care (i.e. 24-hours a day) employed a team of carers working 8 to 12 hour shifts. Live-in paid care was not considered a viable option.

(iii) Level of care: At the time of hospital discharge, all 14 people with brain injury received 24-hour care. At the time of interview, all were still using some type of care and support. Eight of the 14 were still receiving 24-hour care, three at a cost of AU$250,000 per year. Two people with brain injury received between 12 and 15 hours of support each day. Of considerable interest were the four people who had progressed to living alone and received as little as two hours of support each day. These were the individuals who had been ‘allowed’ to spend time alone and who were able to tolerate risk.

(d) Ways of Living with Care

All 14 people with brain injury in the study could be categorised as living in one of four ways: institutional living, living with family, living alone with high support or living alone with low support. A way of living described the living situation (where they lived and with whom), the configuration of carers (paid versus unpaid carers, nature of the shifts and rosters used) and the level of care received (hours and intensity). Half of the sample had experienced two or more ways of living since leaving hospital. Two had been in a nursing home for 10 and 13 years respectively before moving into their own homes with 24-hour paid care.

A preferred way of living was 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 the four people who lived alone with minimal support (2 to 4 hours a day) 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. Data were not available for comparison to show whether handicap measures reduced before or after participants moved into their own homes, however, it is likely that reduced carer presence and living alone
contributed to some degree. The absence of carers for extended periods of the day placed new demands on these individuals who were required to perform household and community living skills. They enjoyed greater privacy and time alone.

A less desirable way of living was 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.

Implications and Recommendations

Quality of Care Decision-Making by Professionals

The amount of time allocated to care decision-making and the quality of this process was less than optimal, particularly in hospital settings.

Recommendation 1: That health professionals improve the quality of care decision-making by incorporating some or all of the following strategies into their practice:

(a) Delivering information about care options and ways of living on more than one occasion, and using different modes of delivery.
(b) Use of informal decision analysis procedures, decision aids and guides
(c) Preparation of a ‘showcase’ of case examples, life stories and care arrangements for use during decision-making;
(d) Encouraging family carers, who spend many weeks, often months in hospital with their relative, to spend more time exploring different ways of living;
(e) Inviting selected family carers and people with brain injury to advise and mentor other families, particularly during the initial phase of care decision-making. These individuals have a wealth of experience and knowledge to share, but are not currently being used as a resource. Such an initiative may require funding, to provide education and support to individuals in their new role.


Involvement of People with Brain Injury in Care Decision-Making

**Recommendation 2:** That health professionals help people with brain injury to become more involved in care decision-making at all levels, through use of decision-aids, guides and informal decision analysis.

The Range of Care Alternatives

The range of care alternatives presented by hospital professionals to people with brain injury and their family was limited. There were typically two options: to either live with family or move to a nursing home. The first arrangement often led to family breakdown and separation within months of hospital discharge. Such outcomes were not unexpected. The second arrangement, transfer to a nursing home was undesirable for many reasons, and took 10 years or more to reverse.

**Recommendation 3:** That health professionals, particularly those who consider themselves experts in brain injury rehabilitation, become better informed about the different ways of living with care beyond living with family. Professionals will in turn then be better able to inform family carers and people with brain injury about the options, in hospital and out in the community. The current research provides examples of other ways of living with care in the community.

Paid Care versus Unpaid Family Care

In this study, a family carer, usually a spouse or mother, provided 75% of the daily care and support after hospital discharge. The ‘norm’ was for health professionals to recommend, and for insurers to approve up to 40 hours of paid care per week, from Monday to Friday. This accounted for only 25% of most individual’s care needs.

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. In the current study, such an arrangement helped to reduce family conflict and improve family relationships but was the exception rather than the rule.

**Recommendation 4:** That health professionals and families give greater consideration to people with brain injury living alone after hospital discharge with a greater proportion of paid care hours, funding permitting.

Health and legal professionals also need to respect the need of some families for privacy and time alone after months in hospital, when a person with brain injury does not return to live with their family. In some cases in the current study, placement of paid carers in a household did more harm than good because they became another source of stress to family carers and people with brain injury.
Live-in Carers and House Couples

No individuals with brain injury in the study used live-in care, even those who received 24-hour paid care. Live-in carers were not considered a viable alternative for most people with brain injury who needed 24-hour care. Instead a team of live-out carers were employed, usually on a casual basis, with each person working eight to 12 hour shifts. For the three people with brain injury who used 24-hour care, the cost was approximately $250,000-$300,000 Australian dollars per year.

Recommendation 5: That health and legal professionals in NSW cease recommending live-in carers and house couples for people with brain injury who need 24-hour care. A team of live-out carers, each working shifts of eight to 12 hours, would more closely match the reality of long-term care for this population.

The Cost of Paid Care

The long-term cost of 24-hour paid care was not sustainable when purchased on an hourly rate from commercial care agencies in NSW. One alternative used by several families was to advertise for, and privately employ their own staff. This family-directed model of care was popular with a number of families in the study.

Recommendation 6: That family carers and health professionals give consideration to employing paid carers privately, in order to reduce long-term care costs when a person with brain injury is living in the community. Carer training and education will be required, such as has been documented in overseas manuals, and provided for many years by Paraquad NSW.

Lack of Specialised Paid Carers

Over time, families found that they were no longer able to recruit new carers. They had exhausted all the known agencies in their region, and typically resorted to finding new staff by word of mouth. This problem arose partly because of the challenging behaviour of the person with brain injury, but also an unwillingness to accept inexperienced agency staff. Even if money had been available, quality affordable staff were not. In the absence of appropriate paid carers, family members filled the gap. There is, therefore, an ongoing problem in NSW meeting the need for paid carers with relevant skills and knowledge. This need was greater in rural areas, where there was a limited supply or pool of local workers.

**Recommendation 7:** That the limited availability of paid carers with experience and an interest in brain injury be investigated further through groups such as the Care Services Network of NSW, the Motor Accidents Authority of NSW and other interested agencies/organisations.

**Quality of Services provided by Care Agencies**

For care agencies, the main message from this study the urgent need for better quality control, accountability and value for money. There were many complaints about care agencies. While a system of voluntary accreditation of care agencies operates in NSW, this system has not noticeably improved the quality of services since 1996, when similar problems were reported[^1]. There are no signs that the industry is planning to engage in self-regulation.

Consequently, other external methods of regulation are now required. Such methods have been introduced to regulate injury management providers and nursing homes in Australia, where providers must be accredited in order to compete, and in some cases, even to operate as a business. Accreditation requires compliance with guidelines on documentation and report writing, occupational health and safety, staff training, and more recently, adherence to guidelines on evidence-based practice when treating injured workers.

