RESPITE SERVICES AND ACQUIRED BRAIN INJURY IN NEW SOUTH WALES:
THE PERSPECTIVES OF PERSONS WITH ACQUIRED BRAIN INJURY, THEIR
CARERS AND SERVICE PROVIDERS

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Respite Services and Acquired Brain Injury in New South Wales:
The perspectives of persons with acquired brain injury, their carers and service providers

I Jeffrey B. Chan, was primarily and principally responsible for the following: development of the research proposal and research questions; submission for ethical approval; selection of research methods; data collection; data management; data analysis; and interpretation and presentation of the findings.

I acknowledge the assistance of my supervisors, who provided constructive feedback and critique throughout all stages of the research and reviewed drafts of the thesis.

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Respite Services and Acquired Brain Injury in New South Wales:
The perspectives of persons with acquired brain injury, their carers and service providers

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Abstract

Persons with acquired brain injury require continuing support and care in various aspects of their lives many years post-injury. Their care and support are mainly provided by family members. While respite is one of a range of critical support systems for carers and people with life-long disability, very little is known about respite in the area of acquired brain injury. The majority of the research on respite has been undertaken in developmental disability, mental health and in aged care, but there is no research to date about respite from the perspectives of the person with a disability, the carer and respite provider. There is also no research that examines these perspectives in the acquired brain injury literature.

This study was aimed to address this gap in the literature by investigating respite from the perspectives of the person with acquired brain injury, the carer and the respite provider. It also examined the profile of respite services being provided in the Australian state of New South Wales as there had not been a comprehensive mapping of respite before. Survey methodology was used to gather information from persons with acquired brain injury and their carers who were members of the New South Wales Brain Injury Association, which is the peak advocacy association of people with brain injury. The same methodology was used to gather similar information from members of Interchange Respite Care New South Wales, which is a peak association representing respite providers in the state.

The survey questionnaires were developed and designed after an extensive review of the literature, and were reviewed by experts in the fields of respite, disability and acquired
brain injury. The survey questionnaire was also trialled on a sample of families. The survey questionnaires for the three participant groups shared several common sections, such as demographic information; factors influencing respite use; expectations of respite; and satisfaction with respite services used by persons or carers. The responses from the three participant groups were analysed and compared using logistic regression and descriptive statistics.

The key findings of the study are (a) several characteristics or factors of the person with acquired brain injury and their carer were significantly associated with the use of respite, (b) there were several common factors that all three participant groups reported to influence respite use, and (c) there were several common expectations of respite among the three participant groups. Some of the characteristics or factors that were significantly associated with respite use included the severity of disability, the high level of dependency of the person with acquired brain injury, and the number of days spent in a coma. Common factors reported by all three participant groups to influence respite use included the stress level of the carer and the severity of disability. Factors reported to influence respite use appear to be consistent with the literature in developmental disability.

There were common perspectives regarding the expectations of respite among all three participant groups, such as the need for trained and qualified respite staff; a wider range of respite services and more flexibility of respite service provision. The study also indicated a reported lack of sufficient respite for persons with acquired brain injury and their carers. Some of the findings of the study appeared to be consistent with the research literature on acquired brain injury; such as the majority of carers being mainly female; there is a reliance
on informal networks for the care and support of the person with acquired brain injury; and the majority of the persons with acquired brain injury being male. The study also found that many respite providers in New South Wales had extensive experience in running a respite service.

The findings of the study have important implications for policy direction and development, practice and service delivery, and research. In terms of policy direction and development, implications explored included: a flexible funding model that is responsive to the needs of carer and person with acquired brain injury, and adequately trained and qualified staff and volunteers play an important role in respite provision. Further research is required to understand empirically the benefits and quality of life outcomes over a period of time, such as what types and extent of respite are more beneficial for certain demographic profiles.

The study highlights the perspectives of persons with acquired brain injury, their carers and respite providers. Respite is an important support system to enable persons with acquired brain injury to receive the continuing care and support from their carers. Respite in acquired brain injury is a new field that merits further research as it holds the potential for addressing the needs of people with acquired brain injury and their carers.
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This research is dedicated to persons with acquired brain injury and their carers who continue to move forward with their lives despite the impact of the injury sustained and personal tragedy experienced. Their resilience has greatly influenced my practice and will continue to guide the way I conduct my day-to-day work. I thank them and their carers for their participation in this project and for sharing honestly their perspectives on respite.

This research is also dedicated to respite practitioners and service providers who work hard to provide the best quality service in an era of competing needs and limited resource.

I am very grateful for the collaboration and participation of the New South Wales Brain Injury Association and the Interchange Respite Care New South Wales Association members in this research. Thank you for the support and co-operation provided.

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Technical Report:

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CHAPTER ONE

Introduction

**Context of the problem**

The aim of this study was to investigate respite services for persons with acquired brain injury. The deleterious and life-time impact of acquired brain injury on the individual, on the family and/or the carer will be presented in the following chapter. The impact of acquired brain injury on the “whole of life” experience is discussed, not just on the physical well-being of the person with an injury but on significant aspects of the life of the person, the family and carer. The impact of acquired brain injury will be discussed predominantly from the perspective of carers and their need for support so that they can continue the care of the person with acquired brain injury. Respite as a potential family support system for carers of persons with acquired brain injury is comprehensively explored. There is a paucity of research in the area of respite and brain injury compared to the area of developmental disability. Hence, the review of respite was drawn mainly from the area of developmental disability in order to have a broader understanding of respite. Respite in other areas such as in mental health or aged care was also explored.

To date, there is a lack of integrated information and profiling of respite services in New South Wales. Little is also known about how current respite services are actually meeting the needs of carers in general, particularly in the area of acquired brain injury. Despite the comprehensive research in respite care and its benefits, there has been minimal research on the factors that predict respite use and non-use by carers. Hence, the aims of the study were to map out what were the available respite services in New South Wales;
ascertain the profile of people with acquired brain injury and carers who may have a need for such a service; and more importantly, determine and compare the expectations and needs from the perspectives of respite care providers, the individuals with acquired brain injury and carers. No research to date has explored the views of key stakeholder groups on respite care. Findings from this study are important for state-level policy formulation and resource allocation.

Acquired brain injury is one of the leading causes of death and life-long disability, and a major health problem worldwide (Teasell et al., 2007; Xu, Liu, Yang & Li, 2007). In Australia, nearly 2% of the population is reported to have acquired brain injury (Australian Institute of Health and Welfare, 2003). There is a large empirical data set on epidemiological aspects of acquired brain injury, but few studies on continuing support service provision for people with acquired brain injury and their carers, following acute rehabilitation. While there has been an approach to care and co-ordination of services to people with acquired brain injury and their families over the years, much of the rehabilitation process tended to focus on physical rehabilitation (Cope, Mayor & Cervelli, 2005). For example, there are numerous studies on the incidence and prevalence of acquired injury (e.g., Australian Institute of Health and Welfare, 2003; Kraus et al., 1984; O’Connor, 2002; Tate, McDonald, & Lulham, 1998). The incidence of acquired brain injury in Australia is between 57 to 377 per 100,000 of the population per year (Australian Institute of Health and Welfare, 2003) with males more likely to acquire a brain injury than females. O’Connor (2002) reported that the incidence rate of traumatic brain injury in 1997-1998 was about 141 per 100,000 of population.
It is also known that majority of persons with acquired brain injury continue to experience significant long-term problems (Basson et al., 1991; Colantonio et al., 2004; Corrigan, Whitney & Mellick, 2004; Florian, Katz & Lahav, 1989; Hoofien, Gilboa, Vakil & Donovick, 2001; Koskien, 1998; Kraus et al., 1984; McCabe et al., 2007; Nabors, Seacatt & Rosenthal, 2002; Onsworth, Turpin, Carlson & Brennan, 2004; Perlesz, Kinsella & Crowe, 1999; Schalen, Hansson, Nordstrom & Nordstrom, 1994; Tate et al., 2004; Tate, Strettles, Hodgkinson & Veerabangsa, 2003; Tomberg, Toomela, Ennock & Tikk, 2007; Willer, Allen, Durnan & Ferry, 1990). The long-term problems experienced by these individuals impact on every facet of their lives. It is also known that their support needs are varied and continue years after the injury (Onsworth et al., 2004; Hoofien et al, 2001; Corrigan et al., 2004; Tate et al., 2003).

Furthermore, acquired brain injury impacts not only the person but also the family or carer (Florian et al., 1989; Marwit & Kaye, 206; Perlesz et al., 1999; Urbach, Sonenklar & Culbert, 1994; Wade, Taylor, Drotar, Stancin & Yeates, 1996; Willer et al., 1990). The impact of acquired brain injury is costly in terms of not only lives lost but also on healthcare expenditures and productivity losses for the community (Max, MacKenzie, & Rice, 1991). Max et al. (1991) developed an economic model to determine the lifetime cost of all head injuries in 1985 in the United States of America. They found that the lifetime associated cost with all head injuries resulting in death or hospitalization was estimated at $37.8 billion. More than 65% of the total cost was accrued among those who survived a head injury. Therefore, from these studies the logical conclusion is that acquired brain injury is a significant problem that has many negative consequences for the individual, his or her family, and society at large. The need for research on aspects of service provision,
such as the use of respite, is therefore obvious. There is also a need to discuss social policy and resource allocation for persons with acquired brain injury to support their needs and those of their carers (DeJong & Batavia, 1989; Goodall, Lawyer, & Webman, 1994; Vaughn & King, 2001).

There has been some research into the development of community-based and home-based rehabilitation for persons with acquired brain injury (Farmer, Clippard, Luehr-Wieman, Wright & Owings, 1996; Freeman, 1997; Geddes & Chamberlain, 2001; Johnston & Lewis, 1991; Kreutzer et al., 2002; McCabe et al., 2007; McColl et al., 1998; Sinnakaruppan & Williams, 2001; Smith et al., 2006; Warden, Salazar, Martin, Schwab, Coyle & Walter, 2000; Willer, Rosenthal, Kreutzer, Gordon & Rempel, 1993). Despite this increasing research, few studies have investigated the provision of support services for the family or carer while the person with acquired brain injury lives at home or in the community (Florian et al., 1989; Willer et al., 1990). Most of the few available studies in this area are focused on counseling, stress management and support networks (Gervasio & Kreutzer, 1997; Kaplan, 1991; Willer et al., 1990). Despite the emerging research on community-based services, there is still a lack of appropriate service and support for people with acquired brain injury, post-inpatient rehabilitation (Pryor, Mott & O’Reilly, 2002; Rotondi, Sinkule, Balzer, Harris & Moldovan, 2007; Winstanley, Simpson, Tate & Myles, 2006).

The potential of respite services as another form of support service for the family or carer and the person with acquired brain injury has been recognized (Marsh, Kersel, Havill, & Sleigh, 1998; Winstanley et al, 2006), but it has received little attention from applied
disability researchers. To redress this relative neglect, this study focussed explicitly on the use of the expressed need for respite by persons with acquired brain injury and by the families who care for them. The study was designed to provide contextualized information by mapping out services or lack of respite services for people with brain injury. It was anticipated that this will lead to a better understanding of the needs of carers and the role of respite care in meeting these needs. Information of this type is critical in the move towards developing evidence-based practice in the rehabilitation of people with acquired brain injury. The same information is also critical for policy development, resource allocation and planning.

A summary of the definition of acquired brain injury and its prevalence in the Australian context is presented. The definitions of dependency are offered as these form part of the study’s research survey questions. Given the paucity of research on respite in the area of acquired brain injury, the definition of respite is also presented. The definitions of the various types of respite are summarized and the definitions of respite discussed are also used in this study’s survey questionnaire. The intention is to ensure consistency with the international literature and as it is defined in the Australian context.

**Definition and Prevalence of Acquired Brain Injury in Australia**

This study adopted the definition of acquired brain injury developed by The National Policy on Services for People with Acquired Brain Injury (Department of Human Services and Health, 1994). According to this definition, the term “acquired brain injury” refers to any injury to the brain which results in deterioration in cognitive, physical, emotional or independent functioning. Acquired brain injury can result from trauma, hypoxia, infection,
tumour, substance abuse, degenerative neurological disease or stroke. Impairments of cognitive or physical ability may be temporary or permanent. It can cause partial or total disability or even psychosocial maladjustment.

Acquired brain injury can be categorized as either traumatic or non-traumatic (Teasell et al., 2007). Non-traumatic brain injury is typically associated with stroke and alcoholism. The two types of traumatic brain injury are open head injury and closed head injury. Open head injury is a result of a penetrating wound to the head that enters the brain and causes soft tissue damage (Liss & Willer, 1990). Closed head injury refers to a non-penetrating injury which results in brain dysfunction (Liss & Willer, 1990). Traumatic brain injury may be the result of motor-vehicle accidents, falls or other injuries to the brain (Australian Institute on Health and Welfare, 2003; Kraus et al., 1984). Young adult males present with the highest incidence of traumatic brain injury (Kraus et al., 1984; Kreutzer, Marwitz & Witol, 1995). According to the Australian Institute on Health and Welfare (2003), almost 70% of traumatic brain injuries occur in males, and males had higher rates than females in all age groups.

Using an approach based on ‘all disabling conditions’ (defined as where people responded positively to the question about long-term effects of their acquired brain injury, whether or not this was their main disabling condition), the estimate of the prevalence of acquired brain injury population is about 2.1% of the total Australian population in 1993 or 370,700 people (Fortune & Wen, 1999). About 1.9% or 338,700 of these with acquired brain injury have a limitation on activities of daily living and participation restrictions (Australian Institute on Health and Welfare, 2003). The prevalence of acquired brain injury
related disability increased with age for both males and females, with males (1.3%) having more disabling conditions than females (0.9%) (Australian Institute on Health and Welfare, 2003). According to the Australian Institute on Health and Welfare, the highest age-specific rate for people with traumatic brain injury was between 15-19 years with an estimated incidence of 285 per 100,000. The next highest rate was for children aged 0-4 (244 per 100,000) and the lowest rate was people aged 45-64 (69 per 100,000).

In the above 65+ years age range, 2.6% were males and 2.1% were females. In the 65 years and under, 1.2% were males and 0.8% were females with acquired brain injury. Around 39% of people with acquired brain injury as their main disabling condition reported that their injury occurred before the age of 20 years. A further 42% reported an age at onset between 20 and 39 years (Australian Institute on Health and Welfare, 2003). The prevalence of acquired brain injury in the older age group reflects a high incidence of brain injury caused by stroke (non-traumatic brain injury). Alcohol-related brain injury is a one of the causes of disability in the middle-adult years. The incidence and prevalence of alcohol-related brain injury are difficult to ascertain because of under-diagnosis and, differences in methodologies and different study populations make study comparisons difficult. Overall, 81% of people with acquired brain injury reported injury or accident as the main cause (Australian Institute on Health and Welfare, 2003). Furthermore, acquired brain injury has the second highest projected growth rate of 5% for the period 2006 – 2010 among people aged 0-64 years (Australian Institute on Health and Welfare, 2007).

The prevalence of the acquired brain injury population was estimated at about 1.9% of the total Australian population. According to Fortune and Wen (1999), there were
approximately 338,700 people with brain injury in Australia. Slightly less than 1% (i.e., 0.9% or 160,200) of these has a severe or profound handicap, meaning they will always or sometimes require personal assistance or supervision in activities of daily living (Australian Institute on Health and Welfare, 2003). Overall, there were about 12,900 persons with acquired brain injury (0.1% of the population). The prevalence of acquired brain injury related disability increased with age for both males and females, with males (1.3%) having more disabling conditions than females (0.9%) (Australian Institute on Health and Welfare, 2003). According to the Australian Institute on Health and Welfare, the highest age-specific rate for people with traumatic brain injury was between 15-19 years with an estimated incidence of 285 per 100,000. The next highest rate was for children aged 0-4 (244 per 100,000) and the lowest rate was people aged 45-64 (69 per 100,000).

There are 8,017 persons identified with acquired brain injury who accessed government funded specialist disability services according to the Australian Institute on Health and Welfare (2006) report. They comprised 4% of the total number of individuals who accessed government funded services, funded through the Commonwealth, State and Territories Disability Agreement (CSTDA). The majority of these people were in the 26 – 44 years age range (3,258 persons) and in 45 – 64 years (3,098 persons). Slightly more than half of these individuals (55.3%) identified themselves as having another significant disability type, such as physical disability or a sensory disability.

The disabling conditions of people with acquired brain injury are defined in four levels of handicap (Australian Institute on Health and Welfare, 1999). The levels of handicap are
(a) profound where personal help or supervision is always required, (b) severe where personal help or supervision is sometimes required, (c) moderate where no personal help or supervision is required, but the person has difficulty in performing one or more tasks, and (d) mild where no personal help or supervision is required and there is no difficulty in performing specified tasks, but the person uses an aid, or has a mild mobility handicap or cannot easily pick up any object from the floor. The levels of handicap as defined by the Australian Institute on Health and Welfare (1999) are important in terms of their implications for service delivery, such as funding, resource allocation (e.g., access to health, disability and other support services), housing, and policy formulation (Department of Human Services & Health, 1994).