**Recommendation 8:** That the Motor Accidents Authority of NSW and/or the Care Services Network of NSW, in consultation with the care industry, unions, and other interested organisations examine ways of improving the performance of care agencies. This may include, but should not be limited to legislative changes such as those affecting other service industries.

**Institutional Care**

There is an urgent 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. A move from nursing home to the community required extensive planning and harnessing of resources over a period of two to three years. Those who wanted to move out and live alone in the community were dependent on the level of interest, experience, knowledge and persistence of individual case managers.

**Recommendation 9:** That health professionals do their utmost to keep people with brain injury out of nursing homes, and seek funding to move those in nursing homes out into a home-like residence of their own.

**Recommendation 10:** That events such as the ‘Young People in Nursing Homes’ conference⁶, and organisations that lobby for policy change⁷ continue to receive funding and support, in order to keep this human rights issue on the political agenda.

**Long-Term Case Management**

Case managers were an important and necessary part of the care ‘team’. They were ‘troubleshooters’ who helped to avert care crises. Case managers were typically paid professionals, but could also be an experienced 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 that there might be a better way of living. Without case management, people with brain injury were unlikely to ever live alone or to significantly reduce their level of care.

The cost and amount of case management decreased over time for those people with brain injury who needed less care and support. A reduced level of care led in turn to less care maintenance and case management. However, those who needed 24-hour ongoing care continued to need regular visits from a case manager (not simply a phone call from time to time).

**Recommendation 11:** That the cost of case management be considered an essential part of long-term care for people with severe traumatic brain injury. Face-to-face visits are an essential part of their role, in order to provide adequate care maintenance and avert care crises (i.e. to monitor care, manage conflict, and support carers).

**Recommendation 12:** Publication of a research-based paper on the skills, attitudes, knowledge and competencies of case managers who engage in care management on behalf of people with severe traumatic brain injury.

**Financial Management and the Office of the Protective Commissioner**

All participants with brain injury in the sample received help with money management and financial planning, either from the Office of the Protective Commissioner (OPC) in NSW, or from a close family member. No-one with brain injury in the study made decisions about money independently.

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Participants’ experience of working with the OPC was generally positive. The OPC should continue to be recommended in appropriate cases as the financial manager of choice. Estate managers at the OPC held valuable experience and had a high tolerance for risk because of their wide and varied experience. They should be consulted more often when professionals are helping clients to make care decisions.

**Recommendation 13:** That health and legal professionals, and legislation continue to encourage people with brain injury to use the OPC for financial management of third-party compensation. The OPC performs an important role, helping to prevent major financial mismanagement and potential abuse.

**Outcome Measures**

Autonomy and interdependence, as opposed to independence, were shared goals of participants in the study. Reduced care levels, and allowing the person with brain injury to enjoy privacy and time alone contributed to feelings of increased autonomy. This concept should be reflected more in the outcome measures used during community-based rehabilitation, to focus clinicians’ attention on autonomy as a desirable outcome. One such measure is the Community Integration Measure or CIM (McColl et al., 2001). Use of measures like the CIM may also encourage professionals to reflect more on priorities for intervention.

**Recommendation 14:** That community-based health professionals use the Community Integration Measure\(^8\) routinely in practice as an outcome measure of choice with people who have sustained a brain injury.

The Care and Needs Scale (CANS)\(^9\) was found to be a more effective measure of level of care needed than the Supervision Rating Scale.

**Recommendation 15:** That health professionals who measure care following traumatic brain injury use the CANS in preference to other published measures.

**Risk and Autonomy**

This study highlights a need to accept, and even welcome risk as a precursor to increased autonomy, reduced care, and to a better way of living after brain injury. Graduated risk needs to be integrated into rehabilitation on an ongoing basis. However, as with the use of decision aids, interventions that provide structured and

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graduated risk do not appear to have been implemented, nor have they been evaluated for efficacy.

Professionals and family carers found the concept of risk easier to manage if decisions about risk-taking were made collectively. The current study highlights the importance of a shared responsibility for risk, which may relieve professionals’ anxiety about client safety and duty of care.

Recommendation 16: That the author of this report develop, deliver and evaluate an intervention program focussed on graduated risk management following brain injury. The program would include education for health professionals who typically have a reduced tolerance for risk because of their training.
Chapter 1  BACKGROUND

Brief description of study methods

The study investigated the process of making decisions about and managing care, and the long-term care arrangements of 14 people with traumatic brain injury in NSW following receipt of compensation. A grounded theory method was used. A total of 51 participants were interviewed between January 1999 and April 2001. Participants included people with a brain injury, their family members, paid carers, directors of care agencies, case managers and one estate manager from the Office of the Protective Commissioner of NSW.

Project aims and objectives

In relation to people with brain injury, this study aimed to:

- Develop a model of care decision-making that describes how people with a brain injury and their families make decisions about and managed care;

- Inform the Motor Accidents Authority, care agencies, health and legal professionals and insurers about the experiences of this population, including their use of, and preferences for care;

- Make recommendations to the above stakeholders about the most appropriate and efficient way of providing care.

- In the longer term, contribute to more cost-effective, long-term care and ensure that damages awarded in the future reflect the actual care needs and preferences of this population.

Relevance of study to stakeholder groups

In addition to the aims stated above, the study has relevance to the following groups:

- Policy makers and organisations such as the MAA and third party insurers, care agencies and medico-legal professionals. Study findings may contribute to policy, practice guidelines and care services for people with brain injury.

- The care industry and health professionals can use feedback from consumers to ensure care needs are more effectively met. Although much research has been conducted about people with a brain injury, few studies seek their opinions on issues that affect their lives.

- Medico-legal professionals, who can use the findings when writing reports or giving evidence in court about future care. Health, legal and actuarial professionals now have access to information about care use post-compensation and the process of managing care. Such information can inform clinical and legal decision-making and contribute to future judgements.
Outcomes

The outcomes of this study include recommendations to the following groups. Key findings and recommendations will be summarised in shorter reports and disseminated upon request:

- *Families and people with a brain injury:* The current report includes practical suggestions for employing and working with paid carers, supporting and training new staff, and containing long-term costs.

- *The Motor Accidents Authority of NSW:* The present report highlights key findings, recommendations and implications for practice, policy and education.

- *The paid care industry (directors and attendant carers):* The present report summarises how people with brain injury and their families make decisions about paid care, their experiences of paid care and competencies required by paid carers. Recommendations are made for carer orientation, support and training. Such information may contribute to reduced staff turnover and help to contain care costs.

- *Health and legal professionals and other service providers that assist families with care management.* The current report highlights how the study sample preferred care to be managed, what care arrangements were used and information on the nature and effectiveness of consultations by professionals with clients about care management.

Duration of the study

The study commenced in late 1998, prior to receipt of MAA funding. A seeding grant of $5000 was received from the University of Western Sydney in 1998. MAA funding commenced in May 2000, and concluded in June 2002.

Funding and expenditure

A total of $60,000 was received from the MAA over 24 months. All funds were used. Major budget items included salary costs for the researcher who conducted face-to-face interviews, analysed the data and wrote up findings; employment of a research assistant to transcribe audiotapes; and travel and accommodation costs, particularly for country interviews.
Chapter 2 THE STUDY

Brief literature review

People injured in a motor vehicle accident and who sustain a severe brain injury often require long-term care. Employment of paid carers can help to alleviate some of the stress of long-term caregiving by allowing a relative to return to paid employment, resume social networks or simply take ‘time out’ (Rees & Hannaford, 1996). The present study focussed on a sub-group of people with serious injuries who required assistance with daily activities and had the potential to buy private care services following compensation.

(i) Paid care services

While there are a number of published studies about the stress and burden on family caregivers following brain injury, few have investigated the experiences of paid carers or care recipients. Most studies are American, more than 10 years old, investigate the carer perspective, and focus on the job satisfaction and duties of paid carers (Atkins, Meyer, & Smith, 1982; Hutchins, Thornock, Lindgre, & Parks, 1978; Stelmach, Postma, Goldstein, & Sheperd, 1981).

One recent Australian study (McCluskey, 2000) found that paid carers can and do play an important role in promoting community integration and often become a friend to people with brain injury. Paid carers discussed the many challenges faced in the course of their work, including occupational health and safety concerns and the ever-present risk of injury due to aggressive behaviour. However, overcoming these challenges enhanced carers’ interest in their work. This study involved five people with brain injury and five paid carers. Therefore, the results have limited application in other contexts. Furthermore, the study did not investigate the use, non-use or change in paid care services by people with brain injury, nor reasons for care decisions being made. Such a study needs to involve family carers and case managers.

Two other Australian studies have focused on paid care services. One study examined the training needs of paid carers (Focus Learning Systems, 1998). The second study examined the cost of paid care for people with severe spinal cord and brain injuries (Bloom & Associates, 1996). The primary training need of paid carers was for interpersonal skills, such as learning how to negotiate and resolve problems with clients, family members and others, and how to manage challenging behaviour (Focus Learning Systems, 1998). The second study by Bloom and associates reviewed 27 case files of clients with high support needs in NSW prior to compensation. The way in which care agencies structured the cost of care, using casual hourly rates, was found to be prohibitive to families in the long term. The fee structure provided little job security or career structure for paid carers. More importantly, the use of casual hourly rates was expected to make paid care unaffordable for many individuals with brain injury within a very short period of time.
(ii) Affordability of paid care services and the adequacy of compensation

The study by Bloom and associates raised concern about the ability of seriously injured people to afford private care services in the long term, even when compensation had been provided for this purpose (Bloom & Associates, 1996). There have been anecdotal reports of individuals making poor financial investment decisions, and spending their compensation money on material goods, leaving insufficient funds for care. There is, however, no research to substantiate the claim that mismanagement of funds is the primary reason why people with severe injuries need to use government funded services when their money is depleted. Such research is warranted.

The long term cost of care and the inadequacy of compensation may be other reasons why people with high support needs and their family manage and make decisions as they do. To this end, researchers in South Australia (Neave & Howell, 1992) collected data on 216 individuals who were seriously injured in motor vehicle accidents after 1976. When these researchers interviewed subjects on average eight years post-compensation, they found that family members were still providing the majority of care for the injured person rather than the compulsory third party system. The researchers concluded that this overdependence on family caregivers was due, in part, to inadequate compensation being awarded to 18.5% of the sample.

(iii) Family care versus paid care services

Family caregivers may decide not to use formal services for a number of reasons. Cost may or may not be a primary concern. In Australia in recent years, only 21.6% of family caregivers received help from community services such as Home Care, which offers low-cost, subsidised services to families in need (Australian Bureau of Statistics, 1995).

Family caregivers of older Australians and those with physical disabilities sometimes choose not to use community services for a variety of reasons. Some caregivers believe that 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 their decision to use or not use formal services includes the unreliability of, and prior negative experiences with service providers (Bast, 1996; Payne & Erhlich, 1998; Twigg & Atkin, 1995). No such studies have been conducted with caregivers of people with severe brain injury to investigate the use of care services post-compensation settlement, or how these decisions are made.

(iv) Decision-making

Decision-making is a process where individuals are required to choose between several courses of action, each of which can have serious personal or societal consequences (Janis & Mann, 1977). Information on the quality of decision-making can be obtained by examining the ‘quality of the procedures used by the decision-maker in selecting a course of action’ (Janis & Mann, 1977, p. 11).

A small number of care decision-making theories have been described in the literature. These include theories that explain how elders make decisions about their home health
care needs (Forbes & Hoffart, 1998), how daughters make decisions about caring for an elderly parent (McGrew, 1998), and how hospital-based health professionals make decisions about an elderly patient’s safety and discharge destination (Clemens & Hayes, 1997). However, none of these theories were intended for generalisation. They apply to a specific domain of decision-making, and to older adults.

On the contrary Janis and Mann developed a comprehensive theory of decision-making which was developed and tested over many years, and applied to multiple life decisions. Their theory was intended for generalisation. They identified seven criteria for judging the quality of a person’s decision-making. These criteria and the processes involved are listed below.

Table 2.1 Criteria for quality decision-making (adapted from Janis & Mann, 1977)

<table>
<thead>
<tr>
<th>Stage</th>
<th>Action/ process</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 the 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>

When a decision-maker focuses on all seven criteria fully and equally, Janis and Mann described this as ‘vigilant’ information processing. 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 by-passed, for example, because of stressful circumstances or deadline pressures, the more likely the decision-maker will be dissatisfied with the outcome, or experience post-decisional 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.
These observations led Janis and Mann to develop a conflict model of decision-making (1977). The model applies when a person is primarily concerned with choosing between two or more courses of action, which may lead to serious personal consequences. People with brain injury, their families and associates fit this criteria when making decisions about a living situation, a configuration of carers, and the level of care and supervision.

**Overview of the problem for investigation**

Previous studies have highlighted the importance of training and support for paid carers, acknowledging the importance of their work. However, little is documented about how, and whether families use paid care services after receiving compensation. No studies have investigated how people with a traumatic brain injury and their family caregivers manage and make decisions about paid care, or factors that contribute to care management. Such information would be useful for legal professionals preparing claims, judges making judgements and those overseeing the compulsory third party system which provides damages for future care needs.