Definition of Respite

There are various definitions of respite care (Australian Institute of Health & Welfare, 2006; Cohen, 1982; Cox, 1997; Hayes, Cotterill, Sloper & Flynn, 1995; MacDonald, Fitzsimons & Walsh, 2007; Parmenter, 1999; Salisbury & Griggs, 1986). In a review of respite services in aged care, in particular, those with Alzheimer’s disease, Cox (1997) defined respite care as “to offer relief to caregivers, not only to contribute to their wellbeing, but also to assist them in maintaining their relative in the community”. Cohen (1982) defined respite care for persons with developmental disabilities as denoting “temporary care given to a disabled individual for the purpose of providing an interval of relief to the individual’s primary caregiver(s)” (p.8). Salisbury and Griggs (1983) defined respite care as “services designed to provide temporary relief for parents from the caretaking responsibilities associated with having a developmentally disabled family...
MacDonald et al. (2007) reiterated that respite as a support system for the family should be flexible and provide a range of options.

In a focus group study of carers, respite service providers and persons with disability who used respite in city and rural areas in New South Wales, Parmenter (1999) defined respite as (a) break or time-out for the carer and the person with disability, (b) “a substitute for natural supports” (p.9) and this notion was noted by Parmenter to be particular for carers in rural and remote areas, (c) flexible enough to meet family needs, (d) preventative in the sense that it assists in keeping the family together longer, and (e) “respite support is not the same as emergency or crises care” (p.10). The study by Parmenter is interesting as it is one of a very few studies that defines respite care from the viewpoints of the carer, the person with a disability and the respite service provider.

Hayes et al. (1995) conducted a survey of 76 Directors of Social Services in England who were asked to supply the definition of respite. Hayes et al. (1995) found a broad range of responses and majority of the responses (63%) referred to the benefits of the respite to the carer. The most frequently mentioned benefit of respite was as a break from caring (28%). Hence it is evident from the above studies that respite may be defined in various ways depending on the perspective of the person who uses respite (e.g., carer or person with disability, or the respite service provider). This was one reason why this thesis examined respite for people with acquired brain injury from multiple perspectives: of the carer, person with disability and the respite provider.

It is important to note that respite may be planned or unplanned (Levy & Levy, 1986). Planned respite can be briefly defined as respite that has been scheduled by the carer at
regular intervals negotiated between the carer and the respite service provider. Carers may use respite to conduct errands, spend time with other family members, seek employment or simply to relax (Levy & Levy, 1986). Unplanned respite care is utilized by carers to attend to emergencies or crises (Levy & Levy, 1986). While this definition of respite is different from Parmenter’s (1999), respite care is used by carers during emergency situations such as hospitalisation of another family member or simply attending to another sick family member. Parmenter (1999) argued that respite support is not the same as emergency or crisis care because in such a situation, a carer would not be able to relax as intended by respite support. The rationale is that respite is intended to be preventative rather than crisis-driven.

Although there may appear to be various definitions of respite care, there are several consistent characteristics. These characteristics include the terms “temporary” or “short-term”, “breaks” or “relief” provided to the “family” or “carer”, it can also be provided to the person with a disability; and that respite care may be “planned” or “unplanned”, or used in an “emergency”. Given that the context of this study is in Australia, the definition of respite care services presented by the Australian Commonwealth Disability Services Act (1986) will be used. The Commonwealth Disability Services Act (1986) defines respite as “services for relief or assistance, for a limited period of time and whether on a planned or unplanned basis to (a) the families of, and other persons who provide care or assistance to, persons with disabilities living in the community, or; (b) persons with disabilities living in the community” (Section 7). A closer analysis of the above definitions indicates that it is consistent with the definition found in the literature on respite.
The Commonwealth Disability Services Act (1986) also defined the primary aim of respite as not only making available to individuals and long-term carers, on a short-term basis, relief from or assistance with their caring responsibilities, but also to maintain the long term viability of the usual arrangements in the community (Department of Community Services and Health, 1990). Implicit in the primary aim is the prevention of (re)institutionalisation of people with a disability and the maintenance of care within the community.

Use of Respite in Australia

According to the Australian Institute of Health and Welfare (2006), there were 200,493 individuals who accessed a range of government CSTDA-funded disability services, such as accommodation and community support. Of these individuals, 23,951 persons (11.5%) accessed respite services across Australia and 4,129 persons accessed respite in New South Wales alone. Males (58%) accessed respite more than females (42%). The age groups of individuals who accessed respite are 0 -4 years (2.6%), 5 – 14 years (29.4%), 15 – 24 years (27.7%), 25 – 44 years (25.6%), 45 – 64 years (12.6%), more than 64 years (1.9%) and not stated (0.3%).

Relating the ‘Context of the Problem’ to Research

The preceding chapter introduced the context of the problem, that is, the life-time impact of acquired brain injury on the person and carers. It also introduced the definition of respite and its potential benefits. A comprehensive review of the life-time impact of acquired brain injury and carers will be presented in Chapter 2. Respite services and their
potential benefits were also reviewed in Chapters 4 and 5 with the intention of demonstrating respite service as a potentially effective service to alleviate the ‘burden’ of care.

There is minimal research on the respite needs of carers of persons with acquired brain injury. There is no research to date that examines what people with acquired brain injury think about respite. Similarly, there is no research that examines the perspectives of carers of people with acquired brain injury regarding respite. There is a lack of a comprehensive mapping of respite services in New South Wales. Hence, there is a need to have a profile of the availability of respite in general and for people with acquired brain injury in particular. Except for a brief report by Parmenter (1999), very little is known about respite and its relationship to its use or non-use from the viewpoints of the person with disability, carers and service providers. Findings obtained from such a research have merit in informing policy development and resource allocation at national and state-level. The findings will be relevant to the respite literature and in particular, in the field of acquired brain injury.

An Overview of the Thesis Plan

Chapter 1 presented the context of the problem regarding people with acquired brain injury and the paucity of research in respite and acquired brain injury. The chapter defined respite and acquired brain injury. The initial step to the research was to examine the impact of acquired brain injury on the person and family or carer (Chapter 2). There is substantial research on the consequences of acquired brain injury relating to the mental health, behaviour and quality of life on the adults and children. A brief discussion linking crime and/or violent behaviour and acquired brain injury was discussed. A descriptive study was
undertaken by the author relating to crime and acquired brain injury but not presented as part of the thesis. The consequences on the family were also examined. An overview of family coping theories were explored and the role respite could play in the resiliency model of family adaptation was presented in Chapter 3. The views of carers were also briefly presented in Chapter 3 to reinforce the experience of families who have to provide continuing care for a person with a disability.

As most of the research on respite had been conducted in the developmental disability sector, a review of respite on the characteristics of persons and carers that might influence respite use or non-use in developmental disability was investigated (Chapter 4). A further review of respite in the developmental disability sector examined whether respite reduced family stress (Chapter 5). The reviews were published and are submitted as part of this doctoral thesis. The next step was to conduct an in-depth review of respite as a support system for the family (Chapter 6) and drew upon the literature in acquired brain injury, developmental disability, mental health, aged care and in children with chronic conditions. The review also examined respite provided to children, adolescents and adults. The in-depth review examined respite in terms of models, availability, predictors of use or non-use, the potential benefits and family expectations of respite.

A descriptive study on an outcome regarding respite leading to long-term residential placement of some adults with developmental disability was undertaken. The purpose was to provide a further understanding of the issues concerning respite provision. The study was published but is not submitted as part of this doctoral thesis as it pertained to some adults with developmental disability who presented with significant challenging
behaviours. The study showed these adults ended up in long-term out-of-home placement even though they were intended for respite placement originally.

It was evident that there is a paucity of research in respite, and in particular, in the area of acquired brain injury. Furthermore, most research considered the perspective of carers and a few examined the perspectives of persons with a disability. There is no research in the area of acquired brain injury that examined the perspectives of the person, his or her carer, and service providers regarding respite.

As the study focused on respite in New South Wales, a brief analysis of the status of respite in the state was presented in Chapter 7 prior to discussing the research methodology. The next step was the development of the research methodology (Chapter 8). The reviews above provided the framework in the development of the survey methodology and the questions that formed part of the survey. A survey methodology was considered because the thesis aimed to reach a broad audience of persons with acquired brain injury, carers and respite providers. A survey methodology rather than a focus group for example, would enable comparison of the perspectives of the participant groups. Key questions in a survey would also enable analysis of associated statistical relationships between factors that may influence respite use with demographic profile and other relevant factors. Consultations with respite providers, government policy officers, carers and expert professionals were conducted to further inform the survey questionnaire. The informal consultations included respite providers in city, regional and rural areas; and with carers of children with acquired disability, including brain injury.
A sample survey was developed with more input from diverse stakeholder groups. The sample survey was trialed on persons with disability and carers. The results of the survey and feedback on the survey questionnaire led to the final survey questionnaire. While the development of the survey questionnaire was in the process, consultations with the peak associations of the New South Wales Brain Injury Association and Interchange Respite Care New South Wales Association occurred. Both associations provided advice and feedback on the development of the survey questionnaire and methodology. The final survey questionnaire was provided to the executive officers of the peak associations for further comments.

The results of the study are presented in the next three chapters (Chapter 9, 10 and 11). One of the chapters has been accepted for publication (Chapter 9) and two chapters have been published (Chapter 10 and 11). Chapter 9 described the results of the survey from the perspective of respite providers in New South Wales and in the Australian Capital Territory, and a profile of respite services was presented. The perspective of carers of people with acquired brain injury was explored and presented in Chapter 10. Chapter 11 explored the perspective of people with acquired brain injury. The results presented were the first study that examined respite in acquired brain injury and explored respite from the views of people with acquired brain injury and their carers.

Chapter 12 pulled together the results presented in the preceding chapters and compared the key findings of the results. The relationship between characteristics of persons with acquired brain injury and carers, and respite provision were discussed, and common factors reported by the three participant groups were presented (Chapter 12).
Other results not published in Chapters 9, 10 and 11 were also presented in Chapter 12.

The final chapter pulled the research findings together and discussed the implications of the study on theory, practice, policy and research (Chapter 13). A final argument of the significance of this study was discussed in Chapter 13.
CHAPTER TWO
Impact of Acquired Brain Injury

Chapter 1 presented the context for people with brain injury and the paucity of research in the area of respite care for this population. Data on the prevalence of acquired brain injury indicated that a high number of people with acquired brain injury with severe to profound handicap live in the community. The definition of respite care revealed common themes underlying the various definitions of respite from the perspectives of the carer, the person with disability and the service provider. Finally, an overview of the thesis plan was also presented with a brief rationale for the methodology used for the study.

The first section of Chapter 2 presents an overview on the impact of acquired brain injury on the person with the injury and on the family or carer. It is not within the scope of this thesis to review the research literature on all the aspects of the impact of acquired brain injury. Rather, the focus is to highlight some of long-term implications of acquired brain injury on the person; in particular, on behavioural and psychological functioning. The person with acquired brain injury may be an adult or a child. This section focuses on the impact of acquired brain injury on the family, in terms of family functioning and coping experienced by spouses, parents and other immediate family members. Most of the research selected for review have been in the area of traumatic brain injury, given that majority of the members of the Brain Injury Association of New South Wales (BIA NSW) are from this population. BIA NSW is the peak State advocacy organization that represents persons with acquired brain injury and their carers, and it plays a role in influencing
government policy direction on services. It also has an education and information role to its members, as well as promoting community awareness on acquired brain injury.

Impact of Acquired Brain Injury on Adults

It is important to understand the drastic changes that affect the person with acquired brain injury. Most of the individuals with acquired brain injury will have a long-term disability that will impact on the quality of their lives (Australian Institute of Health and Welfare, 1999; Doigh, Fleming & Tooth, 2001; Engberg & Teasdale, 2004; Kneafsey & Gawthorpe, 2004; Man, Lee, Tong, Yip, Lui & Lam, 2004; Mittenberg, DiGiulio, Perrin & Bass, 1992; Rotondi et al., 2007; Tate et al., 2003; Tate et al, 2004; Sloan, Winkler & Callaway, 2004; Smout, Koudstal, Ribbers, Janssen & Passchier, 2001; Stalnacke, 2007; Steadman-Pare, Colantino, Ratcliff, Chase & Vernich, 2001; Pickelsimer et al., 2007; Thornhill et al., 2000; Tomberg et al., 2007). The impact of acquired brain injury on the person can be grouped in several different domains, such as functional or activities of daily living, psychosocial behaviour, personal coping, employment and changes within the person (e.g., psychiatric symptoms) (Florian et al., 1989; Urbach et al., 1994).

The direct consequences of acquired brain injury, such as the physical impairments and neurological limitations (e.g., cognitive impairment or language difficulties) experienced by the person, are demonstrated across the various biopsychosocial domains over many years (Giles, 1994; Koskinen, 1998; Kraus et al., 1984; Stalnacke, 2007; Urbach et al., 1994). While most of the research literature focuses on the impact of traumatic brain injury, persons with minor head injury may also show symptoms that may persist over a few years (Binder, 1986). These symptoms included headache, dizziness, irritability, anxiety, blurred
vision or memory difficulty (Binder, 1986). The following sections will further discuss the long-term impact of acquired brain injury on the domains mentioned above.

**Psychiatric Consequences.**

People with acquired brain injury might experience a range of psychiatric symptoms such as (a) depression (Alderfer, Arciniegas & Silver, 2005; Deb, Lyons, Koutzoukis, Ali & McCarthy, 1999; Douglas & Spellacy, 2000; Fann, Burrington, Leonetti, Jaffe, Katon & Thompson, 2004; Fann, Katon, Uomoto & Esselman, 1995; Glenn, O’Neil-Pirozzi, Goldstein, Burke & Jacob, 2001; Jorge, Robinson, Starkstein & Arndt, 1993; Koskinen, 1998; Jorge, Starkstein & Sergio, 2005; Kreutzer, Seel & Gourley, 2001; Leon-Carrion, Serdio-Arias, Cabezas, Roldan, Dominguez-Morales, Martins & Sanchez, 2001, Van Reekum, Bolago, Finlayson, Garner & Links, 1996; Robinson, Crespo-Fecarro & Ardnt, 2004; Stalnacke, 2007), (b) anxiety disorders (Deb et al., 1999; Fann et al, 1995; Jorge et al., 1993; Van Reekum et al.,1996), (c) mood disorders (Bowen, Neumann, Conner, Tennant & Chamberlain, 1998; Jorge et al, 2005); (d) personality disorders (Slagle, 1990; Van Reekum et al., 1996), (e) schizophrenia (Nielsen, Mortensen, O’Callaghan, Mors & Ewald, 2002), and (e) panic disorder (Deb et al., 1999). These individuals are also at a higher risk of suicide than the non-brain injured population (Leon-Carrion et al., 2001; Oquendo, Friedman, Grunebaum, Burke, Silver & Mann, 2004; Kishi, Robinson & Kosier, 2001; Simpson & Tate, 2002; Simpson, 2004). It appears that depression and anxiety disorders may be common in people with traumatic brain injury (Alderfer et al., 2005; Fann et al., 1995; Jorge et al., 2005). According to Jorge et al. (2005), 40% of persons with traumatic brain injury experienced major depression. The also noted that anxiety disorders,
substance abuse, dysregulation of emotional expression and aggression were frequently associated with major depression.

Leon-Carrion et al. (2001) conducted a series of neuropsychological assessments in a study of 39 persons with traumatic brain injury 18 months after being discharged from the hospital. The individuals attended the hospital voluntarily seeking neuropsychological assessment and rehabilitation recommendations. The Rorschach test was administered to these individuals. The majority of them had open head injury (82%) and 78% were males. Leon-Carrion et al. (2001) found that 48.6% of these individuals met the diagnostic criteria of clinical depression and 65% of them had suicide ideation or tendencies (or 33.3% of the total group). These researchers found that many of these individuals had difficulty coping with complex life situations and had difficulty making decisions. Hence they argued for emotional support for these individuals and in particular, those who appeared to be prone to suicidal ideation.

In another small study conducted 10 years post-injury, Koskinen (1998) evaluated the quality of life of 15 persons with traumatic brain injury. The study involved a series of questionnaires completed by the person and a close relative. Koskinen found that 60% reported functional problems and 73% reported the tendency to be depressed. Eighty-five per cent reported emotional or personality changes (Koskinen, 1998). Douglas and Spellacy (2000) also reported that 57% adults with traumatic brain injury of about 3.5 to 10 years post-injury and 60% of their carers showed significant symptoms of depression. There are several limitations to the above studies, such as their small sample size, the use of clinical samples and a lack of comprehensive assessment to ascertain clinical depression.
For example, only the Rorschach test was administered in Leon-Carrion et al.’s study; whereas the study by Koskinen depended on a self-reporting method. Both studies also did not provide previous history as to whether these individuals might have been prone to depression or anxiety. There is also a question of selection bias in the studies described.

In a larger sample study, Fann et al. (1995) examined 50 outpatient individuals with traumatic brain injury at a rehabilitation clinic. These individuals varied in the number of years post-injury ($M = 32.5$ months) and majority were males (74%). Fifty-eight per cent had mild injury and 42% had moderate-severe injury. Fann et al. (1995) administered the National Institute of Mental Health Diagnostic Interview Schedule that is based on DSM-III criteria and the individuals also completed a series of questionnaires. The study also included psychiatric disorder prior to injury (50%) and family history of psychiatric disorder (42%).

Fann at al. (1995) found that 26% met the criteria for major depression and 24% had current generalized anxiety disorder. For the purpose of analysis, Fann et al. (1995) grouped those with depression and anxiety (42%) and compared them to those without current major depression and anxiety (58%). They found that 81% of the depressed/anxious group were males whose mean age was 40.8 years, 71.4% had mild traumatic brain injury and 28.6% had moderate/severe brain injury. The depressed/anxious group also reported significantly higher scores for other psychiatric disorders such as obsessive-compulsive behaviour, paranoia, psychotism and hostility.