In summary, a number of factors may affect a person and their family’s decision to use, continue to use, or cease to use paid care services after receipt of a compensation settlement. Of those people who do use paid care services after brain injury, limited information has been documented about patterns of care-use in Australia, or the benefits and problems of using paid care services.

**Research questions**

- What process and strategies do people with a brain injury, their families and others use to make decisions about, and manage care?

- What factors influence care decisions and care management?

- What are the resulting care outcomes?

**Choice of study design**

The study used qualitative research methods, enabling questions to be asked about how and why care decisions were made, and why care was managed in a particular way. The aim was to characterise the processes of care decision-making and care management, identify similarities and differences in care patterns across cases, and strategies used. The intention was to explore and not simply measure variables. The experiences of people with traumatic brain injury and their families was a primary focus.
Chapter 3 STUDY METHODS

A total of 51 participants were interviewed between January 1999 and April 2001 using semi-structured interviews. All participants were associated with one of 14 ‘cases’. A ‘case’ refers to a person with brain injury and other participants associated with their care. Other participants included family members, case managers, paid carers, care agency directors and staff from the Office of the Protective Commissioner. Between three and six people were interviewed in each case. The Human Ethics Review Committee of the University of Western Sydney (Macarthur) granted ethics approval in late 1998.

Eligibility criteria

To be included in the study, people with brain injury had to:

(a) Be able to communicate their responses verbally or in writing without a carer being present,
(b) Be a recipient of paid care or domestic services, or have received such services within the previous six months,
(c) Be a recipient of compensation, or be likely to have settled their compensation claim by the end of 2001 when data collection concluded, and
(d) Be aged over 16.

The last criterion excluded people with brain injury under 16 who might still be receiving care and support from a guardian for legal reasons. People with brain injury already known to the researcher through clinical or medico-legal consultations were also excluded.

The recruitment process

Participant recruitment began in late 1998. People with brain injury were identified and recruited via occupational therapists in private practice, care agencies and community service organisations such as Headway. Participants were sought from both city and country areas. Country-based participants were included because families and care agencies in the country have different experiences of accessing and using paid care to those based in Sydney. For the purpose of this study, ‘country-based’ was defined as anyone living 100 km outside the Sydney central business district (beyond Katoomba to the west, Bowral and Wollongong to the south and south-west, and Gosford to the north).

Recruitment letters and emails were sent to private occupational therapists, care agencies and community organisations, who were asked to contact anyone they knew that fitted the eligibility criteria. If a person with brain injury agreed to participate, they and their family were sent a consent form, a 5-page background information / demographics form, and a stamped addressed envelope. Initial interviews were undertaken one to two weeks after receipt of the completed consent and background information /demographics forms (available upon request). participants in each case
were recruited by asking the person with brain injury or family carer to nominate people who provided or coordinated their care.

Initial cases were selected for their similarities. For example, the first three people with brain injury all lived alone and received a high level of paid care. Later, participants were selected for their differences. For example, people with brain injury were recruited who used minimal paid care services, lived with their family, or had ceased using paid care services, in order to provide a cross section of participants, and confirm or clarify findings. This approach is called theoretical sampling, whereby the researcher seeks informants who might confirm a theory or explain differences (Glaser, 1978).

The interview procedure

Participants were interviewed at a location of their choice. In most cases, the venue chosen was the participant’s home. Other venues included the researcher’s work premises (n=1), a community centre in a country town (n=1) and a local hospital meeting room (n=2).

In each case, the person with brain injury was interviewed first. This arrangement enabled the researcher to obtain opinions about care arrangements from the person with brain injury without influence from carers or professionals. Subsequent interviews with family or paid carers helped to clarify factual information such as dates, names, places and other details which the person with brain injury may have forgotten.

Interviews took one to two hours, were tape-recorded and later transcribed. Approval to tape record interviews was recorded live on the audiotape and in writing. On one occasion, a joint interview was conducted with two family members. Another interview involved two paid carers together. In one case, the person with brain injury and a family member were interviewed prior to and after compensation had been received. Therefore, although 52 interviews were conducted, 51 participants were included in the sample.

Semi-structured interviews

Semi-structured interviews were conducted as opposed to a formal structured format, because of the exploratory nature of the research. Interviews were guided by predetermined topic areas and questions (Berg, 1995), but without fixed wording or ordering of questions (Minichiello, Aroni, Timewell, & Alexander, 1995). For example, people with brain injury were asked to ‘Tell me about a typical day/week’ and ‘Tell me about some of the changes and events in your life since the accident’. Family carers were asked similar questions, as well as questions related to their role as carer. For example, ‘Tell me about your involvement with the person with brain injury to date’ and ‘Tell me about some of the decisions that have to be made in relation to the person with brain injury’. A full list of interview questions is included in Appendix A. Prompts were developed to assist participants who had difficulty responding to questions. Questions were modified over time, as information about care decision-making and care management processes and conditions arose. The early questions are shown in Appendix A-1. Later questions and prompts are shown in Appendix A-2.
Measurement scales

Four sets of measurements were collected from each of the 14 people with brain injury, immediately after their interviews. These measures captured information about level of handicap, psychosocial reintegration and the level of care and supervision received, against which other people with brain injury in the sample could be compared. These measures also gave an indication of how the sample compared with the wider brain injury population.

Frequently, it is person’s level of disability that is measured in a research study. However, a person can be physically disabled but still participate fully in society as a worker, parent, or homemaker if the right level of support and equipment are provided, and handicap is minimised. Measures of handicap and reintegration were used in the present study instead of measures of disability. A lower level of handicap allows a person with a disability to participate more fully in society. Participation and integration back into the community, and resumption of valued societal roles imply a good rehabilitation outcome. The four measures used in this study were:

(a) The Revised Craig Handicap Assessment and Reporting Technique (or R-CHART) (Mellick, Walker, Brooks, & Whiteneck, 1999; Whiteneck, Charlifue, Gerhart, Overholser, & Richardson, 1992);
(b) The Sydney Psychosocial Reintegration Scale (or SPRS) (Tate, Hodgkinson, Veerabangsa, & Maggiotto, 1999);
(c) The Supervision Rating Scale (or SRS) (Boake, 1996); and
(d) Hours of direct care and supervision, both paid and unpaid.

The R-CHART measures level of handicap. The SPRS measures psychosocial reintegration. The SRS measures the level of supervision received from family and paid carers. The SPRS and SRS were developed specifically for use with people with brain injury, whereas the R-CHART was adapted from an earlier instrument designed to measure handicap in people with physical disabilities. Copies of each measure are available upon request.

(a) The R-CHART enquires about deviations from a person’s life roles, and, like the original CHART, 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. There are six domains in the R-CHART: Physical Independence; Cognitive Independence; Mobility; Occupation; Social Integration; and Economic Self-Sufficiency. The Cognitive Independence domain was added to the original CHART. Each of the six domains has between two and seven questions, with a maximum score of 100 for each domain. Lower scores indicate a high level of handicap and low levels of social and community participation.

In the current study, the R-CHART was completed initially with the person who had a brain injury, at the conclusion of their interview. This procedure took about 10 to 15 minutes. A family member or significant other also completed the R-CHART when possible, in addition to the person with brain injury. The researcher in the current study then decided which score to record for each question, following interaction with the person with brain injury and consideration of the two sets of scores.
Hall and colleagues have previously advised against calculating and comparing total CHART scores, because there are commonly large amounts of missing data for the Economic Self-Sufficiency item (Hall, Dijkers, Whiteneck, Brooks, & Krause, 1998). Only sub-scores should ideally be reported. The Economic Self-Sufficiency score for the R-CHART was not calculated in the current study because it was felt that participants would be unlikely to reveal details of their income, particularly from a compensation payment. Furthermore, they may not have known their weekly or fortnightly income nor the source of this income. Therefore, only sub-scores for five domains of the R-CHART were collected and reported.

For the purposes of presentation in this report, 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).

(b) The Sydney Psychosocial Reintegration Scale (SPRS) was the second measurement scale used in the present study. The SPRS measures psychosocial reintegration and level of change in psychosocial functioning following traumatic brain injury. Psychosocial reintegration refers to the ability of a person with brain injury to resume valued societal roles, including those of worker, driver, parent and spouse. The scale comprises three domains and 12 questions, four questions for each domain.

The three domains of the SPRS 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. The maximum score for each of the three domains is 24, which implies that the person with brain injury has achieved good psychosocial reintegration for that domain. It was anticipated that some people with brain injury in the study would have good psychosocial reintegration, and receive a high score for one or more domains, while other participants would receive a low score for all three domains.

In the current study, the SPRS was completed first by the person with brain injury, with assistance from the researcher. When possible, a second copy of the SPRS was completed by a relative or other informant. Again, the researcher decided which score to record for each question, based on interaction with participants and the two sets of scores.

For the purpose of presentation in this report, and on the advice of the author of the scale (Dr Robyn Tate), mean scores are 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).

(c) The Supervision Rating Scale (SRS) measures the level of supervision that a person with brain injury receives from family members or paid carers. 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
rating scale with five classifications. A rating of one indicates that a person is living alone or with others, but does not require any supervision. At the other end of the scale, a rating of 13 indicates that the person with brain injury requires full-time, direct supervision and physical restraint. Each of the five classifications aims to discriminate between monitoring or prompting, and hands-on physical assistance.

The five classifications of the SRS 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). Each classification has between one and four choices of descriptors. In the current study, the researcher completed the SRS scoring sheet after leaving the interviews, based on observation and discussion with participants.

(d) Hours of direct care and supervision, paid and unpaid were calculated by the researcher. If a person with brain injury was rarely or never left unsupervised, 24-hour care was recorded. These hours of care were the easiest to calculate. In other cases, the hours of paid and unpaid care were calculated separately and combined. Unlike the SRS, unpaid hours of care were calculated whether they involved the physical presence of a family member or off-site telephone support.

Analysis

Analysis of qualitative data: Interviews for new cases were held several weeks apart, to allow sufficient time for transcribing and analysis before subsequent interviews. Each interview was transcribed word-for-word and imported into a computer software package called NVivo. This software helped manage the large amount of text data. Like-material and quotes from each interview were clustered together into separate categories and sub-categories (a process known as open coding). Similarities and differences within and between cases were identified. Categories were given a descriptive or conceptual label such as ‘Risk-taking’ or ‘Living Situation’. Using the constant comparative method described by Glaser and Strauss (Glaser & Strauss, 1967) and Glaser (1978), relationships between categories were then identified and reported. For example, interviews with participants who spoke most about 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’ (a grounded theory term) also known as the main concern shared by participants was sought during analysis (Glaser, 1998, 2001). When investigating a process and developing a theory based on (or grounded in) interview data, the ‘basic social problem’ is one that drives the collective behaviour of participants. Their actions and behaviour are aimed at managing, dealing with or resolving this one main concern. In this study, I was seeking the problem or concern that caused participants to make decisions about care and/or change care arrangements.

Verification of the categories and analysis generally was conducted by asking two research colleagues/supervisors to read the transcripts regularly and independently, much in the same way that studies of interrater reliability are conducted in quantitative research.
**Analysis of quantitative data:** The R-CHART, SPRS, and SRS data for the 14 people with brain injury were analysed in Excel using descriptive statistics, in addition to the hours of care and supervision. Raw data and frequencies have been summarised and presented using tables, bargraphs and piecharts.

**Demographics of the sample**

The number and type of participants interviewed for each case are shown in Table 3.1. A total of 51 participants were interviewed. Table 3.2 summarises the characteristics and demographics of the 14 people with brain injury. Pseudonyms have been used for each of the 14 people with brain injury in order to maintain confidentiality.

**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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<tbody>
<tr>
<td>1</td>
<td>1 (sibling)</td>
<td>1</td>
<td>1</td>
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<td>0</td>
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<td>3</td>
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<tr>
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<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
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<td>3</td>
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<tr>
<td>3</td>
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<td>3</td>
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<td>2</td>
<td>0</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>7</td>
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<tr>
<td>12</td>
<td>1 (husband)</td>
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<td>0</td>
<td>0</td>
<td>3</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>14</td>
<td>12</td>
<td>14</td>
<td>4</td>
<td>6</td>
<td>1</td>
<td>51</td>
<td>52</td>
</tr>
</tbody>
</table>

*Notes.*  
* a Estate Manager at the Office of the Protective Commissioner.  
* b Two interviews were conducted on two separate occasions with the person with brain injury and with his wife (four interviews in total).  
* c The coordinator and person responsible for rostering were interviewed together.  
* d Two family members were interviewed together.
There were eight male and six female participants with brain injury in the sample. Seven participants lived in Sydney, and seven lived in country NSW. The mean age of people with brain injury at interview was 36.5 years, median 38 years (range 19 to 56 years). The mean time post-injury was 9.9 years, median 8.7 years (range 2.5 to 37 years). Eight of the 14 people with brain injury lived alone. The remaining six lived with one or more family members. These different ways of living will be described in more detail later. All received some level of support, either paid, unpaid or both.