Fann et al. (1995) found that the depressed/anxious group was more disabled than the nondepressed/nonanxious group according to the Medical Outcomes Study Health Survey.
They argued that depression and anxiety are associated with significantly more functional disability. According to Fann et al. (1995), their findings suggested that early diagnosis and treatment of depression and anxiety may alleviate potential problems post-injury and increase level of functioning for such individuals.

Fann et al. (2004) reviewed the prevalence of psychiatric illness following traumatic brain injury in an adult population one year prior to injury and three years post-injury. They found that 49% of patients with moderate to severe traumatic brain injury demonstrated evidence of psychiatric illness one year after injury, compared to 34% of those with mild injury and 18% of those non-traumatic brain injury comparison groups. The study indicated that those with a prior history of psychiatric illness had a higher incidence of psychiatric disorders following injury. They also found that the risk of psychiatric illness was more likely in the first six to twelve months following injury. Hence, Fann et al. (2004) argued that it is important to monitor individuals with traumatic brain injury for psychiatric disorders, in particular, those with a history of prior psychiatric illness.

Stalnacke (2007) investigated the relation between psychosocial functioning as measured by community integration, life satisfaction and social support and symptoms as measured by post-concussion, post-traumatic stress and depression in 163 persons with mild traumatic brain injury 3 years after the injury. Stalnacke found that many of these individuals experienced low levels of life satisfaction (46%), vocation (42%), leisure (43%) and psychological health (60%). Depression was the most frequent secondary condition after injury and was significantly associated with life satisfaction measures (p <.0001), that is, the level of life satisfaction decreases with increasing scores of depression.
In another larger sample study, Kreutzer et al. (2001) conducted a comprehensive assessment of 722 persons with brain injury (M = 2.5 years post-injury). They found 42% of the sample met the criteria for a DSM-IV diagnosis of major depressive disorder. Similar findings have also been reported by Deb et al. (1999); Jorge et al. (1993); and Van Reekum et al. (1996). Deb et al. (1999) found that depression was common in 164 persons one-year post-injury. They identified 13.9% of the sample had depression compared to 2.1% of the general population. Panic disorder was reported in 9% compared to 0.8% of the general population. Jorge et al. (2004) found that 51.6% of their patients developed a mood disorder within one year following injury as compared to 22% of a control group. They also found that anxiety disorders and aggressive behaviour were frequent; and that those who developed major depression had a significantly higher history of mood and anxiety disorders.

Therefore there is increasing evidence that depression and anxiety may be common in people with traumatic brain injury varying from 13.9% (Deb et al., 1999) to 73% (Koskinen, 1998). Depression and anxiety appear to be more common in those with mild traumatic brain injury and/or a history of psychiatric disorder before their injury. The studies described so far have highlighted other psychiatric disorders that may affect people with traumatic brain injury. For example, Van Reekum et al. (1996) reported the presence of bipolar affective disorder and borderline personality disorder whereas Bowen et al. (1998) reported that 38% of their sample of 99 adults with traumatic brain injury had significant mood disorders.
The studies reviewed show that the prevalence of psychiatric disorder following traumatic brain injury is high, therefore suggesting an association between traumatic brain injury and psychiatric disorder in this population group. Such an association is noted by Hoofien et al. (2001) in a longitudinal study of 76 patients ten to twenty years later. Hence the quality of life of these persons may be greatly affected (Hoofien et al., 2001; Koskinen, 1998; Kreutzer et al., 2001) and the impact may also be experienced many years after the injury (Koskinen, 1998). Hoofien et al. (2001) further argued that the families of persons with traumatic brain injury may need professional assistance to maintain a reasonable quality of life, even several years after the injury.

The review above focussed on persons with traumatic brain injury. Persons with non-traumatic brain injury, such as stroke also exhibit symptoms of psychiatric disorders (Robinson, Bolduc & Price, 1987; Morris, Robinson, Andrzejewski, Samuels & Price, 1993). One of the more common psychiatric disorders is depression (Clark & Smith, 1998; Parikh, Robinson, Lipsey, Starkstein, Fedoroff & Price, 1990). Depression in these persons can significantly impact on recovery in activities of daily living (Parikh et al., 1990) and on social functioning (Clark & Smith, 1998). Morris et al. (1993) reported that depressed mood following a stroke is associated with an increased risk of subsequent mortality.

Difficulties with memory, concentration, physical impairments and psychosocial problems limit the functional activities of the person with acquired brain injury (Florian et al., 1989; Giles, 1994; Koskinen, 1998; Liss & Willer, 1990; Wade et al., 1996). The study by Koskinen (1998) indicated that 93% still reported functional problems in mobility and 80% reported balance and memory difficulties 10 years post-injury. Other problems
reported in the study included slowness, irritability, fatigue and sensory impairments (Koskinen, 1998). The impact of brain injury can also affect everyday functional activities such as meal preparation and social interactions (Giles, 1994).

Clearly the impact of acquired brain injury is significant. It can affect activities of daily living and hence day-to-day functioning. These individuals may experience a range of psychiatric disorders such as depression and anxiety which further limit their functioning in activities of daily living or impact on the recovery or rehabilitation process. The impact of acquired brain injury on the behaviour patterns of the individual is another area of concern that receives much attention from researchers in the field (see below).

A growing area of concern is the issue of suicidality in persons with brain injury. Research indicates that suicide ideation is common in persons with traumatic brain injury (Kishi et al., 2001; Oquendo et al., 2004; Simpson, 2004; Simpson & Tate, 2002). While it is not within the scope of this thesis to explore this issue in-depth, these studies highlight the urgency to address the issue of suicidality. In a study of 172 persons with traumatic brain injury, Simpson (2004) found clinically significant levels of hopelessness (35%), suicide ideation (22%) and suicide attempts (19%). Simpson also found that there is a lifetime prevalence of 1.86 suicide attempts, with the median time of 2.5 years after the injury.

In a sample of 496 patients who were in rehabilitation following life threatening physical illness, such as traumatic brain injury, stroke or myocardial infarction; 7.3% developed suicide ideation and 11.3% of them developed it during rehabilitation (Kishi et al., 2001). In a sample of 255 persons with mild traumatic brain injury, Oqueno et al.
(2004) found that that suicide attempts may be predicted by aggression. Therefore, there is ample evidence to suggest a link between brain injury and suicidality. More importantly, the research indicated the need for early detection and intervention for the person, and family support to minimize the risk of suicide in persons with brain injury (Kishi et al., 2001; Oquendo et al., 2004; Simpson, 2004; Simpson & Tate, 2002).

*Behavioural concerns following acquired brain injury.*

Behavioral problems are common in persons with acquired brain injury (Baguley, Cooper & Felmingham, 2006; Florian et al., 1989; Hall, Karzmark, Stevens, Englander, O’Hare & Wright, 1994; Johnson & Balleny, 1996; Kersel, Marsh, Havill, & Sleigh, 2001; Kreutzer et al., 1995; Koskinen, 1998; Kraus et al., 1984; Leon-Carrion et al., 2001; Urbach et al., 1994; Winkler, Unsworth & Sloan, 2006; Wood, 1986). The studies also suggest that these behavioral problems often last for many months and even years (Baguley et al., 2006; Johnson & Balleny, 1996; Wood, 1986). Baguley et al. (2006) conducted a 5-year study at 6, 24 and 60 months post-discharge. They found that at any given follow-up period, 25% of the participants were classified as aggressive. Baguley et al. also found that higher depression and younger age at injury were significant predictors of aggression. Winkler et al. (2006) reported that challenging behaviour was predictive of whether community integration was successful post-injury. They recommended that appropriate intervention to reduce challenging behaviour may make a difference to the level of community integration experienced by people with ABI.

The nature, extent, and circumstances of behavior problems among persons with acquired brain injury have not been very well delineated and require further investigation.
Koskinen (1998) found that 53% of the persons with severe traumatic brain injury had difficulties in behavioral control. The finding was based on the Neurobehavioural Rating Scale (NRS) that consisted of 27 items, such as anxiety, disinhibition, or agitation. In their review, Urbach et al. (1994) also used the same description of “behavioral dyscontrol” (p. 290) and described disruptive symptoms to include “irritability, anger, demandingness, inappropriate laughter”. In a study of the neurobehavioural profiles of 39 persons, Leon-Carrion et al. (2001) described the participants as being unable to cope with complex problems, having internalized anger, opposition and negativity. Both studies by Koskinen (1998) and Leon et al. (2001) were based on a small sample, 15 persons in Koskinen (1998) and 39 in the study by Leon et al. (2001). Furthermore the NRS is a tool that specifically looked at behaviors related to neuro-cognitive functioning, hence the items consisted of “inattention/reduced alertness, anxiety, disinhibition, agitation” rather than observed behaviors such as aggression, property damage, etc. In addition, the NRS tool does not fully measure the frequency and intensity of the difficult behaviors.

Hall et al. (1994) reported family members described problem behaviors as severe temper outbursts and self-centredness, their study examined the psychosocial impact following traumatic brain injury and its relationship to family stress in 51 persons at 6, 12, and 24 months post-injury. They reported that these behaviors increased in severity over a 2-year period. In a comparison study of 40 children with and without head injury, and 80 children following emergency appendectomy, Basson, Guinn, McElligott, Vitale, Brown and Fielding (1991) found that 34% of traumatized children and 28% of children with head injury showed substantial psychobehavioral change. Psychobehavioral change is defined as
behaviors related to psychological functioning. The behavioral changes included rage attacks, poor academic functioning and episodic depression.

Johnson and Balleny (1996) investigated the incidence of behaviour problems in 33 patients three years following severe head injury. They found that family members reported more behavioural problems than therapy and nursing staff. Nearly 80% of relatives reported behaviour change and 45% of these patients were reported to have behavioural problems that caused significant distress for the families. Many of these behaviour problems persisted for more than 18 months since injury. The behaviours identified were irritability (78%), aggression (55.5%), apathy (55%), or disruptive behaviour (39%). They also reported that severity of the behaviour difficulties was unrelated to the severity of the injury. Furthermore, the studies were based on persons with severe traumatic brain injury. The behaviours defined included “depression” or “irritability”, these behaviours could be also defined as “psychological” problems.

Kreutzer et al. (1995) examined the nature of the relationship between alcohol use, criminal offending, and aggression among 327 persons with traumatic brain injury. They found that nearly a quarter of the sample were arrested either pre- or post-injury, and compared to the annual arrest rate for the general population, their findings suggest persons with traumatic brain injury have a higher incidence of criminal behaviour. Aggressive behaviours were frequently reported by the informants of the study. Aggression had an adverse effect on the rehabilitation of such individuals. They cited the example that such persons who engaged in arguing, yelling or cursing at others have an increased risk of legal problems. Aggression also decreased the opportunities for social support and increased the
social isolation commonly reported post-injury (Kreutzer et al., 1995). The authors also argued for early intervention for such individuals.

Kersel et al. (2001) assessed 65 adults with severe traumatic brain injury at 6 months and 1-year post injury to examine their psychosocial functioning. Based on the findings of self-report questionnaires by these adults, Kersel et al. (2001) indicated that the only behaviour problems reported were impatience (51%) at 6 months followed by irritability (49%), argumentativeness (44%), anger (42%) and depression (42%). At 1-year post injury, it was reported that impatience continued to be a behavioural problem reported by 64% of the patients followed by depression (47%) or irritability (44%). As discussed earlier, the studies by Kersel et al. (2001) and Johnson and Bellany (1996) used self-report measures or family completed surveys rather than observed behaviours. The studies also did not clearly define “behavioural problems” as they included psychological or emotional concerns such as “depression”, “irritability”, “anger”, “mood changes” or anxiety (Kersel et al., 2001).

Behavioral problems appear to be one of the long-lasting impacts of brain injury, in particular with traumatic brain injury. However, the studies do not clearly delineate the nature, extent and circumstances of the behaviors. The definition of “behavioural problems” used in the studies above was problematic as many of the behaviours listed may also be defined as psychological or emotional concerns. For this reason, this study will seek to determine the impact of behavior problems on the use of and need for respite care, and will clearly define observed behaviour problems. The prediction is that individuals with behavior problems will use respite care more and family members will report a greater
need for respite care. That is, the presence of behavior problems will predict the need for the use of respite care.

**Criminality and sexual offending issues.**

There are several studies that have established a link between crime and/or violent behaviour and acquired brain injury (Brower & Price, 2001; Chan, Hudson & Parmenter, 2004; Kreutzer et al., 1995; Leon-Carrion & Ramos, 2003). Other studies have highlighted the sexually inappropriate and sexual offending behaviours of persons with acquired brain injury, predominantly in persons with traumatic brain injury (Bezeau, Bogod & Mateer, 2004; Simpson, Tate, Ferry, Hodgkinson & Blaszczynski, 2001; Simpson, Blaszczynski & Hodgkinson, 1999).

In a review of 276 persons who were presented to the New South Wales Mental Health Review Tribunal, Chan et al. (2004) found that 9 persons (3.3%) were diagnosed as having brain injury and psychiatric disorders related to drug and alcohol abuse. Chan et al. (2004) found that the offences committed by these individuals were serious and included murder, intent to murder, sexual and physical assaults. Leon-Carrion and Ramos (2003) investigated the link between violent criminal behaviour and brain injury in 49 male prisoners. They found that blows to the head during development, regardless of severity, pose a risk factor for later delinquent behaviour. In a review, Brower and Price (2001) argued that there is a clinically significant association between frontal lobe dysfunction and violent criminal behaviour. Leon-Carrion and Ramos (2003) strongly advocated for early detection and treatment of head injury before it impacts more severely later on in life of these individuals.
Sexual offending and sexually inappropriate behaviours appear to be another consequence of acquired brain injury, particularly for those with traumatic brain injury (Simpson et al., 1999; Simpson et al., 2001). Bezeau et al. (2004) offered some strategies to address the issue of sexually intrusive behaviour following brain injury. The purpose of highlighting these studies is to demonstrate the long-term impact of acquired brain injury on the individual. These studies also demonstrated the severity of the impact on the quality of life of persons with acquired brain injury. As such, it may be argued that the impact of acquired brain injury is not simply an issue of medical and health concern, but more importantly, there is a case to argue that the impact is also a social issue for the community and government.

Quality of life issues.

The research reviewed above clearly highlights the long-term and deleterious impact of acquired brain injury on adults, with consequences such as psychiatric, behavioural, criminality and sexual offending behaviours. It appears obvious that these consequences may adversely impact on the quality of life of these persons.

Doigh et al. (2001) conducted a retrospective 2 – 5 year study of 208 persons admitted to a brain injury rehabilitation unit in Brisbane, Australia, using the Community Integration Questionnaire. The results were grouped into three clusters and labeled as the ‘working group’ (n = 78), ‘balanced group’ (n = 46), and ‘poorly integrated group’ (n = 84). The ‘working group’ was identified by the high level of productive integration based on the mean raw score of the questionnaire. Productive integration included employment or attendance at school. The ‘balanced group’ was characterised by their high levels of
integration in all areas, such as performing home maintenance or planning their own social events; and the ‘poorly integrated group’ was determined by their low levels of integration across all areas of the questionnaire.

The ‘working group’ was poorly integrated into the home as evidenced by the fact that most of them had someone else do their housework (50%), grocery shopping (42.3%) or meal preparation (47.4%) (Doigh et al., 2001). Although 56% of the ‘working group’ participated in full-time work or studying, with 13% doing the same on a part-time basis, Doigh et al. (2001) found that just under half of them reported they went shopping, visiting or participated in leisure activities, and only a few did leisure activities alone (9%).

The cluster labeled ‘balanced’ was highly integrated into the home and was also socially integrated. For example, 83% reported having a best friend and nobody in this cluster reported that they never went shopping. Most also indicated that they performed home maintenance tasks alone including managing their own financial affairs (85%), planning their own social activities (83%), and grocery shopping (89%).

The ‘poorly integrated’ cluster scored poorly in all areas described in the above groupings. They were least integrated across all areas, such as 74% who were not looking for work or were not working. Only 2% were employed full-time or studying, with a further 2% doing the same on a part-time basis. Doigh et al. (2001) also noted that 36% of them were unemployed prior to injury.

The findings by Doigh et al. (2001) confirmed previous studies that persons with brain injury who have part-time work were more socially integrated and engaged in more home activities when compared to those who work full-time or those who did not work at all.
This study highlights findings in other studies that reported social isolation and reduced social integration as one of the biggest problems facing persons with acquired brain injury. Doigh et al. thus argued that careful consideration should be given in the rehabilitation process prior to discharge into the community and how services may be delivered effectively to facilitate appropriate community re-integration.

In a similar study in Hong Kong, Man et al. (2004) examined the quality of life in 35 adults post-injury. Using the Comprehensive Quality of Life questionnaire, they found that 90% of the participants were unemployed, and that they scored poorly in community re-integration, productivity and material well-being. Man et al. (2004) suggested that the participants’ low score in their social role function and community integration might also be predictors of their lower quality of life scores. Smout et al. (2001) also examined quality of life in elderly persons following stroke. They found that the quality of life of stroke patients decreased by 20.1%.

Steadman et al. (2001) explored the factors associated with quality of life eight to 24 years after traumatic brain injury in 274 persons, using a series of questionnaire instruments. They found that psychosocial factors such as mental health well-being and social support were strongly related to better quality of life. That is, persons who experienced depression reported lower quality of life ratings, and those who were in relationships also reported significantly higher quality of life than those who were single (Steadman et al., 2001). Other factors that had a strong correlation with higher ratings of quality of life were the ability to get along with people, the ability to afford things and the ability to engage in work and leisure (Steadman et al., 2001).
Quality of life following acquired brain injury may be impacted by the coping strategies and social support of the person. Tomberg et al. (2007) explored the coping strategies and social support of 85 persons with traumatic brain injury about 5.7 years after the injury. They found that health-related quality of life and return to work did not improve significantly, and only 54% of the participants resumed work. Several variables such as level of social support, various psychological problems, educational level and satisfaction with support played a role in influencing the probability of returning to work. They also found that the participants reported an increase in seeking social/emotional support ($p < .05$), frequent use of avoidance-oriented styles and reduced use of task-oriented styles; and this was correlated with low social support and low satisfaction with support. Tomberg et al. (2007) argued that continuing social and psychological support are required years after injury.

The studies discussed in previous sections have noted the severity and long-term impact of acquired brain injury and reiterate the importance of careful planning of rehabilitation services for people with acquired brain injury post-discharge into the community. The research also highlighted the need to establish more comprehensive support services aimed at enhancing the quality of life of people with acquired brain injury.

*Impact of Acquired Brain Injury on Children and Adolescents*

The consequences of acquired brain injury on children and adolescents are similar to those experienced by adults. Children and adolescents who survive acquired brain injury are at significant risk of on-going health, psychosocial, behavioural, functional and academic problems (Barker-Collo, 2007; Farmer, Clippard, Luehr-Wiemann, Wright &
Owings, 1996; Hawley, 2004; Hessen, Nestvold & Anderson, 2007; Wade et al., 1996; Max, Robin, Lindgreen, Smith, Sato, Matthesis, Stierwalt & Castillo, 1997; Viguier, Dellatolos, Gasquet, Martin, & Choquet, 2001; Ylivisaker, Adelson, Braga, Burnett, Glang, Feeney, Moore, Rumey, & Todis, 2005). The impact may also be experienced several years after the injury (Farmer et al., 1996; Hessen et al., 2007; Max et al., 1997) and hence present several challenges for families (Conoley & Sheridan, 1996; Fay & Barker-Colla, 2003; Wade et al., 1996).

Hessen et al. (2007) investigated long-term neuropsychological outcome after mild traumatic brain injury in paediatric (n = 47) and adult (n = 74) population groups 23 years after the injury. A positive outcome of this study was that, overall, participants with mild traumatic brain injury had neurological test scores within the normal range and had average levels of education. A lower percentage of them were on disability benefit compared to demographically matched Norwegian population. However, they found significant relationships between severity of head injury and current neurological function; particularly, post-traumatic amnesia (PTA) sustained for more than 30 minutes or a combination of PTA for more than 30 minutes and pathological EEG within 24 hours in the paediatric group could significantly predict poor neurological outcome after 23 years. For children with complicated mild head injuries poorer neuropsychological outcome was found than for adults with similar head injuries. The study calls into question a currently common conception that young children with traumatic brain injury have better prognosis than adults (Hessen et al., 2007).
An important part of any child and adolescent’s life is education. Persistent cognitive impairments can adversely affect several domains of the child or adolescent’s academic performance. Some of the problems reported most frequently are difficulties in attention and memory, speed of processing information and expression, sensory-motor functioning, reasoning and problem-solving skills (Barker-Collo, 2007; Farmer et al., 1996). These problems pose a barrier to academic achievement. Farmer et al. (1996) and Conoley and Sheridan (1996) argued strongly for a multi-disciplinary approach in assisting these children and adolescents to overcome the barriers posed by brain injury. In a study of 74 children with traumatic brain injury in comparison with 13 children with orthopaedic injury, Barer-Collo (2007) found that severity of injury correlated with increased mental health concerns (such as anxiety and depression), social and thought problems, and in particular, attention problems. She also found that increased age related to increased parental reports of attention problems; while increased hospital stay related to increased withdrawal and thought problems.

While academic performance appears to be the most obvious impact following brain injury, psychiatric disorders may also be evident in children and adolescents with traumatic brain injury (Max et al., 1997; McGuire & Rothenberg, 1986). Max et al. (1997) conducted a prospective follow-up study of 42 children and adolescents aged 6 – 14 years at the time of hospitalization following traumatic brain injury. A series of neurological, psychological, behaviour functioning and family measures were administered to the participants.

They found that 15 participants showed a psychiatric disorder, such as obsessive-compulsive disorder, anxiety, mania, hypomania or simple phobia. They also noted that the
severity of injury, pre-injury function and pre-injury life-time psychiatric history predicted the development of psychiatric disorders in the second year following brain injury. There are a few limitations noted in the study, such as the small sample size, the fact that psychiatric assessments were based on limited measurement tools and a lack of a control group.

Similar to adults with acquired brain injury, another significant consequence is behaviour problems following acquired brain injury (Asarnow, Satz, Light, Lewis & Neumann, 1991; Fletcher, Ewing-Cobbs, Miner, Levin & Eisenberg, 1990; Hawley, 2004; McGuire & Rothenberg, 1986). Fletcher et al. (1990) conducted a follow-up of the behaviours of 45 children with mild, moderate and severe closed head injuries at the time of injury, and at 6 and 12 months post-injury. The children were aged 3 – 15 years at injury and two behaviour measures were used. They found that children with severe injury performed significantly more poorly on adaptive functioning than children with mild or moderate injuries.

Fletcher et al. (1990) also found that severely injured children had more school problems and participated in fewer social activities. Therefore Fletcher et al. (1990) demonstrated that there are significant negative behaviour changes in children with severe injuries. Asarnow et al. (1991) conducted a similar study of 11 children with severe and 10 children with mild closed head injury. The results of their study were congruent with the findings of Fletcher et al. (1990), that is, children with severe injury exhibited serious behaviour problems and poorer adaptive functioning. However, they also found that
children with mild injuries had similar rates of behaviour problems comparable with that of children with severe injuries.

Hawley (2004) examined the relationship between behavioural problems and school performance following traumatic brain injury in 67 school-aged children matched with 14 uninjured children. She found that two-thirds of children with traumatic brain injury showed significant behavioural problems more than the control group. These children also had a lower mean IQ than those without behavioural problems and 76% of children with behavioural problems also had difficulty with school work.

One of the problems with the studies by Fletcher et al. (1990) and Asarnow (1991) is the lack of description of the behaviours that might explain the difficulties these children experienced at school. Furthermore, the sample size of both studies was small and therefore one has to be cautious in interpreting the results. Even so, given the limitations of the studies, it is important to highlight that the impact of acquired brain injury on children and adolescents is significant.

In a review of major developments of the past twenty years in the management of children with traumatic brain injury, Ylvisaker et al. (2005) reported that long-term family and child outcomes are inter-related. That is, positive/negative child outcomes following traumatic brain injury increase the likelihood of positive/negative family adjustment outcomes. Ylvisaker et al. (2005) also reported that recent research has indicated that well-conceived interventions can improve family resilience and problem-solving ability, thereby improving the child’s outcome, particularly in behavioural outcomes. They argued that there is strong rationale for intensive and on-going services and supports for families.
Impact of Acquired Brain Injury on the Family

There are numerous studies that highlight the distress many families and carers experience following acquired brain injury of a family member (Florian et al., 1989; Godfrey, Harnett, Knight, Marsh, Kesel, Partridge & Robertson, 2003; Kreutzer, Gervasio & Camplair, 1994a; Kreutzer, Gervasio & Camplair, 1994b; Liss & Willer, 1990; Novack, Berquist, Bennett & Gouvier, 1991; Perlesz et al., 1999; Rotondi et al., 2007; Wade et al., 1996; Wade, Taylor, Drotar, Stancin & Yeates, 1998; Willer et al.1990; Winstanley et al., 2007). The distress and impact on family functioning are noted shortly after the injury (Novack et al., 1991) and several years after the injury (Kreutzer et al., 1994a; Perlesz et al., 1999; Wade et al., 1998). Studies on the impact of acquired brain injury on caregiver distress and family functioning at 3 months (Novack et al., 1991), 6 months (Marsh et al., 1998), 2 years (Curtiss, Klenz & Vanderploeg, 2000; Hall et al., 1994) and 3 years or more post-injury (Kaplan, 1991; Knight, Devereux & Godfrey, 1998) all indicated that family members or carers experience significant stress, depression, anxiety, and emotional distress.

Impact on marital relationships.

Brain injury adds significant strain on marital relationships between spouses and persons with brain injury (Liss & Willer, 1990; Perlesz, Kinsella & Crowe, 2000; Willer, Allen, Liss & Zicht, 1991; Wood, Liossi & Wood, 2005; Wood & Yurdakul, 1997). In an extensive review of the effects of traumatic brain injury on marital relationship, Liss and Willer (1990) reported that the typical problems identified in persons with traumatic brain injury not only impede community re-integration but also become an additional strain on
the spouse. According to Liss and Willer, spouses reported feelings of anxiety, isolation and a sense of loss.

In a structured small-group discussion study of 20 men and 11 women with traumatic brain injury and their spouses, Willer et al. (1991) reported significant problems in their marital relationship. Women with traumatic brain injury identified the loss of autonomy such as gainful employment, loneliness and depression. Their husbands also identified the same concerns. The men with traumatic brain injury reported loss of independence and role as “bread winner” of the family, and noted memory loss and personality changes in themselves. Their wives also reported similar concerns as their spouses with traumatic brain injury.

The women with traumatic brain injury reported that support received from their families, in particular their husbands as an important coping strategy. It is interesting to note that women with traumatic brain injury and wives of men with traumatic brain injury found support groups useful. Men on the other hand, engaged in problem-focussed coping strategies. Both groups found difficulty accepting unemployment, and the men in the study found day-time activities made them feel more productive. Willer et al. (1991) noted other problems associated with disabilities resulting from the brain injury, such as aggression in the men and role performance, for example, sexual functions.

Wood and Yurdakul (1997) looked at the relationship status of 131 persons with traumatic brain injury. They found that 49% of the sample reported that they had divorced or separated from their partners during a 5 – 8 year period following brain injury. The study did not appear to suggest a relationship between the severity of brain injury and the
risk of a breakdown in marital relationship. Wood and Yurdakul (1997) suggested that the neurobehavioural consequences may be a factor instead. Wood et al. (2005) found that 23 couples in the group of 48 partners of people with head injury had separated or divorced in the years following injury. Unpredictable patterns of behaviours as perceived by partners imposed the greatest burden on personal relationships. Evidence to date suggests that the consequences of acquired brain injury do severely impact on marital relationships.

Anderson, Parmenter and Mok (2002) investigated the relationship between neurobehavioural problems of traumatic brain injury, family functioning and the psychological well-being of the 47 female and 17 male spouse/caregivers, in a cross-sectional design. The results of the study indicated that the neurobehavioural problems of traumatic brain injury adversely affected family functioning and caused psychological distress in spouses/caregivers. The high levels of family dysfunction is concerning, partly because the psychological distress experienced may negatively impact on the rehabilitation of the person with injury.

Perlesz et al. (2000) assessed psychosocial outcomes following traumatic brain injury in all family members, including relatives more peripheral to the person with the injury. They used a cross-sectional design to gather data from 79 primary, secondary and tertiary carers, about 19.3 months after injury. They found that although a majority of family members did not report significant psychological distress, primary carers, particularly wives, reported greater risk of adverse psychosocial outcomes. Wives were significantly angrier and less satisfied with their families than mothers. They postulated that wives may
have lost peer-based support and reciprocal supportive partnerships as they assumed more responsibility in caring for the person with traumatic brain injury.

Impact on mental health of caregivers.

Perlesz et al. (2000) reported that primary carers, mainly wives and mothers were at greater risk of poor psychosocial outcome, compared to other carers. The results of the study confirmed earlier studies that family members who act as caregivers of people with acquired brain injury experience significant levels of stress and mental health issues as a result of caregiving (Novack et al., 1991). Novack et al. examined primary caregiver distress in 45 carers following brain injury of an adult family member during the rehabilitation phase and shortly thereafter. They noted anxiety (33%) and not depression (9%) as being a major problem during the rehabilitation phase. They found that the level of anxiety diminished by the time of discharge (7%) and remained stable at 3-month follow-up (8%). The frequency of those who showed clinical depression remained low through discharge (4%) and at 3-month follow-up (0%). To explain the low frequency of depression and anxiety in their sample, Novack et al. (1991) suggested that the learned coping strategies during the rehabilitation process were being used effectively by family members.

The limitations in the study by Novack et al. (1991) are evident in terms of the small sample size and the methodology. The methodology was based on self-reporting measures and it was acknowledged by Novack et al. (1991) that these measures were administered while the family member with brain injury was in rehabilitation and not living at home. Clinical anxiety and depression of carers might be higher if the same measurements were conducted when the family member with brain injury was living at home. Furthermore
Novack et al. (1991) presumed that coping strategies were learned during the rehabilitation phase when carer coping strategies were not the focus of the study and were not assessed.

Compared to Novack et al. (1991), other studies found higher levels of anxiety and depression (Gillen, Tennen, Affleck & Steinpreis, 1998; Marsh et al., 1998). Marsh et al. (1998) studied caregiver burden in 69 family members at 6 months following traumatic brain injury. Caregivers in the study included a parent (62%), spouse/partner (29%), sibling (4%), a relative (1%) or a friend (3%). The majority of the caregivers were female (86%). Marsh et al. (1998) found significant clinical levels of anxiety (39%), depression (37%) and reports of impaired social adjustment (38%) in the group. They also found that caregivers were most distressed by the impact that caregiving had on their personal health and free time. For example, 73% reported “less time for myself” and 62% disruption to sleep patterns. The impact of caregiving following traumatic brain injury is also noted in their relationships (55%), privacy (55%), financial situation (54%), employment (39%), appetite (29%) and housing (26%). Substance (e.g., alcohol) and medication (9%) use were also reported by carers.

Correlational analysis indicated that behavioural problems of the family member with traumatic brain injury have the most severe and pervasive impact on all aspects of caregiving (Marsh et al., 1998). In a study of 59 carers, Gillen et al. (1998) found 47% of carers met the criteria for depression initially and 43% met the criteria 6 months later. They also found that 17% of those who were not depressed initially subsequently met the criteria for depression. Gillen et al. (1998) also reported that a predictor of depression was a previous depressive episode prior to the injury being sustained. They found that lifetime
depression of carers related to the individuals with traumatic brain injury who had histories of alcohol and substance abuse, risk-taking behaviours and anti-social behaviour.

A similar finding of the relationship between behavioural problems and caregiver distress was also found by Anderson et al. (2002), Kreutzer et al. (1994b), and Godfrey et al. (2003). Marsh et al. (1998) reported that cognitive difficulties caused least distress compared to the social isolation of the person with brain injury. Marsh et al. (1998) argued that social isolation tends to increase rather than decrease as a function of time following traumatic brain injury. Hence they expressed concern that the level of caregiver distress will increase as the degree of social isolation increases for the person with traumatic brain injury. Marsh et al. (1998) also reported that the types of behavioural problems that caused most distress to caregivers were aggression, sudden mood changes and argumentativeness. These findings are similar to an earlier study by Brooks, Campsie, Symington, Beattie and McKinlay (1987) of 137 patients with severe head injury and their carers.

The findings by Marsh et al. (1998) are also similar to a previous study by Hall et al. (1994). Hall et al. conducted a telephone interview of 51 family members of persons with traumatic brain injury at rehabilitation over a 2-year period at 2, 12 and 24 months post-injury. They found that stress was significantly higher for those caregivers with an at risk psychosocial history and without sufficient funds for services. Almost half of the caregivers (47%) had given up their jobs a year post-injury and 33% at 2 years post-injury to care for the relative with brain injury. Hence financial strain increased 22% after the person with brain injury was admitted to rehabilitation. While perceived stress based on
self-reporting did not increase over time, Hall et al. (1994) found that there were notable increases in medication and substance use.

Hall et al. (1994) argued that, given the risk of social isolation for the person with traumatic brain injury, community services should focus on respite care to facilitate community reintegration and reduce the stress experienced by families. The risk of family members turning to substance and medication use (Hall et al., 1994; Marsh et al., 1998) should also direct support services for families in mental health well-being and to assist families in times of financial strain. While the findings by Hall et al. (1994) and Marsh et al. (1998) are significant in terms of the impact of acquired brain injury, the sample size of their studies was small and hence it is difficult to interpret the results to the entire population of families who care for a person with brain injury. There is a questionable assumption that male or female carers would experience similar distress levels or coping problems. There is also the issue of whether cultural differences might account for how one views the “burden” of caring.

Using a larger sample size of 116, Gervasio and Kreutzer (1997) investigated the level and type of psychological distress by caregivers of adults with traumatic brain injury. The majority of the caregivers were females (n = 89). Caregivers in the study included spouses/partners (59.5%) and parent/relative/sibling (40.5%). A self-reporting questionnaire was mailed to the caregivers. Gervasio and Kreutzer (1997) found that 44% had clinically elevated scores on the questionnaire indicating psychological concerns in caregivers, in particular obsessive-compulsive behaviour, anxiety, hostility and psychoticism.
Gervasio and Kreutzer (1997) also examined whether there might be differences between caregivers. They noted that spouses reported significantly more distress than other relatives (e.g., parents) on almost all subscales of the questionnaire except for three. They also reported that male caregivers yielded significantly higher scores on the global severity index. Gervasio and Kreutzer explained the higher score reported by male caregivers in terms of unfamiliarity with a change of roles, that is, traditionally men are less likely to engage in a nursing and nurturing role.