Table 3.2 Characteristics 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>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 Male 28 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>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Lara Female 49 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>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Thomas Male 49 2.5</td>
<td>CTP b</td>
<td>Alone. Daily family visits</td>
<td>24 hr paid care/day (168 hrs/wk); 6 paid carers + family</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 Sheila Female 28 11.5</td>
<td>CTP</td>
<td>With defacto. Intermittent family contact</td>
<td>8 hrs paid care/wk; 2 paid carers + family</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 Will Male 37 2.5</td>
<td>CTP</td>
<td>Alone. Daily family visits</td>
<td>6 hrs paid care/wk; 1 paid carer + family</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 Moira Female 49 2.5</td>
<td>CTP</td>
<td>With husband</td>
<td>42 hrs paid care/wk; 2 paid carers + family</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 Gary Male 23 7.5</td>
<td>CTP</td>
<td>With parents</td>
<td>9 hrs paid care/wk; 1 paid carer + family</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8 Angus Male 19 8</td>
<td>CTP</td>
<td>With mother and sibling</td>
<td>30 hrs paid care/wk; 1 paid carer + family</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9 Wendy Female 56 35</td>
<td>CTP equivalent in 1965</td>
<td>With parents</td>
<td>36.5 hrs paid care/wk; 7 paid carers + family</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10 Keith Male 27 13</td>
<td>Non-compensable c</td>
<td>Alone. Minimal family contact</td>
<td>28 hrs wk paid care; 3 paid carers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11 Dora Female 38 3.5</td>
<td>CTP</td>
<td>With husband and child</td>
<td>No paid care; family only</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12 Paul Male 41 7</td>
<td>Workers Compensation</td>
<td>Alone. Daily family visits</td>
<td>14 hrs paid care/wk; 2 paid carers + family</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13 Joe Male 37 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>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14 Dayna Female 50 8.5</td>
<td>CTP</td>
<td>With husband.</td>
<td>No paid care; family only</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Notes. *Pseudonyms have been used. bCTP= Compulsory Third Party insurance. cCompensation status confirmed at the time of interview; this participant was incorrectly categorised as compensable at the time of recruitment.
Chapter summary

The focus of this chapter has been a description of, and justification for the study methods used. 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 study was semi-structured interviewing. Participants were interviewed once between 1999 and 2001, in their home or local community. Interviews were taped, transcribed and the text entered into a computer software program ready for analysis.

The second data collection method was administration of four quantitative measures: the R-CHART; the SPRS; the SRS; and hours of care and supervision received. These measures allowed similarities and differences to be identified across the 14 people with brain injury.

The following four chapters present study findings. 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, two cases are presented from the study to highlight the outcome of optimal and sub-optimal care management.
Chapter 4 WAYS OF LIVING WITH CARE

The previous chapter described the methods used to gather data from the 51 participants, and a short summary of the sample. This chapter summarises the level of handicap, psychosocial reintegration, care and supervision of the 14 people with brain injury, followed by their ways of living with care.

Characteristics of the people with brain injury

Level of Handicap

R-CHART data are presented in Figure 4.1. 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.

![Figure 4.1 Levels of Handicap as Measured by the R-CHART (n=14)](image)

Notes. High handicap = scores between 0 and 33; moderate handicap = scores between 34 and 66; low handicap = scores between 67 and 100. Phys Ind = Physical Independence; Mob = Mobility; Cog Ind = Cognitive Independence; Occ = Occupation; Soc Int = Social Integration.
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.

**Level of Psychosocial Reintegration**

Data from the SPRS, presented in Figure 4.2, 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 4.2 Level of Psychosocial Reintegration based on SPRS scores (n=14)](image)

**Notes.** Major change = poor reintegration, scores 0, 1 or 2; some change = limited reintegration, scores 3 or 4; no significant change = good reintegration, scores 5 or 6.
Level of Care and Supervision

SRS data are presented in Figure 4.3. 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).

Figure 4.3 Levels of Supervision on the SRS (n=14)

*Note. Level 1 = Independent. Level 2 = Overnight Supervision. Level 3 = Part-Time Supervision. Level 4 = Full-Time Indirect Supervision. Level 5 = Full-Time Direct Supervision.*
Actual hours of care and supervision, both paid and unpaid are presented in Figures 4.4 and 4.5 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).

**Figure 4.4  Actual Hours of Direct Care and Supervision**

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 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.

![Figure 4.5 Mean Hours of Paid and Unpaid Care per Week.](image)

*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.

Finally, a comparison is presented in Table 4.1 of SRS scores, hours of care and supervision received, and paid and unpaid hours for each of the 14 people with brain injury.
<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</td>
<td>(n=0)</td>
<td>Overnight (2)</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</td>
<td>(n=0)</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</td>
<td>(n=0)</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</td>
<td>(n=0)</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></td>
<td>11-13</td>
<td>(n=0)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
In summary, data presented in this section show similarities and differences between the 14 participants with brain injury. The reader is reminded that all participants received 24-hour care at the time of hospital discharge. At the time of interview, on average 10 years post-injury, most were physically able and independently mobile. However, most had difficulty with psychosocial functioning. A range of levels of cognitive independence and occupational functioning were evident. Most participants with brain injury in the study had difficulty with psychosocial functioning and social integration, as measured by the SPRS.

A range of levels of care and supervision were also evident at the time of interview. 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). Eight people with brain injury - more than half the group – still received 24-hour care, seven days a week. Three had no family involvement, and relied entirely on paid carers. The number of paid carers employed per household ranged from one to seven. After compensation had been received, two participants ceased using paid care, relying instead on their spouse. The remaining 12 people with brain injury all used some paid care. The following section presents four different ways of living with care.

Ways of Living with Care

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 characteristics and features of each way of living are presented in Table 4.2, and further defined below.

Characteristics of each Way of Living

(i) 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.

(ii) 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.

(iii) 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>
<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 (^e)</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 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>

\(^a\) Although 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.  
\(^b\) Supervision Rating Scale scores: High 8-13; Moderate 4-7; Low 1-3.  
\(^c\) Revised-Craig Handicap Assessment and Reporting Technique scores: High 0-33; Moderate 34-66; Low 67-100.  
\(^d\) Sydney Psychosocial Reintegration Scale scores: High 17-24 (no significant change); Moderate 9-16 (some change); Low 0-8 (major change).
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 (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.
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 5.2). 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 below (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.

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**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.
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). 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). 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 below (Case Study 3) illustrates the features of this third way of living. 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.

**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). 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). 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 features of this fourth way of living (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.

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 5  CARE DECISION-MAKING

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. 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.

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 Office of the Protective Commissioner (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.