As indicated in the studies above, the prevalence of mental illness such as depression and anxiety impacts not just the persons but also carers. This affects family cohesion and carers’ ability to care for the person with brain injury (Douglas & Spellacy, 2000; Harris, Godfrey, Partridge & Knight, 2001; Gillen et al., 1998; Leach, Frank, Bouman & Farmer, 1994). These studies also suggest that social support and family coping strategies may mediate the effects of brain injury (Douglas & Spellacy, 2000; Harris et al., 2001; Gillen et al., 1998; Leach et al., 1994). Carers play a pivotal role in the rehabilitation process and therefore it is important to understand how families adjust to the adverse effects of brain injury (Leach et al., 1994).

Leach et al. (1994) examined how family functioning impacts the re-adjustment of the person with traumatic brain injury. They hypothesized that a person with traumatic brain injury who received good social support would experience reduced levels of depression. Leach et al. (1994) interviewed 39 persons (15 females and 24 males) in an out-patient day rehabilitation program and a series of psychological measures were administered. Most of the participants had sustained severe traumatic brain injury (n = 28). The results indicated
that 73% of the participants were mildly depressed with only 2 individuals reporting severe depression and 8 reporting no depression. They found that social support was predictive of less depression in individuals with traumatic brain injury. Leach et al. (1994) showed that family use of problem-solving and behavioural coping strategies as a response to the person with traumatic brain injury was significantly related to lower levels of depression in the person with brain injury.

Douglas and Spellacy (2000) conducted a similar study of the linkage between depression in adults with severe traumatic brain injury and their carers. Douglas and Spellacy were more interested in investigating the indicators of depression in both groups, and its association with social support. They interviewed 35 adults and their carers, and administered a series of measures that examined level of disability, depression and social support. They found that 57% of adults with traumatic brain injury and 60% of carers continued to have significant symptoms of depression.

The social support items that received the highest self-reported mean frequency ratings varied, although two items were similar for both individuals and carers: “Not having enough money” and “Not having a satisfactory sex life”. Some of the social support problems reported by individuals with traumatic brain injury include: the lack of transportation, being unable to see people who they feel close to, not having enough money, not having a satisfying job, and having people interfere with things you want to do. Carers reported excessive demands on their time, having too little leisure time, and too many responsibilities for the social problems they encountered.
Lack of money appeared to be a significant predictor of psychological well-being of the individual with traumatic brain injury (Douglas & Spellacy, 2000). Individuals with traumatic brain injury expressed the lack of social network in terms of friendship or relationship with others. These are expressed in terms “loss of friends” or “I feel lonely”. They also expressed the lack of instrumental support such as the lack of services or facilities to work or play sport tailored for people with brain injury. About 57% of the adults in the study commented on the theme of the lack of friendship and involvement.

For carers, the daily demands of living with a person with acquired brain injury are overwhelming. Many carers indicated a great need for activities for the brain injured person to do in the community. According to Douglas and Spellacy (2000), 45% of carers’ depression scores were predicted by their scores on social support, linking lack of money and excessive responsibilities in caring for the person with brain injury. The comments by carers in the study reflected the needs for respite care and day activity services for people with brain injury that would mitigate the excessive responsibilities experienced by carers (Douglas & Spellacy, 2000). Current stressful life events also appeared to be linked to depression.

So far the review of the impact of acquired brain injury on families or caregivers has demonstrated the deleterious effects on the psychological well-being of caregivers as evidenced in the level of mental health concerns in families. The review has also reported on factors other than the behaviour of the person with brain injury that might be predictive of caregiver adjustment to the injury, such as social support or the lack of social supports. It is also important to identify the potential factors that might moderate the impact on families
and caregivers in terms of psychological well-being and emotional re-adjustment in caregivers (Harris et al., 2001).

Harris et al. (2001) evaluated the role of family and caregiver appraisal and resources in predicting caregiver emotional status, that is, what are the potential predictors of caregiver depression and what are the potential moderating influences on emotional adjustment. They measured caregiver appraisal of behaviour changes in the person with traumatic brain injury, and the daily effect of those changes on themselves and others within the family. Fifty-eight carers of persons with severe traumatic brain injury participated in the study. Many of the carers were parents (47%) and partners or spouses (27%). The majority of the carers resided in the same house as the person with traumatic brain injury (70%). A series of psychological measures were administered, such as stress levels, psychological distress, support effectiveness and emotional adjustment (Harris et al., 2001).

Harris et al. (2001) found that there were several factors that had no significant relationship with self-reported carer depression. The factors were patient and carer age, patient and carer gender, relationship of carer to patient, the socio-economic status of the family, time since injury, severity of injury, concurrent stressful life events and cohabitation status. The results appeared inconsistent with previous research. For example, Knight et al. (1998) found that male caregivers were more likely to report higher levels of depression than female caregivers. Stressful negative life events predicted family functioning (Douglas & Spellacy, 2000).

The findings by Harris et al. (2001) revealed that carers experienced a greater level of distress about behavioural and social problems, and adverse effects on families were
correlated with depression scores. They found that multiple regression analysis indicated that the sole significant predictor of caregiver mood was the measure of adverse effects on the family. Briefly, the adverse effects included physical ill-health, emotional ill-health, lack of social or leisure time, concerns regarding loss of schooling or school performance (or educational or work performance for adults), or disruption to the carer’s life. While the behavioural and social problems of the person with traumatic brain injury were distressing, it may not be the behaviour itself that concerns carers. According to Harris et al. (2001), it was the effects that the behavioural and social changes have on the carers and other members of the family that was predictive of depression scores.

With regard to the potential factors that might moderate caregiver depression, Harris et al. (2001) found that if carers appraised stressors as highly distressing then their depression scores were likely to be higher than those who appraised the same stressors as less distressing. Their results suggested that support effectiveness was a moderator between depression scores and adverse family effects following traumatic brain injury. Behavioural problems can have adverse effects on families and that these adverse effects were predictive of emotional adjustment. However, the results also suggested the adverse effects on caregiver mood are mediated by caregivers’ appraisal of them, and that mood was also moderated by the level of professional and social support received by families.

Harris et al. (2001) have highlighted the limitations of their study, such as the failure to use coping measures in assessing carers, and that the carers were assessed at 6 months, 12 months, 2 years, or 3 years post-injury. They acknowledged the need for a longitudinal design with assessments of carers at several stages in the recovery process. Furthermore, as
with many of the studies reviewed above, some of the measures used were not specific to traumatic brain injury. The lack of opportunity for carers to express any satisfaction they may feel in caring for the person with traumatic brain injury was another limitation of the study.

In a similar study to identify factors that might potentially mitigate caregiver distress, Kaplan (1991) examined the relationship of social support and family cohesion in 25 persons with traumatic brain injury 3 years post-injury. He found that the individual’s psychosocial and vocational status were related to family cohesion and perceived social support. He reported that families who rated themselves as having higher levels of organisation tended to show better temperament and social behaviour than those from less ordered family systems. Kaplan argued that since traumatic brain injury can reduce the person’s ability to organise for himself/herself, families who provide organisation are more likely to give a sense of security and predictability to the person with traumatic brain injury.

Ergh, Rapport, Coleman and Hanks (2002) also examined the predictors of caregiver and family functioning following traumatic brain injury in 60 pairs of persons with injury and their caregivers. Their results are similar to the studies reviewed above. Ergh et al. found that neurobehavioural disturbance was the strongest predictor of caregiver distress and social support was powerful moderator of such distress. They also found that in the absence of social support, caregiver distress increased with longer time after injury.

Widespread psychological distress was evident among 134 close relatives, where 50% of relatives met the criteria for “caseness” on the GHQ28 associated with heightened levels
of anxiety and somatic complaints (Winstanley et al., 2006). They found that the poor level of participation in occupational activities and independent living skills was an additional factor contributing to relative distress. Family members who perceived their needs as being adequately met were less likely to be distressed, and more likely to report more positive levels of family functioning. These findings by Winstanley et al. (2007) are similar to Ergh et al. (2002). Winstanley et al. (2007) suggested that increasing resources such as respite and case management may have positive effects for relatives.

The studies reviewed highlight the adverse impact on spouses and carers of individuals with acquired brain injury, in particular those with traumatic brain injury. Factors that might mediate caregiver distress in caring for the person with acquired brain injury were discussed, in terms of how family members cope and adjust to the effects of brain injury. The support and assistance that need to be provided to families and caregivers are important, as they form part of the rehabilitation process of the person with acquired brain injury. Therefore, it is essential to understand the needs of families and caregivers in order to support them to care for the person.

The research reviewed also highlighted to clinicians, social policy makers and service providers that the “client” in the rehabilitation process is not just the person with acquired brain injury, rather the “client” should include primary carers of the person with brain injury. The issue of defining “who is the client” in rehabilitation presents a need to focus not only on the person with brain injury, but also on those who support the person on an on-going basis. The shift in focus is important for appropriate planning, formulation of policy and allocation of adequate resources to ensure better re-integration into the
community. Failure to do so will only be costly for the society and government as when families break-down, the “burden” of caring will become the responsibility of government agencies.

What are the needs of families and caregivers?

Serio, Kreutzer and Gervasio (1995) noted that family members continue to provide ongoing support to the person with acquired brain injury in the absence of continuing professional treatment programs. Many of these families’ needs go unrecognised and unmet (Rotondi et al. 2007). Serio et al. therefore sought to broaden understanding of family outcome by assessing a large heterogeneous sample of 180 persons of brain injury and their relatives two years post-injury. A series of standardized instruments were administered that included a family needs questionnaire. The purpose of the study was to identify the predictors of families at risk for having unmet needs and to develop preliminary intervention strategies.

Serio et al. (1995) found that on average 55% of needs were perceived as being met. They reported that medical needs were perceived to be most important, as well as most frequently met (63%), whereas only 14% reported it as an unmet need. However 30% of families reported emotional support as lacking and unmet. Serio et al. suggested that unmet emotional support needs may reflect a lack of attention to emotional needs on the part of the rehabilitation professionals. In terms of prognostic predictors of unmet needs, they found that the predictors differ for caregivers who are parents and spouses. Parents reported more met needs where they perceived the person with brain injury as having more physical problems, whereas spouses reported fewer met needs. Serio et al. argued that the difference
in the results may reflect role differences and related dependency issues. For example, spouses who may feel less at ease with “nursing” than do parents, and may also feel more burdened. When two parents are in the house, they are able to give each other respite from physical tasks, as well as emotional support. In contrast, Serio et al. reported that a spouse having no adult companion, may have more unmet needs for respite care.

Serio et al. (1995) found that behaviour problems were especially predictive of relatives’ unmet needs. They also found that brain injury, patient and family characteristics were among the least consistent predictors of family needs. Serio et al. (1995) argued important variables must be considered such as availability of support systems. They reported that currently there is no direct evidence to support the assertion that families who report many unmet needs are poorly adjusted. They also noted that family needs may differ at each stage of recovery and several years post-injury. Serio, Kreutzer and Witol (1997) also reported similar findings in that information, emotional support and practical advice are highly valued by families and caregivers.

Stebbins and Leung (1998) explored longer term changes in family needs after brain injury (e.g., strokes, motor-vehicle accidents or epilepsy) using a family needs questionnaire to 29 participants divided into 2 groups. The first group was 8 family members who were living with and/or caring for a person with brain injury during the first two years post-trauma and the second group consisted of 21 family members who were living with and/or caring for a person with brain injury beyond the first two years. Family members included parents \( (n = 12) \) and spouses \( (n = 12) \).
Stebbins and Leung (1998) found that family members and caregivers experienced changing and expanding needs as time since injury progressed. The results suggested that family needs changed from focused acute medical and professional supports during the first two years to an expanded range of needs such as community supports, financial resources, caregiver supports and health information. Caregiver and family supports included respite care, and nursing or day care for the person with brain injury. Another finding was an increasing level of unmet needs as time since injury progressed. They suggested the possibility of a relationship between unmet needs and stress and burden in family members caring for a person with brain injury.

Stebbins and Leung’s (1998) study had several limitations, such as its small sample size and the lack of respondent information such as socio-economic status, family systems or ethnicity. Even so, the study highlighted the needs of family and caregivers of the person with brain injury. Family and caregivers face an enormous task in caring for the person with brain injury. Meeting family or caregiver needs may alleviate the burden of caring.

Hodgkinson, Veerabangsa, Drane and McCluskey (2000) examined the service utilization by 119 Australians with traumatic brain injury at different times post-injury. They identified that use of services by people with traumatic brain injury remained high for many years after injury. The identified services often used by people with injury were medical and allied health services (81%), transport (66%), financial services (58%), legal matters (49%), and vocational services (40%). Other services used included accommodation (23%), day activity (21%), home support (19%), crisis service (8%), respite (8%), and ethnic services (8%). Hodgkinson et al. also found that psychosocial
disability may be a better predictor of service use than physical and cognitive disability alone.

The study by Hodgkinson et al. (2000) provided a significant documentation of service utilization by people with brain injury at different times post-injury. It highlighted on-going needs of people with brain injury. While the study reported service utilization, it did not critique as to whether minimal use or non-use of services might be due to the fact that these services were not known by or to families or persons with traumatic brain injury. Minimal use might also be due to the fact that there was a lack of such services, such as respite or day activity programs (Friss, 1990).

Rotondi et al. (2007) examined the expressed needs of 80 persons with traumatic brain injury and 85 primary caregivers in a semi-structured interview. Caregivers expressed the need for a better understanding of emotional and behavioural consequences of traumatic brain injury, in particular how to respond to them in terms of treatment and management. These findings are consistent with the studies reviewed in the earlier section of this chapter.

Summary

This chapter provides an overview of the life-long impact on the person and caregiver following injury. The consequences of acquired brain injury on the person included psychiatric, behavioural concerns, criminality and sexual offending behaviours, and a negative impact on quality of life. Depression, elevated levels of anxiety and mood disorders are not uncommon among people with acquired brain injury. The mental health of the person is also significantly impacted upon and may lead to thoughts of suicide. There appears to be a link between acquired brain injury and involvement with the criminal
justice system for some people with acquired brain injury. Inappropriate behaviours appear to be common among people with acquired brain injury. Concerns with the behaviours of persons with acquired brain injury appear to be a significant issue for carers too. These may impact on marital relationships and on the mental health of some carers. The studies reviewed in this chapter highlighted the need for continuing support services for the person and the carer. Some of the studies suggested that support service interventions, such as respite and case management may have positive effects on carers.
CHAPTER THREE
Listening to the Voice of Carers

The findings reviewed so far confirm the deleterious impact acquired brain injury can have on the person, the family and carers. There is also emerging research to suggest that the impact of acquired brain injury is not necessarily similar on all persons, family members or carers. That is, not everyone person is affected in the same way. The literature reviewed so far indicates differential impact among carers or family members, and also suggests certain factors that might mediate the negative impact of acquired brain injury.

Perlesz et al. (1999) argued that future research in the area should focus on the individual and family adaptation to the impact of acquired brain injury. That is, what are the factors that might facilitate adaptation by the individual and family member? For example, are there support systems that might assist the family in caring for the person with acquired brain injury and maintain family cohesion. There is no doubt in the research data available of the distress and burden of caring for the person with acquired brain injury. Perhaps what is more important is for research in the area to explore and determine factors that might contribute to individual and family resilience and coping following acquired brain injury. Respite care is one such option for the individual and family to consider that might facilitate adaptation to acquired brain injury.

Perlesz et al. (1999) further argued for the necessity to have an understanding of a coherent theoretical family adaptation framework that might predict outcome and identify those individuals and families most at risk of poor psychosocial adaptation to acquired brain injury. In the context of the present study, it is also important to determine the role
respite care has in the theoretical family adaptation framework. Furthermore it is pertinent to understand how, when and where in the family adaptation framework that access to respite care might be most effective in supporting family resilience and coping.

An Overview of Family Coping Theories

The family coping theory developed by Hill (1949) has been extensively tested and applied to families dealing with the stress of chronic illness or traumatic events. This theoretical framework remains an influential view of family coping of stress today. Briefly, the theoretical model named as the ABCX model postulates that a stressor (A) interacts with the family resources for dealing with an identified crises (B) and what the family interprets of the event (C) to produce the crises (X) (Hill, 1949). This is the most common understanding of the family coping theory.

A stressor is defined as a life event that impacts on the family unit which produces a change in the family social system (Hill, 1949). Family stress may be defined as a state that arises from an actual or perceived demand that leads to an imbalance in family functioning. As such, stress becomes distress for the family, whether it is real or perceived. Acquired brain injury is defined as a stressor in this context as the event (that is, acquired brain injury) impacts on the individual and on some or all of the family members.

The model developed by Hill (1949) focuses on factors preceding the crisis that determine the capacity of the family unit to cope with the stressful event, and to what degree the outcome becomes a crisis. Increasing research in the area of family coping and adaptation led to the development of other models of family coping building on the original ABCX model, and in particular the double ABCX model by McCubbin and Patterson.
The double ABCX model has been used to represent family functioning after rehabilitation from stroke (Clark, 1999). The study by Clark (1999) provides a framework for understanding causal relationships in family functioning following rehabilitation from stroke, such as how and under what conditions stroke impacts on family functioning and to suggest pathways for intervention.

Further research in the area of family adaptation and adjustment at a time of crisis led to the development of the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1996). This model has been used to provide a theoretical framework of family adaptation in the acquired brain injury population (Kosciulek, McCubbin & McCubbin, 1993; Kosciulek, 1994). It is not a primary focus of this thesis to discuss or review the suitability of the Resiliency Model for this population group. The purpose is to present an overview of the model as it relates to the role respite care plays in this model for the population group being investigated in this thesis.

The Resiliency Model of Family Adjustment and Adaptation

The Resiliency Model of Family Adjustment and Adaptation represents an advancement of previous family coping theory and expands the importance of family adaptation rather than adjustment to illness. Previous theories focussed on the illness (or acquired brain injury) as a stressor, a family’s resources such as economic or psychological factors, the family’s evaluation of the injury and family coping patterns developed to protect the family from breakdown and facilitate adjustment to acquired brain injury (Kosciulek et al., 1993). The Resiliency Model reframes previous theories and emphasises family adaptation as a
central concept in understanding the family’s efforts to manage a family member with acquired brain injury over time (Kosciulek et al., 1993; McCubbin & McCubbin, 1996).

There are two phases in the Resiliency Model: adjustment and adaptation. Briefly, during the adjustment phase families attempt to maintain patterns of interactions, roles and rules that have been established to guide routine family activity (Kosciulek et al., 1993). Several components characterise the adjustment phase. These include the (a) stressor, that is, acquired brain injury; (b) the family’s vulnerability to stress; and (c) family functioning patterns and capabilities such as resources, coping and appraisal that act as buffers to the stress imposed on families by acquired brain injury. The interaction of the above components shapes the family process and outcomes. Outcomes vary along a continuum from bonadjustment to maladjustment (Kosciulek et al., 1993).

Bonadjustment is described as the maintenance of established family functioning and a sense of family control over the environmental influence brought about by the stressor, such as acquired brain injury (Kosciulek, 1993). Simply it means that the family is able to adjust through the stressful situation with relative ease. Maladjustment on the other hand, can be described as a family crisis that demands changes in the established patterns of functioning resulting in a deterioration of family development and ability to accomplish routine family life tasks (Kosciulek, 1993). The literature reviewed indicates that there are deleterious consequences as a result of acquired brain injury for the individual and family. The various demands placed on the family and the impact of the injury on the person and family functioning often lead to a family crisis (Kosciulek, 1993).
The adaptation phase of the Resiliency Model is described as the family efforts and response to the stressor in order to restore balance and harmony in family functioning. The level of family adaptation in the face of a crisis is determined by a number of interacting components. The positive outcome of the interaction of these components may result in either bonadaptation or maladaptation (McCubbin & McCubbin, 1996). According to McCubbin and McCubbin (1996) bonadaptation is characterised by a positive psycho-social outcome of the individual family members, the maintenance of the family unit with control over the environmental influence, and continued optimal family functioning. Maladaptation is the reverse of bonadaptation. Maladaptation may result in deterioration of the individual in the family unit or within the family unit itself.

Figure 1 illustrates briefly the Resiliency Model of Family Adaptation. It is similar to family adjustment in that it occurs along a continuum of outcomes that reflect family efforts to achieve a balance in functioning (Kosciulek, 1993). Kosciulek notes that an important distinction between adaptation and adjustment, is that adaptation evolves over a longer period of time and has a longer period of consequences, and that the demands placed on the family by acquired brain injury and family functioning over time determine the level of family adaptation. The figure is an adapted version of the Resiliency Model of Adaptation as illustrated by Kosciulek (1993) and specifically addresses the context of acquired brain injury within the family system.
As shown in Figure 1, the Resiliency Model comprises interacting components that illustrate the family adaptation process. Each of the components will be discussed briefly within the context of acquired brain injury. The family crisis is the presentation of acquired brain injury in the family unit experienced by an individual member in the family.

Pile-up stressors: It is important to recognise that families deal with acquired brain injury over a period of time. Families do not only deal with the acquired brain injury and its impact but that a pile-up of demands following a family member’s acquired brain injury is
common. These stressors include severity of disability following injury, level of care required by the person with injury, changes in marital relationships, or difficult behaviours demonstrated by the person with injury. The literature reviewed so far has indicated long-term consequences of acquired brain injury on the individual, family, sibling and spousal relationships. Families face conflicts and difficulties not just due to medical and rehabilitation demands but also from other factors such as financial hardships (Brooks, 1991).

It is also important to acknowledge that families undergo normative transitions as a result of development and needs of younger family members, career development, family events such as a death, and other family changes. These normative transitions are affected by acquired brain injury and in turn affect the family’s transition. Furthermore, family members experience strains accumulated over time. The situational demands and contextual difficulties of acquired brain injury, such as attending to rehabilitation and other medical requirements present as pile-up stressors on the family unit (Kosciulek, 1993). The support needs of the individual with acquired brain injury such as behaviour management or the impact of brain injury on other family members (e.g., suppression of feelings) may have further negative impact on family coping. The impact of brain injury also alters the family structure and roles resulting in role ambiguity (Kosciulek, 1993).

**Family Type:** This is defined as a set of basic family patterns of behaviour that describe how the family system operates (Kosciulek, 1993). According to Kosciulek (1993), research on families faced with a crisis has introduced two family types that are critical for positive family adaptation. Regenerative families are those families who show
internal strength and internal locus of control, and rhythmic families are those who focus on family time together and routines in order to maintain family stability in the face of acquired brain injury as a stressor (McCubbin & McCubbin, 1996). As discussed in the literature review on the impact of acquired brain injury (Chapter 2), established patterns of family functioning are often permanently altered.

**Family Resources and Social Support:** A family’s capability in meeting the demands of acquired brain injury rely on (a) personal resources available to the family and (b) coping behaviours and strategies that the family or individual members use to deal with the demands. Kosciulek (1993) further identified three potential resources available to the family following acquired brain injury. They are personal resources available to the family, the family working as a cohesive unit, and community resources.

Personal resources include the innate intelligence of family members, knowledge and skills acquired from education and training, personality traits (e.g., sense of humour), physical and emotional health, a sense of control over the circumstances, self-esteem, a sense of coherence (i.e., a view that life is predictable and manageable), and a world view adopted by the family to guide the family functioning (McCubbin & McCubbin, 1996). Other family system resources that a family may draw on include cohesion (i.e., the bonds of unity that link family members together) and adaptability (i.e., the family’s capacity to meet barriers and change course as required). Other types of family system resources described by McCubbin and McCubbin include family organisation such as agreements, clarity of roles and consistency in roles and boundaries; and family hardiness that includes
the ability of the family to maintain a sense of control over the outcomes of acquired brain injury.

Community resources and social supports include all individuals and institutions that the family may access to manage a crisis situation such as acquired brain injury. It is at this point that respite services play an important role in acting as a buffer against the demands of acquired brain injury. Briefly at the institutional level, community resources may include schools, religious organizations or employers who may provide assistance and services to the family in crisis. At the wider social level, social supports and community resources include government policies and services that support the person with acquired brain injury and the family. Such social supports and community resources may function as a buffer between stress and family breakdown (McCubbin & McCubbin, 1996).

Respite service is a form of community resource and social support system available to the individual with acquired brain injury and the family. Respite may directly benefit the person with acquired brain injury and/or the supporting family of the person. The benefits of respite will be discussed in detail in the Chapter 4. It is important to note that respite does play a role in the Resiliency Model of Family Adaptation as illustrated in Figure 2.
Figure 2. Resiliency Model of Family Adaptation and Role of Respite Services

Family Situational Appraisal: In this component of the Resiliency Model is the family’s evaluation of the impact acquired brain injury has on the family, that is, how the family assesses the degree of control they have over the situation and the amount of change expected of the family system.

Family Schema and Meaning: Briefly this component describes the family’s world view in the face of a crisis. The family is required to make changes in the family system and adopt new patterns of family behaviour in order to facilitate adaptation.
Family Problem-Solving and Coping: In the context of the Resiliency Model, coping is defined as a specific effort (covert or overt) by which an individual family member or the family as a unit attempts to reduce or manage a demand on the family system brought about by acquired brain injury (McCubbin & McCubbin, 1996). Coping patterns are generalised rather than stressor specific. According to Kosciulek (1993) there are four categories that define the ways in which coping facilitates family adaptation to acquired brain injury: (a) coping can involve direct action to reduce or eliminate the number and/or intensity of demands generated by acquired brain injury; (b) coping can involve direct action to acquire additional resources not already available to the family; (c) coping may involve managing the tension associated with continuing strains resulting from the acquired brain injury; and (d) coping may also involve family-level appraisal to create, shape and evaluate meanings families may give to acquired brain injury to make it more acceptable, manageable and constructive, such as maintaining an optimistic outlook.

The Resiliency Model describes the adaptation process in which families engage in direct response to the demands created by acquired brain injury and the need to make systematic changes in family functioning in order to restore family stability and satisfaction. Family adaptation is not confined to internal changes within the family (Kosciulek, 1993). Responsive and quality social support systems, and community resources, such as respite are critical factors for positive family adaptation to acquired brain injury (Kosciulek, 1993).

An overview of a theoretical framework of family coping has been presented above, following discussion of the impact of a catastrophic event, such as acquired brain injury, on
the individual and the family. It is argued that responsive and quality social support systems, such as respite, can play a critical role in positive family adaptation to a catastrophic event. While it is important to understand the theoretical family framework of coping and to offer respite as one potential factor in alleviating the stress of caring, it is more important to listen to the voices of family carers. What is it that family carers need from government? How can government policies and allocation of community resources meet the needs of family carers? This is not to suggest that there has been government inaction in providing assistance and relief to family carers. However, government action on such issues may not necessarily address the needs of family carers.

The Voice of Family Carers

In 2004, the National Family Carers Voice (NFCV) presented a significant interim report to the Australian Federal Minister of Family and Community Services. The NFCV is a representative group of unpaid family carers to provide advice and consultation to the Australian Federal Government on the concerns and needs of family carers. The NFCV Interim Report is significant in terms of highlighting at the national level, the plight of family carers and the impact of disability and caring for a person with a disability has on family life. The issues in the Interim Report were presented in terms of frequency of occurrence, beginning with the most frequently experienced issue.

The first key issue highlighted in this Interim Report is respite. Respite is identified as of major importance to families, and as respite is delivered through three levels of Government (Federal, State and Local); there are variations across Australia in service delivery, the type of respite available, and the length of time respite is available to the
family (NFCV, 2004). The families argued for longer breaks rather than small breaks (e.g., 4 hours a week) and for the urgency for appropriately supervised care. Families expressed concern that the current Government ethos of “user pays” has placed respite out of the affordable range for most families (NFCV, 2004).

The report also highlighted the impact of the lack of respite that can lead to inappropriate placement into nursing homes for young people with disability. Other concerns expressed included the unavailability of respite to people with complex support needs and/or challenging behaviours, extensive travel required to take a person for respite, geographical boundaries that impose barriers to accessing respite, inequitable resource allocation and the need to increase emergency respite places. A mother with two sons with severe disabilities had the following to say to the Minister:

Life seems a constant struggle. Limited finances means puts stress on relationships and health. Paid work is out of the question due to high care needs – I’d be too exhausted anyway. Respite is very difficult to access. Limited support from Government or the community groups to access to even basic equipment or services……No one really understands how greatly our lives are affected unless they are directly involved in the caring role. And most of the time we continue to put on a brave face and pretend that everything is fine. After all who else would do it if the parents can’t. (p. 5).

Another carer, a 63-year old mother of a son with Down syndrome had this to say to the Minister, in the Interim Report:
I would ask her (the Minister) for more Respite Houses and CRU’s (Crises Respite Unit) to be built. With no family support in Australia it’s becoming more difficult over the last 2 years due to my son’s depression and aggression and anger management. At the moment I get two days respite service. At times last year I felt so exhausted I felt like crouching into a corner for a bit of silence. Do we have to breakdown before the Government will do something to help us? We keep our children with us as long as we are physically and emotionally able. For 23 years I have looked after my son….it gets harder with age. (p. 6).

There were other concerns identified in the Interim Report, such as financial costs of caring; concerns about the future should the carer die, the lack of access to services and information, the need to understand family carers, supported employment, health of carers or disability impacting on immediate and extended family. It is not within the scope of the thesis to elaborate other concerns raised in the Interim Report by NFCV. The focus is on respite as the key concern identified by family carers. The experience of family carers in the NFCV Interim Report (2004) and the concerns expressed are identified in similar studies conducted overseas.

Sawatzky and Fowler-Kerry (2003) conducted a qualitative study to examine the effects of caring in a small group of urban women carers (n = 11), particularly on their well-being and health. The study uses a descriptive/narrative naturalistic research design. Sawatzky and Fowler-Kerry found that the caregiving experience was life changing and consuming for the caregivers, the caregivers described caregiving as a 24-hour a day, 7-day week responsibility. The analysis revealed three main domains: loss and grieving, adapting
and coping, and short- and long-term impact of caregiving. Nine of the 11 women had to give up their employment and hence, there was a loss of personal identity. The caregivers also noted a significant impact on changes in their relationships with the loved one and with others. The changes in the relationship included how the caregiving role takes dominance over the marital relationship as indicated in two of the participants’ statements:

There’s times when I do have to do some personal care, and I mean after doing that, one doesn’t feel very romantic…..if you probably did everything all the time you would move out of a wife role and become the nurse type role, the caring type thing. (p. 280).

It’s changed everything about our relationship. In our marriage it was an equal partnership, it’s not equal anymore. It’s very one-sided and I’m doing it all and I don’t know that there’s much of the relationship that’s the same. (p. 280).

Sawatzky and Fowler-Kerry (2003) reported the on-going cycle of grieving of the caregivers regarding the changes in the relationship and the impact of the disability on caring. The grieving can span from the loss of the person with a disability to the feelings of grief of the carer. Other loss experienced by the caregivers in the study included the lack of spontaneity in their lives because caring for the person has to be planned, and the loss of privacy and control over their lives. All of the participants relied on support systems such as other family members, caregiver support groups, neighbours and friends. At the same time, many of them also identified the dilemma of often needing help, but not wanting to ask for it (Sawatzky and Fowler-Kerry, 2003). The participants in the study also identified the varied types of help required, such as help with physical tasks or financial assistance.
The support from family and friends was identified as crucial in maintaining both physical and mental health of the carers.

Sawatzky and Fowler-Kerry (2003) also reported that respite services played a critical support role for the carers in eight of the 11 participants. Anger and frustration were expressed by a participant at the lack of government help and responsiveness to the needs of carers:

We have justified our needs and they still don’t (respond)….a parent or whoever is advocating for them, has to totally beg for a basic need…..the government will just wait till you go away, till you are burnt out……there is no dignity as a caregiver when you can justify stuff and they still have an excuse for why you’re acting like this…. (p. 283).

Similar to the NFCV Interim Report (2004), the carers in the study also identified several areas of need, such as financial matters (Sawatzky and Fowler-Kerry, 2003). Sawatzky and Fowler-Kerry argued that the voice of the carers in their study is strong and consistent, and should be heard by policy makers. The stories told in this study are consistent with the NFCV Interim Report (2004) and in other similar studies (Hartrey & Wells, 2003; Horsburgh, Trenholme & Huckle, 2002; Strang & Haughey, 1998).

Summary

The deleterious and long-term impact of acquired brain injury on the individual and carer are discussed in the previous chapter. A theoretical family adaptation framework that might predict outcome and identify those individuals and carers who might be at risk of
poor psychosocial adaptation to ABI in the context of this present study is discussed. This chapter suggested a role for respite as a one form of community and social support system to assist in the family’s adaptation to ABI. The “voice” of carers identified a lack of respite as the first key issue they wish for governments to address. The concerns of carers are elaborated in this chapter, such as a lack of respite can lead to inappropriate placement into nursing homes for young people with a disability.

To date there is no comprehensive profile of respite services in New South Wales. A comprehensive profile of the current state of respite will perhaps provide information for planning and resource allocation for respite to families that need it. Having an understanding of the predictors of respite use may assist in identifying carers who need it most and reduce the stress of caring. The knowledge of such predictors and having an understanding of carers’ expectations of respite may potentially assist in better adaptation to the catastrophic event of ABI. Hence the study aims to provide a comprehensive profile of respite in NSW and explore the factors that might predict respite use and gather carers’ expectations of respite.
CHAPTER FOUR

A Review of Child and Family Characteristics Related to the Use of Respite Care in Developmental Disability Services

Unlike the acquired brain injury literature there is extensive research in respite services within the developmental disability literature, so the review of research on respite will begin with the developmental disability field. In this chapter, the characteristics of family carers who used or do not use respite are examined. The review of the characteristics that may influence respite use or non-use will assist in the development of the survey questionnaire for this thesis. The next chapter will review whether respite services actually provide the type and amount of respite that the research suggests.

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Note:

Chapters 4 and 5 were co-authored by Professor Jeff Sigafoos. Professor Sigafoos was the first supervisor of this doctoral study. He did not continue to be the doctoral supervisor following his resignation from The University of Sydney.
A Review of Child and Family Characteristics Related to the Use of Respite Care in Developmental Disability Services

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ABSTRACT: This article reviews the literature on child and family characteristics that influence the use of respite care among families who have a child with a developmental disability. On the child side, these characteristics include severity of disability, level of required care, presence of challenging behaviors, and communication difficulties. On the family side, relevant factors include level of family stress, access to support systems, and family size. In some cases, marital status may also influence the decision of a parent to make use of respite care. Knowledge of these factors would seem crucial for effective planning and organization of respite care.