The Focus of Care-Related Decisions

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

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.
### 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>
</tr>
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<tbody>
<tr>
<td>Living Situation</td>
<td>‘Should he/she return home to live with the family?’</td>
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<tr>
<td></td>
<td>‘Should he/she leave the family home/nursing home and live alone with paid care?’</td>
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<tr>
<td>Configuration of Carers</td>
<td>‘Should he/she/we use paid care? If so, how much?’</td>
<td></td>
</tr>
<tr>
<td></td>
<td>‘Is he/she at risk of abuse from that paid carer or family member?’</td>
<td></td>
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<tr>
<td></td>
<td>‘Can we recruit self-employed paid carers privately for him/her?’</td>
<td></td>
</tr>
<tr>
<td>Level of Care and Supervision</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>Other Related Issues</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>
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| Note.  aBefore and immediately after leaving hospital.  bUp to two years after leaving hospital. Two or more years after leaving hospital.  cOPC = Office of the Protective Commissioner. |

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 in Figure 5.1.
<table>
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<th>Sub-processes</th>
<th>Strategies</th>
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<td>Gathering Information</td>
<td>Consulting Experts</td>
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<td>Managing Barriers</td>
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<td>Appraising Alternatives</td>
<td>Anticipating Benefits</td>
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<td>Remaining Open</td>
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<td>Enacting a Decision</td>
<td>Obtaining Resources</td>
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<td></td>
<td>Building Skills</td>
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<td></td>
<td>Adjusting Expectations</td>
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</tbody>
</table>

*Figure 5.1 The Process of Care Decision-Making*

**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.

**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 Offices of the Protective Commissioner
(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.

*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.

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.

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.
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, irretreivable 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.

*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.


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.

Obtaining Resources

When enacting or implementing 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.

*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.

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.
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.
Chapter 6  CARE MAINTENANCE

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. 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).

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Figure 6.1 The Process of Care Maintenance

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).
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.

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.

**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.
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.

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
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.

**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.

**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.

**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.

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 7  A THEORY OF CARE MANAGEMENT

Introduction

The aim of this study was to explore the processes of care decision-making and care management, factors that influenced care decisions and care management, and care outcomes after brain injury. The previous two chapters described care decision-making and care maintenance, processes that were necessary for optimal care.

In this chapter, a condensed interpretation of data will be presented, summarising the content of Chapters 4, 5 and 6. Two case studies illustrate the processes, strategies used, factors influencing care and the outcomes 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.

The Story of Care Management

During the initial phase of decision-making, whether by choice or by default, family members typically assumed the role of primary decision-maker, regardless of their pre-injury relationship with the injured person. Early care decision-making was also shared with members of the rehabilitation team.

Decision-makers started by gathering information about alternatives, particularly the living situation. Family members consulted experts such as health professionals, directors of care agencies and insurer representatives in order to obtain the necessary information. These experts met with and offered advice to family decision-makers. These experts provided information about care alternatives and made recommendations about the possible and recommended ways of living. These experts typically advised that recovery would be enhanced if the person with brain injury lived in a familiar environment with their family, and if paid carers were used. However, if no close family member was available to become the primary live-in carer, or if the injured person was very impaired, the experts were likely to suggest nursing home placement. The limited alternatives were appraised by family decision-makers. They considered the benefits and risks of each alternative, to the person with brain injury and the family as a whole. A spouse or parent usually decided to live with the person with brain injury and become their primary carer. Most received some insurer-funded care if a third party insurer had accepted liability.

Implementing the preferred way of living and enacting a decision involved obtaining resources. These resources typically included a private case manager, a care agency, a team of paid carers, accessible housing and specialist disability equipment. Insurer approval and funding were required. Furthermore, skills such as mobility and transfer skills had to be developed prior to hospital discharge, as well as learning how to manage challenging behaviour. Both carers and the person with brain injury required additional skills. Performance of these skills would be tested and refined in hospital and at home.
When the person with brain injury returned home, participants held expectations about the contribution of the living situation and configuration of carers to recovery. They reflected on and learned to adjust their expectations as experience increased. They recognised that staying together as a family may or may not be possible because of the brain injury. Some family carers recognised that the presence of paid carers increased rather than decreased their work. This was not what had been expected. Some learned to accept risk, recognising that a risk-free existence was unrealistic if care was to be reduced and autonomy increased.

The process of care maintenance began at this time and continued indefinitely. Although care decision-making had been the focus up to this point, priorities changed. Care maintenance involved monitoring the way of living, managing conflict, and supporting carers. Monitoring the way of living, the quality of care and performance of carers was part of maintaining a stable way of living. Some ways of living required more monitoring than others. Everyone in the team, except the person with brain injury monitored the performance of others. Paid carers monitored the work of other paid carers and of family carers. Case managers did likewise. Family carers monitored the work of paid carers. Everyone checked the wellbeing of the person with brain injury. They looked for physical signs or changes in behaviour that might indicate a problem.

Managing conflict consumed a large part of most family carers’ time. Challenging behaviour of the person with brain injury meant that conflict was never far away. Case managers and family carers learned to recognise conditions that might trigger conflict. They tried to eliminate these triggers. They also acted as a mediator when conflict arose in the home.

Supporting carers was the role of a case manager in most instances. They regularly contacted, visited and liaised with family, paid carers and care agencies to help with problem solving. Others such as siblings, friends and respite service providers also tried to share responsibility for care. Family carers provided much of the necessary support to paid carers, because they worked closely together in the home. Paid carers were often not as experienced as care agencies promised. Consequently, many did not cope well with the demands of the job. Care agency directors were also not available to support staff when they most needed help. Paid carers often left during or after their first shift.

In roughly half the cases, the living situation, configuration of carers and level of care stabilised, and minimal care maintenance was required. However, the constancy of care maintenance work became too great for some family carers. In other cases, the person with brain injury preferred a different way of living. At this time, care decision-making began again, shared by the family carer and case manager. The process of care decision-making proceeded as before. The identified decision-maker engaged 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 was needed about the implications and long-term cost of each alternative. This information was obtained from experts such as estate managers at the Office of the Protective Commissioner (OPC). An independent medicolegal assessment was sometimes requested, to objectively assess abilities and needs. New barriers to
information had to be overcome, such as a slow or obstructive insurance company. Allies, such as a local Member of Parliament were recruited for this purpose.

The benefits and risks of each new alternative were appraised but now in more depth. Benefits to the person with brain injury and their family had to outweigh risks. Tolerance for risk increased 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 developed an increased and mutual tolerance for risk. The person with brain injury and their family often recognised a need to live apart. Shared living may have failed or the person with brain injury may have developed a readiness for change and more autonomy. A decision was then made to find a new home and purchase more paid care, to replace family care. Decision-makers tried to remain open to any alternatives that might optimise the way of living. They considered 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 implementing these decisions, resources had to be obtained. A new home needed to be bought or rented. Skills such as budgeting and cooking had to be developed, to increase the chance of success. Goals were set and routines established. Money was an important resource at this stage if the person with brain injury moved into his or her own home with paid care. In order to contain long-term costs and find satisfactory staff, some decision-makers recruited carers privately and bypassed care agencies. The family decision-maker then ceased being primary on-site care provider, but remained involved in monitoring care. Care maintenance work required renewed vigilance when the person with brain injury moved into his or her own home, but reduced later.