Many parents report significant stress in caring for a child with a developmental disability (Ainge, 1995; Barnett & Boyce, 1995; Beckman, 1991; Bouma & Schweitzer, 1990; Tumali & Power, 1993; Wikler, Hanusa, & Stoycheff, 1986). The development of effective support services to assist families in the care of children with developmental disabilities is therefore of obvious importance (Wikler et al., 1986). Effective services are those that assist families with care and lead to reduced levels of stress, thereby preventing possible family breakdown and the need for long-term, out-of-home care. In recent years, respite care has emerged as an important component in the array of services that have been developed to support families who have a child with a developmental disability. Several factors have led to the growth of respite care models in developmental disability services including advocacy by parents and reduction in institutional placements (Cohen, 1982; Hoare, Harris, Jackson, & Kerley, 1998; Wikler et al., 1986).

To inform policy development in the planning of respite care services, it is important to consider some of the child and family characteristics

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that influence the use of respite care. An understanding of these characteristics can inform service planning and delivery (Treneman, Corkery, Dowdney, & Hammond, 1997). Such information is pertinent to policymakers and providers of respite care, and it is needed to ensure there is the capacity to meet the expected level of need. The aim of the present article is to review literature relevant to these issues.

For the purpose of this article, respite care refers to the use of an organized service that is designed to provide temporary relief from the caretaking responsibilities associated with parenting a child with a developmental disability. Because the level of care required by such children can be substantial, respite care is seen as an important type of family support (Cox, 1997). Implicit in this definition is the goal to prevent institutionalization and to maintain the ability of families to provide a home for their sons or daughters with developmental disability.

It is recognized that various models exist for the provision of respite care services. These range from in-home personal care attendants to out-of-home day and recreational services (Janicki, Krauss, Cotton, & Seltzer, 1986; Upshur, 1988). Given this range, it would be surprising if these different models did not have a major influence on child and family functioning. In reviewing issues relevant to child and family characteristics that predict the use of respite care, it is therefore important to determine the extent to which the research has specified the precise model of service under consideration.

**Child Characteristics Related to the Use of Respite Care**

*Severity of Disability*

Considerable evidence suggests that families who have children with more severe levels of disability are more likely to use respite care (Cohen, 1982; Factor, Perry, & Freeman, 1990; Halpern, 1985; Hoare et al., 1998; Jawed, Krishnan, & Oliver, 1992; Marc & MacDonald, 1988; Treneman et al., 1997). Factor et al. found that families with children with severe autism used respite care more often than families who had a child with less severe autism. Similarly, Jawed et al. (1992) found that children with multiple impairment, such as speech difficulties and epilepsy, were more likely to use respite care. A possible limitation in both of these studies is the small sample size. Both studies had less than 40 participants. However similar findings have been reported in studies with larger sample sizes. Marc and MacDonald (1988), for example, examined the influence of severity of impairment in 124 families. The more severe the child's level of intellectual disability, the more
likely it was that the child’s family would make use of respite care. Hoare et al. (1998) conducted a community survey of 145 carers of children with severe intellectual disability. They found that carer stress was related to severity of disability. A link has been suggested between carer stress and severity of disability, which in turn leads to increased use of respite care (Factor et al., 1990; Hoare et al., 1998; Jawed et al., 1992).

**Level of Care**

Children who require higher levels of personal care from family members are more likely to be involved in respite care (Factor et al., 1990; Grant & McGrath, 1990; Hoare et al., 1998; Jawed et al., 1992; Salisbury, 1990; Treneman et al., 1997). In their study of 145 children with severe intellectual disability, Hoare et al. (1998) found that the level of dependency of these children on their families was high. For example, 74% were dependent on their carers for eating, 96% for washing, and 96% for dressing. Hoare et al. found that the general health of the carers was associated with certain child characteristics, such as whether or not the child was toilet trained and could walk independently. Salisbury (1990) examined the characteristics of users and nonusers of respite care in a representative sample of 105 families. Mothers of children with severe disabilities did not differ significantly from mothers of children with less severe handicaps in terms of their use of respite care. This finding may initially appear to be contrary to previous studies suggesting that severity of disability was a strong predictor of respite use. However, examination of the verbatim comments from monthly interviews with the families revealed that nonusers did not use respite care because other family members assisted in the care of the child or because they were unable to obtain services when needed.

Salisbury (1990) also found that the mothers’ level of stress was significantly related to the child’s level of functioning. Mothers of children with more severe disabilities reported significantly greater levels of stress than did mothers of children with mild and moderate disabilities. Mothers who made use of respite care reported greater levels of stress at the point of enrollment for the service than did nonusers. The level of stress among users was inversely related to the child’s degree of cognitive impairment. Again, levels of stress appeared to be linked to severity of disability, which in turn influenced the decision to use respite care.

Treneman et al. (1997) investigated the respite care needs of 308 families with children over 3 years of age who had intellectual and physical disabilities. Parents were asked to rate the child’s level of dependency in terms of daily tasks of feeding, washing, dressing, and
toileting. Communication difficulties and behavioral problems were also rated. Treneman et al. (1997) found that families with children who were rated as having medium to high levels of dependency reported significantly greater stress than did the parents of children in the low dependency group. The parents of these high-dependency children also used respite care significantly more than did the families of low-dependency children (Treneman et al., 1997). Freedman, Griffiths, Krauss, and Sletzer (1999) investigated the patterns of respite use by mothers who were 55 years of age or older and who had an adult offspring with intellectual disability. The variables that influenced the use of respite care included higher levels of caregiving needs owing to the poor functional skills of the child.

The above studies suggest that level of care (Freedman et al., 1999; Grant & McGrath, 1990) or level of dependency (Factor et al., 1990; Treneman et al., 1997) may influence the use of respite care. Level of dependency is obviously related in part to the child’s degree of disability and to caregiver stress (Hoare et al., 1998; Salisbury, 1990). Parenting a child with severe or profound disability can be emotionally, physically, and financially stressful (Salisbury, 1990).

*Presence of Problem Behaviors*

The presence of frequent and severe problem behaviors is associated with increased use of respite care (Duff, 1992; Factor et al., 1990; Grant & McGrath, 1990; Hoare et al., 1998; Jawed et al., 1992; Marc & MacDonald, 1988; Treneman et al., 1997). Common problem behaviors in children with developmental disabilities include (a) aggression, (b) extreme tantrums, (c) self-injury, (d) property destruction, (d) overactivity, and (f) sleep disturbance. Hoare et al. (1998) found that behavior problems were common in their sample of 145 children. Specifically, 29% of the children showed aggression towards others, 27% engaged in self-injury, and 53% had major sleeping problems. Hoare et al. (1998) argued that there was some evidence of an association between behavior problems in the child and carer stress, with carer stress being a major factor influencing the use of respite care. Marc and MacDonald (1988) found that children placed in respite care tended to have more severe behavior problems. Jawed et al. (1992) reported that problem behaviors were present in two-thirds of the population sampled who were involved in respite care. Problem behaviors included tantrums (58%), overactivity (54%), self-injury (29%), and aggression (29%). Grant and McGrath (1990) found that severe behavior problems had a 70% predictive value in the need for additional assistance.

Treneman et al. (1997) reported that parents of children who had few behavioral problems experienced significantly less stress than
those with medium or high levels of behavior problems. However, there was no significant relation between behavioral problems and the use of respite care. That is, while 6 of the 8 parents with children who had severe behavioral problems reported high levels of stress, only one actually made use of respite care. The nonuse of respite by the other parents is difficult to reconcile with previous research. However, Treneman et al. (1997) argued that children with behavioral problems might be difficult to place in respite care. As a result, the nonuse of respite care may reflect the lack of suitable services rather than a lack of need.

Gender

Salisbury (1990) reported that mothers of daughters with a developmental disability were more likely to make use of respite services than mothers of sons. Grant and McGrath (1990) reported a similar trend. They found five variables that appeared to predict whether or not a family would make use of respite care. These variables were (a) lonely caregivers, (b) younger caregivers, (c) caregivers of children with challenging behaviors, (d) caregivers who faced financial burdens; and (e) caregivers who had daughters with developmental disabilities. In contrast, Jawed et al. (1992) found that families who had a male child (versus a female child) with a developmental disability were more likely to place that child in respite care on a regular basis (i.e., 6 or more times per year). Further complicating the picture is the fact that Robinson and Stalker (1993) found that gender did not significantly influence the extent to which families made use of respite care.

Age

Robinson and Stalker (1993) reported that children under 5 years of age received less respite care than did older children. The extent of use for respite care peaked between 11 and 16 years of age. There was a subsequent decrease in the use of respite care after 16 years of age, but this was probably due to a shortage of services and the fact that older adolescents often went into full-time, adult residential placements. Salisbury (1990) found that 37% of children from birth to 5 years of age used respite care, 45% between the ages of 5 and 18 years, and 18% of those 18 years of age or older used respite care. Similar results were reported by Treneman et al. (1997). The above studies suggest that families with school-aged children use respite care most heavily.

Communication Difficulties

A significant percentage of the children who are placed in respite care have some form of communication impairment (Grant & McGrath,
1990; Hoare et al., 1998; Jawed et al., 1992; Treneman et al., 1997). This is not surprising given that communication impairment is linked to severity of disability and parental stress, both of which influence a family's decision to make use of respite care. For example, Treneman et al. (1997) reported that 42% of their respondents experienced moderate stress, and 15% experienced significant stress because of the child's communication impairment. This study also found that parents of children who had moderate to severe communication difficulties used respite care significantly more often than parents whose children had no communication difficulties. Jawed et al. (1992) also found that regular attendees in respite care tended to be children with speech impairments.

Family Characteristics Related to the Use of Respite Care

Mothers are the primary caregiver in most of the research on respite care (Botuck & Winsberg, 1991; Duff, 1992; Grant & McGrath, 1990; Hoare et al., 1998; Salisbury, 1990). Most of these studies are based on samples of younger families, generally with children under 18 years of age (Botuck & Winsberg, 1991; Dossetor, Nicol, & Stretch, 1993; Factor et al., 1990; Freedman et al., 1999; Halpern, 1985; Marc & MacDonald, 1988). There is also an emerging research literature investigating the needs of adults with intellectual disability who live at home with aging parents (Freedman et al., 1999; Smith, 1997; Todd & Shearn, 1996).

Level of Family Stress/Perceived Stress

As discussed previously, there is a consistent association between stress and the use of respite care. Hoare et al. (1998) argued that carer stress was a major predictor in the decision to use respite care and that nonusers of respite care expressed greater optimism about their coping ability than did those parents who made use of respite care. Factor et al. (1990) also found that parents who made use of respite care for their child scored higher on measures of parental stress than did nonusers. Additional evidence of a link between parental stress and the use of respite care comes from Treneman et al. (1997) and Salisbury (1990).

Level of Family Support Systems

Research investigating support systems and social networks for families caring for children with developmental disabilities suggests that
the quality of support provided to such families plays an important role in mitigating the effects of stress (Salisbury, 1990). A social support network might include relatives, neighbors, co-workers, and friends who assist the family in caring for the child with a developmental disability (Salisbury, 1990). Respite care services can be seen within this context as a social system of support for the family. For example, Sherman (1988) reported that families who placed their child into permanent residential care cited a greater need for respite care, but had not received any such services. Nearly one-third of those families who placed their child into residential care reported that they needed respite care and one-quarter of those who cared for their child at home also reported the need for respite care.

Grant and McGrath (1990) revealed several factors in the life experience of caregivers that appeared to influence the need for respite care. As indicated before, one factor identified by Grant and McGrath was the sense of loneliness expressed by the caregivers. The perception of caregivers regarding the acceptance or rejection by the local community and/or neighborhood is also a factor to consider in the need for respite services. Underlying these factors then is the perception of the level of support these families feel they are receiving from their support networks. According to Grant and McGrath, the moral support of the local community and/or neighborhood appears to be highly valued by families who care for children with developmental disabilities.

Salisbury (1990) found that families who did not use respite care had access to informal sources of support that they could turn to for assistance when compared to families who made use of respite care. Cohen (1982) and Factor et al. (1990) also reported that families who made use of respite care tended to be those who lacked a network of support outside the home. The lack of support networks may contribute to the use of respite care.

Dossetor et al. (1993) examined the use of hostel-based respite care by adolescents with developmental disabilities and their families. Ninety-two families were interviewed on a range of family functioning measures and to determine the self-help and communication skills of the adolescents. Dossetor et al. (1993) found that the use of hostel-based respite care services was more strongly related to family functioning than to characteristics of the adolescents. In addition, users of the hostel-based respite care tended to be families who had fewer resources, including limited social support and greater tension in family functioning, when compared to families who did not make use of hostel-based respite care. Dossetor et al. (1993) also found that the home life of those adolescents who accessed the hostel-based respite care was characterized by less stimulation, less independence in family roles, and fewer community outings with the family.
Family Size

Robinson and Stalker (1993) reported that larger families tended to make greater use of respite care than smaller families. For example, 30% of user-families had five or more children, 23% of those had four children, 22% had three children, and 17% had one or two children. They also found that single-parent families were more likely to make frequent use of respite care. That is, 26% of this group used respite care services for 8 or more weeks in a 1-year period.

Marital Status

It is unclear if marital status is related to the use of respite care (Hoare et al., 1998; Marc & MacDonald, 1988). According to Hoare et al. (1998), only 3% of their sample of families that used respite care were single parents, but the proportion increased to 14% when separated, divorced, and widowed carers were considered. Salisbury (1990) found that single parents tended to report higher levels of stress than married carers. Parents of children with disabilities also tended to report difficulties in marital integration or personal well-being. Mothers of such children also reported less marital satisfaction. Given the link between stress and the use of respite care, marital status would be expected to influence the use of respite care in some cases.

Other Family Factors

Grant and McGrath (1990) indicated that younger carers and those who faced financial burden were more likely to use respite care. Salisbury (1990) also found that families who used respite care had lower incomes. Robinson and Stalker (1993) reported that low-income families tended to use institution-based respite care services. Unemployment rates were particularly high among fathers whose children used institution-based respite care. However, Marc and MacDonald (1988) did not find any significant differences in social-economic status or educational backgrounds between users and nonusers of respite care.

Summary

Several factors appear to influence the use of respite care among families of children with developmental disabilities. Some of these factors are related to the individual with a developmental disability and other factors are related to family characteristics. Those that relate
to the individual include severity of disability, level of required care, presence of challenging behaviors, age of the child, and the child’s degree of communication impairment. Family characteristics that appear to influence the use of respite care include the level of family stress, access to informal support networks, family size, and possibly marital status. One of the more powerful child related variables is the presence of challenging behaviors, and yet there appears to be little research on effective models of respite care for individuals with developmental disability and severe behavior problems. This is clearly an area for further research.

Another area that needs to be more fully explored is the benefit of respite care. While there has been some discussion regarding the benefits of respite care in general, the research literature examining benefits and outcomes from the use of respite care services for individuals with developmental disabilities and their families has been minimal (McNally, Ben-Shlomo, & Newman, 1999). While there is general agreement that respite care is beneficial to families who use it (Apolloni & Triest, 1983; Botuck & Winsberg, 1991; Rimmerman, 1989; Rimmerman, Kramer, Levy, & Levy, 1989; Ptacek, Sommers, Graves, Lukoieicz, Keena, Haglund, & Nycz, 1982; Wikler et al., 1986), there is a need for more research on outcomes for individuals with a developmental disability and their families.

Families may seek respite care for a variety of reasons. Some of these reasons may be planned in advance, but others may arise unexpectedly due to a family illness or some other crisis (Salisbury & Griggs, 1983; Upshur, 1982). Little is known about the planned versus the emergency use of respite care.

Upshur (1982) argued that respite care is a cost-effective model for providing support to families with a child with a developmentally disability. Unfortunately, information regarding the availability for such services is lacking (Cotterill, Hayes, Flynn, & Sloper, 1997). At the same time there appears to be growing demand for respite care services. Further research exploring the availability, use, and benefits of respite care is needed so that service providers and funding agencies will be in a better position to plan and manage this vital service.

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CERTIFICATE CONFIRMING AUTHORSHIP CONTRIBUTION
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A Review of Child and Family Characteristics Related to the Use of Respite Care in
Developmental Disability Services

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As co-author of this paper, I, Professor Jeff Sigafous confirm that Jeffrey Chan has made the following contributions to this paper:

1. Conception and design of the research
2. Reading and review of the research literature
3. Analysis and interpretation of the review
4. Writing the paper and critical appraisal of content

Signed: ........................................ (Professor Jeff Sigafous)

Date: 17/08/2007
CHAPTER FIVE

Does Respite Care Reduce Parental Stress in Families with Developmentally Disabled Children?

The previous chapter reviewed the literature on family and child characteristics that may influence the use of respite care among families who have a child with a developmental disability. The level of severity of disability, level of required care, presence of challenging behaviors, and communication difficulties are the characteristics that appear to influence respite use. On the family side, relevant factors include level of family stress, access to support systems, and family size. In some cases, marital status may also influence the decision of a parent to make use of respite care. In this chapter, a review is provided of the studies that have evaluated the effects of respite used by families of children with developmental disabilities. The review focuses on parental stress and examines whether respite reduces family stress in families of children with developmental disability.