While implementing a decision, the person with brain injury and their family reflected on the outcome and adjusted expectations again. Often the way of living and outcomes of decision-making were better than expected. The person with brain injury enjoyed autonomy and privacy for the first time in years. They took greater control of their daily routine and made small but independent day-to-day decisions. They were given permission once again to learn from their mistakes and enjoy the dignity of risk. Relationships with family often improved. The person with brain injury wanted and hoped for more. They wanted friends, intimacy, more control over their life and less supervision. Family carers and case managers, now more experienced, agreed with these goals and the cycle continued.

This story describes how participants established and then maintained the best possible living situation, configuration of carers and level of care. The presence of a care manager contributed to the success of the resulting way of living. As time passed, risk tolerance increased. When this tolerance for risk was mutual, decisions were made that led to reduced care, supported low-level risk taking and led to a more satisfying and autonomous way of living. The model is represented visually in Figure 7.1. Two cases from the study will now be used to illustrate the process of care management and the cycle of care decision-making and care maintenance. The first case illustrates a successful transition from living with family to living alone. The second case highlights the consequences for a person with brain injury when the process of care management and the necessary conditions were less optimal.
Figure 7.1 The Process of Care Management
Case 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 try 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 their children. A variety of physical and human resources were obtained; a house was rented 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, all carers needed some training and skill development. Carers 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. Few 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 day-care 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 run 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.

**Case 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.

Chapter Summary

A 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 care management. 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 7  DISCUSSION

Introduction

The consequences of a severe traumatic brain injury are substantial, both socially and financially for the person affected, their family and society. 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 appear to vary unduly, and inequities exist between people with and without compensation, those with and without family carers. This study sought to redress gaps in knowledge about care decision-making and care management following brain injury by exploring how and why care decisions were made, and how care was managed.

This 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 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, and recommendations made for practice, policy, education and research.

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). Men 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.

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.

(a) 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 the 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 a ‘showcase’ of potential living options 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 will give people with brain injury greater choice in how they live because they can buy paid care. Unfortunately, paid care is not the panacea everyone assumes it will be.

(b) 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, although 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.

(c) 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 about effective ways to recruit and manage 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.

(d) 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 recent 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 a 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 factored into compensation.

(e) 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 to, and 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).

(f) 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.

(h) 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 family (n=12, 85.7%). 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 times post-injury (14% and 33%; Hoofien et al., 2001, and Koskinen, 1998 respectively).

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 Bruzny 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 perhaps living with family should be avoided entirely.

(i) 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 in the study, 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 the study who needed 24-hour care and did not live with their family 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.

**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 the 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.

(a) *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.

(b) *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.

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.

(a) 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.

(b) Assisted Decision-Making. Assisted decision-making is a specialised process that may benefit family carers and people with brain injury. Assisted decision-making
includes 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.

*(c) 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.

*(d) 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 Office of the Protective Commissioner (OPC) by the majority of participants. Nonetheless, even when the OPC was involved, family carers still engaged in shared or assisted decision-making.

(e) 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, Seacat, & Rosenthal, 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.

(f) 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 bypassing 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.

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.

(a) 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.

(b) 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.

(c ) 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) recently 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.

Factors or Conditions that Influenced Care

Another question posed at the beginning of this study related to factors or 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.
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.

(a) 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.

(b) 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.
(c) 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.

(d) 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.

(e) 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. Estate managers at the OPC appeared to have a particularly high tolerance for risk because of their 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.

‘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.

(a) 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.

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.

(a) 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.

(b) 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.

(c) 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, DeJong, & Ward, 2002; Grimby, 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, Davies, Carlson, Johnston, & Minnes, 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.

Limitations of the Study

This study was designed to explore and develop a theory or model 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 or central 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 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, and reviewing this information 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.

**CONCLUSIONS**

This study explored care decision-making and care management after brain injury. The study was guided by three questions about (i) the preferred models of care, (ii) the processes and strategies involved, and (iii) the factors 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 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 one of the study participants 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.*

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Appendix A-1
Interview Questions and Prompts
(Early/Intermediate Interviews)

For the person with the brain injury

“I’d like to draw a picture of your life - it’s called a lifeline - could you tell me about some of the changes and events in your life after your accident?”

Prompts: New paths, new choices, transitions, events, what alternatives were there at each transition, did the person see a choice, changes in carers, try to describe series of carers, and decisions along the way.

“Tell me about some of the decisions that have to be made since you left hospital?”

Prompts: Ask about events on their life-line, then later ask about changes in care, include them in lifeline as person talks, ask about why carers may have left, why things did or did not work out, check if there are any changes in care that have not yet been discussed/mentioned.

“Tell me a story about one of your carers?”

“I’d like to ask you about some of the activities on your daily/weekly timetable”

Prompts: Who helps with different tasks; roles of family vs paid carers; frequency and type of social contacts.

What happens when (primary carer) is not available, for example they are ill or on holiday?”

Prompts: Explore what happened in specific circumstances, care recipients preferences, options available to them, how often this happens, how they feel, future plans, explore decision making and choices.

“What worked well?”

(Prompts: Characteristics, attributes, values of carers, gender, age, qualifications and experience)

“When (name 2 carers) were employed, were you involved in staff selection and interviewing?” “Would you like to be?”

“Do you have any comments or views on the cost of care?”

“And your views on live-in versus live-out carers?”
Appendix A-2
Interview Questions and Prompts (Later Interviews)

“Tell me about about some of the decisions that have had to be made since the accident?”

Prompts: Events that happened after hospital, getting care staff, new activities; getting a new home; deciding on a school, deciding on an agency; quals of carers; live-in versus live-out; leaving school; temper control management; learning new living skills; getting out more; personal goals and aims; exercises/therapy; falls – risks; holidays; care shifts/hours; getting rid of carers; induction; cost issues

“What process or steps did you follow?”

Prompts: Style of decision-making (quick vs deferrer); accepting the challenge (when, why);

“Did you seek out any information? If so, from whom?”

Prompts: What were the options or alternatives? Advantages and disadvantages of each; costs;

“Was there any difficulty making the decision? (decisional conflict)”

“How did you feel after you had made this decision?”

Prompts: Responses to decision-making = feelings, actions, regret. Was anyone around them anxious?; Was the risk worth the decision; partner support; case manager or someone else trying to control their life; too tired to recruit own carers)