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Does Respite Care Reduce Parental Stress in Families with Developmentally Disabled Children?

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_ABSTRACT:_ Caring for a developmentally disabled child can be extremely stressful for many parents. Respite care is designed in part to alleviate this stress. This paper reviews studies that have evaluated the effects of respite care services used by families who have children with developmental disabilities, with an emphasis on parental stress. In general the results of this review suggest that, at least in the short-term, respite care is associated with significant reductions in parental stress for the majority of parents who use it. However, the database on this issue is relatively small and many studies have significant limitations, particularly in their almost exclusive reliance on indirect measures of stress reduction and associated benefits (e.g., increased coping, improved quality of life). Additional research is needed to address these limitations. In the meantime, respite care providers should seek to evaluate the effects on, appropriateness for, and acceptability of its services at the level of the individual family.

_KEY WORDS:_ respite care; parental stress; developmentally challenged children; developmentally disabled children.

Introduction

Study after study has confirmed that caring for a child with a developmental disability can be extremely stressful for many parents (Ainge, 1995; Barnett & Boyce, 1995; Bouma & Schweitzer, 1990; Tunali & Power, 1993; Wikler, Hanusa, & Stoycheff, 1986). It is not inconceivable that the stress some parents experience as a result of caring for a child with developmental disability could be disruptive to family functioning leading to family breakdown and institutionalization of the child (Blacher & Bromley, 1990).
To reduce parental stress, many developmental disability services have pinned their hopes on respite care. In the developmental disability field, respite care typically involves the provision of an organized service that takes over the parental role for a short period of time on some regular basis. The child might, for example, spend one weekend each month at a foster-care home or a staff person might come to the parents’ home one day each week to care for the child. There are many variations of respite care available to families (Levy & Levy, 1986), but in each there is the common objective to temporarily relieve parents from the stressful demands of caring for the child. When the level of stress is reduced, parents should enjoy a higher quality of life and be less likely to seek out of home placement for their child (Storey, 1993).

These are reasonable expectations, based on what appears to be a logical argument. It is, however, conceivable that respite care could simply become another source of stress. This might occur if families have to worry about the quality of care that the child receives from untrained respite care staff or has to take on the added responsibility of arranging transportation to and from a respite service. A service designed to reduce stress may in fact create stress. If stress reduction, with all its attendant spin-offs, is touted as a major potential benefit of respite care, then one must examine whether this is in fact a likely outcome when families with developmental disabilities make use of respite care services.

The aim of this paper is to review studies that have evaluated the effects of respite care services used by families who have children with developmental disabilities, with an emphasis on parental stress. A review of this type may help determine what if any benefit respite care provides to families. Does it reduce parental stress, improve family functioning, and increase quality of life? In attempting to answer these questions, a review of this type may also help to tease out variables associated with better outcomes for families and this, in turn, may enable disability professionals to design better respite care services.

As might be expected, others have also attempted to evaluate the overall impact of respite care by reviewing the literature. However, other recent surveys have either not directed their attention exclusively to the effects on parental stress (Chan & Sigafoos, 2000) or have included such a wide range of disability conditions (McNally, Ben-Shlomo, & Newman, 1999) that the specific effects for families with developmentally disabled children remain somewhat clouded.

Chan and Sigafoos (2000) focused their review on variables that predicted use versus non-use of respite care among families with developmentally disabled children. They found a number of specific child (e.g., severity of disability, level of required care, presence of behavior problems, degree of communication impairment) and family variables
(e.g., level of family stress, access to support networks, family size) that influenced the use of respite care. Their review did not, however, address the issue of whether the use of respite care had any significant impact on parental stress. Although the McNally et al. (1999) review examined the effects of respite on parental stress, they included only four studies that focused exclusively on persons with developmental disabilities. Given that the needs of children with developmental disabilities and their families may differ substantially from other groups, such as persons with chronic illness or aged persons (Tepper & Toner, 1993), a more narrowly focused review would seem warranted.

**Effects of Respite Care on Parental Stress**

In a study with multiple aims, Rimmerman (1989) examined the changes in maternal stress and coping over an 18-month period. The study involved 32 families who had been using home-based respite care and 25 families who did not use respite care. All families had children with comparable levels and types of developmental disabilities. Families who used respite care reported reduced levels of stress and better coping. In comparison, the 25 families who did not use respite care during the 18-month period reported increased stress and reduced coping. These data would seem to show that the use of home-based respite care was in fact achieving what must be seen as one of its fundamental goals; that is, reducing families' stress and increasing the family's ability to cope with caring for their developmentally disabled child.

One study does not however prove the case and this study is limited because the results are derived from maternal reports of stress and coping and the study evaluated only one type of respite care (i.e., home-based). It is possible that mothers' responses were influenced by an implicit expectation that respite care is supposed to make life less stressful and help them cope better. Families are not of course blind to the fact that they are making use of respite care services. The effects on fathers' stress and coping would also seem important, but fathers were not included. In addition, the study was limited to a period of 18-months and so the longer-term benefits of respite care in this particular sample are unknown. Furthermore, it is possible that the two groups of families differed in important ways at the onset, which may in fact have influenced why they either did or did not use respite care. Perhaps highly stressed families who were less able to cope with the care of the child were also less able to seek out respite care services. Still these findings showed that respite care was associated with reduced levels of self-reported maternal stress and with maternal reports of improved coping. This does not mean that respite care was in any way directly,
responsible for these positive reports. However, the results are consistent with other similar studies (e.g., Apolloni & Triest, 1983; Botuck & Winsberg, 1991; Joyce, Singer, & Isralowitz, 1983; Wikler et al., 1986).

The generally positive findings from the Rimmerman (1989) study started to decline when the families were assessed at 12 and 18 months. Close examination of the data at 12 and 18 months show declining trends in the scores on some measures, such as increased reports of parent and family problems and more pessimistic attitudes about their child's care and development. Furthermore, some mothers perceived that their child's physical incapacitation was getting worse.

These declining trends are not necessarily related to the use of respite care of course. However, the fact that the most positive ratings from the families who used respite occurred at 6 or 12 months and then these ratings started to decline from 12 to 18 months, suggests that the perceived benefits of respite care may be relatively short-term even if the families continue to use the service. These declines were, however, similar to trends recorded for the comparison group. Is it therefore the actual service that is important or merely the fact that something new and promising is on offer? Perhaps any new and seemingly supportive service or program might make families feel better and relieve stress for a while (i.e., for 6 to 12 months). Additional research is needed to determine whether the stress reduction effects of respite care are durable beyond 12 months or only temporary.

Botuck and Winsberg (1991) investigated the immediate and short-term effects of the planned use (i.e., not emergency use) of respite care on 14 mothers of school-aged and adult children with multiple (i.e., physical and intellectual) disabilities. They evaluated changes in maternal mood, well-being, and activity patterns before, during, and after respite. The results indicated that mothers were "happier" (i.e., increased feelings of well-being and less depressed mood) during respite than they were before or after respite, and the data also indicated that the mothers experienced a greater sense of well-being after respite than before respite. They also found that the mothers spent more time resting, sleeping, grooming, and had improved personal care, increased leisure activities, and more social interactions when their children were in respite care.

At least at the time when the child is in respite, these data suggest dramatic improvement in quality of life along several dimensions. One might argue that this in itself is an important and sufficient outcome, but one must consider the possibility of a negative side effect owing to the contrast between the two conditions; that is, the contrast between when the child is in respite care versus when the child is at home. If the mothers are happier and more active when their children are in respite care, then they must in contrast be relatively unhappy and less
active when the child is at home. With frequent use of respite care, the ‘child-at-home’ condition might become associated with feelings of unhappiness and less fulfilling activities for the mother. (Parenthetically, it is important to mention here that from these first two studies, we still don’t know the effects on fathers.) This in turn could increase the probability that the child would spend more and more time in respite care. Chan, Sigafoos, Watego, and Potter (2001) have documented 10 cases in which respite care services were used as a long-term and essentially permanent out-of-home placement. Far from protecting the child from being placed out-of-home, the initial use of respite care might in some cases lead parents to seek more and longer out-of-home care for their child. Unfortunately, there are no data that would enable us to say with certainty whether this speculation has any merit. Our intent is merely to alert readers to the fact that the short-term benefits of respite care reported in the studies reviewed so far could have other long-term effects that are not what the service providers are aiming to achieve when they offer respite care to families.

So far we have reviewed two studies showing that respite care, at least in the short-term and at least for mothers, is associated with reduced stress, improved coping, and general improvement in quality of life. The findings in these two studies are consistent with other similar research (e.g., Apolloni & Triest, 1983; Joyce et al., 1983; Wikler et al., 1986), and so the weight of accumulating evidence does suggest that these could be some of the more general and ‘real’ effects of respite care. It would, however, be surprising indeed if these general effects were not moderated by individual characteristics of the families, the children, and the type, amount and quality of respite services received.

Along these lines, Rimmerman, Kramer, Levy, and Levy (1989) investigated the effects of home-based and center-based respite care service. The study involved 78 mothers with minor and adult developmentally disabled children. These mothers completed a series of questionnaires about their levels of stress, coping, self-esteem, and perceptions of family functioning and support. The results showed that the reduced stress and improved coping associated with the use of respite care were mediated by the mothers’ self-esteem, family cohesion and adaptation, and to a lesser degree, by the child’s age and functioning level. They discovered that respite care was of most benefit to mothers with high self-esteem who had younger and more severely disabled children.

Based on these results, Rimmerman et al. (1989) speculated that perhaps mothers of younger children benefited most because it is these mothers who are most heavily involved in nurturing and fostering the emotional growth of the child. Furthermore, mothers with higher self-esteem may be better prepared psychologically to embrace the newfound freedom that respite can provide. As an aside, Rimmerman et
al. also found that families with younger children preferred home-based respite care, whereas families with older adult children preferred center-based services. This suggests that the type of service best suited to individual families may change over time. Unless providers are able to adjust to shifting family preferences any benefits that were once realized may evaporate.

Results of one study suggest that stress may be reduced in more or fewer families depending on the configuration of the service. Stalker and Robinson (1994) conducted interviews with 160 parents in the United Kingdom who made use of various models of respite care (e.g., family-based, local authority, larger health authority). These three types of services can be thought of as differing in location of service, size of service organization, and in the geographic region covered by the service. That is, family-based was the most personal and localized level of service, followed by services organized by the local (council) authority, followed by services that were organized by the larger regional (or county) health authority. They asked families whether the service was helpful in reducing stress and found that the percentage of families reporting reduced stress was similar for those receiving family-based (44%) and local authority services (49%), but much lower for families receiving respite services from the health authority (22%).

Another relevant study looked at the effects of the amount of respite care received (Halpern, 1985), rather than type or location as in the Stalker and Robinson (1994) study. Halpern investigated the benefits of respite care in 30 families who used respite and 31 families who did not use respite. The results showed that there were several benefits associated with the use of respite care, including an overall improvement in family functioning and better parental attitudes towards the child with disability. Indeed, the strength of these associations was related to the amount of respite services received. The more time that the families made use of respite care, the lower were their scores on measures of perceived family conflict and the more time they spent on recreation/leisure activities. These positive findings have also been replicated in two other studies (Marc & MacDonald, 1988; Wikler et al., 1986). The Marc and MacDonald (1988) study, for example, showed that the overwhelming majority of participating families reported that they had gained many positive benefits from respite care. To illustrate, 81% reported that they now got along better as a family, 83% reported being able to do more things for themselves, and 83% reported stress reduction.

In a more involved study, Wikler et al. (1986) implemented and evaluated two home-based respite care projects for children with developmental disabilities and severe behavior problems. In the first project, 5 children who were at-risk of being reinstitutionalized due to their
severe behavior problems were recruited. These children had just been discharged from a hospital after an admission owing to severe behavior problems and there was concern regarding the return to home care. Hence the project was designed to assist in the transition to home care. To achieve this, 5 college students were trained in how to manage behavior problems in children with developmental disability and assigned to the 5 families. The students were to assist the families in the management of the children’s problem behaviors and to provide respite care to the families over a 4-month period. Evaluation of the project included direct observational data on child problem behaviors as well as results from parent completed questionnaires on their attitudes towards the child and satisfaction with the service.

The results of the evaluation indicated no increase in problem behaviors or deterioration for any of the five children. In fact there was some reduction in observed problem behaviors. The parents in turn were unanimously satisfied with the program. Parents reported a sense of relief at having access to well-trained staff to assist in the care and management of their child. None of the families sought readmission of their child into the hospital or to any other institutional or out-of-home placement over the 4-month period. The results suggest that at least in the short-term this rather unique type of respite care may help prevent institutionalization of children who are at-risk for out-of-home placements due to their severe behavior problems.

In the second project by Wikler et al. (1986), 10 families participated in the respite care project. These families were home to 6 male and 4 female children with developmental disability who ranged from 2 to 20 years of age. This project was similar to the first in that trained college students were allocated to each family at no cost to the family. The students provided respite care to the families over a 2-month period. Pre-post measures showed that levels of family stress were significantly lower at the end of the project. All of the families also reported positive changes in their social relations, attitudes, and in the child’s behavior problems. As in the first project, these families too were highly satisfied with the project.

The findings from both projects in the Wikler et al. (1986) study suggest a dramatic possibility. Respite care could be organized in such a way as to help prevent the need for families to seek out-of-home placement for their developmentally disabled child. Wikler et al. (1986) argued that providing regular respite care may reduce the social isolation of the family and may also function to increase the resilience of the mother in the care of the child with disability. They also further argued that by providing trained respite carers, these parents were given the opportunity to observe the respite worker’s attitudes, skills, and knowledge as he or she interacted with the child. Through such
modeling, parents may come to change their attitude towards the child. One of the keys to effective respite care may thus lie in the skills of the respite care workers.

There are, however, a few significant limitations of the Wikler at el. (1986) study that indicate the need for caution in interpreting the results. Both projects in the study had relatively small sample sizes and short timeframes (i.e., 4 months in the first project and 2 months in the second). In addition, the researchers focused primarily on the perspectives of the parents, although this was one of the few studies that included direct observations. Furthermore, the care that was provided focused on behavior management, which may not be the only relevant support needed by other families. Finally, the lack of a control group means that the effects cannot be attributed with confidence to the program of respite care.

In one of the few studies to include a random experimental control, Singer, Irvin, Irvine, Hawkins and Cooley (1989) compared the benefits of two types of community-based respite support services. It is important to note that fathers were included in this study. Forty-nine parents from 32 families participated in the study. Families were randomly assigned to one of two groups. The first group (less intensive support group) received a modest level of respite support, which consisted of respite care and case management. The second group (more intensive support) received a more intensive service that included stress management, respite care, parenting skills training, and parent support groups. Both groups received in-home respite care and case management services for 16 weeks, while the Intensive Support group received additional training in coping skills, extended social support in integrated community settings, and access to community volunteers who provided out-of-home respite. The study is also notable because it had a relatively long timeline (1 year).

Over the year, Singer et al. (1989) collected data on the child's adaptive behavior and on parent's ratings of their own levels of stress, depression, and anxiety as well as parental satisfaction with the service they received. Singer et al. found that mothers in both groups showed significant improvement in measures of depression and anxiety, with mothers in the Intensive Support group indicating less distress than the Less Intensive Support group. Fathers in the Intensive Support group also experienced significantly more positive results on measures of stress, depression, and anxiety.

Singer et al. (1989) reported that it was difficult to control case management and respite care in an experimental design because, ethically, parents were free to purchase additional respite hours or request more or less assistance. While focused on respite care, Singer et al. (1989) actually concluded that their data suggested that, for some par-
ents, alleviation of anxiety and depression is likely to require more than respite care and case management. In addition, they argued, parents might be expected to need a combination of services that include coping skills training and access to networks of informal social supports from community volunteers. Other additional services, such as stress management and child behavior management training, may also be needed. Respite care is one service that may assist parents greatly, but it is by no means the only service needed to reduce parental stress and improve coping skills.

**Summary and Conclusion**

In general the results of this review suggest that, at least in the short-term, respite care is associated with significant reductions in parental stress, at least for mothers and perhaps also for fathers. As might be expected, the extent of stress reduction may depend heavily on the type, extent, and quality of services received as well as on numerous other child and family variables. Still, this general reductive effect on parental stress would seem sufficient evidence to warrant the current general enthusiasm for respite care among developmental disability services (Chan & Sigafoos, 2000), although more research that includes fathers and other members of the family in addition to mothers is clearly warranted. Still, our general conclusion from this review of the literature is that the use of respite care is associated with reduced parental stress in a majority of the participating families with developmentally disabled children.

However, this conclusion needs to be interpreted with caution because of several limitations in the studies that have examined the effects of respite care on parental stress. First of all there are simply too few studies to do a meta-analysis, which would have provided a useful quantitative supplement to this more qualitative and narrative review. It should be noted that we conducted our search via electronic databases and limited it to peer-reviewed English language journals. We may have missed some relevant studies.

Second, nearly all of the studies relied on indirect measures (parental reports) of stress, coping, and quality of life. Such indirect measures are often of unknown reliability and validity. Including more direct measures of stress, coping, and quality of life, such as direct observations with inter-observer agreement data, is needed to bolster the rigor of the dependent variables that have been studied to date. Third, there has been limited follow-up (18 months or less) and so the longer-term benefits of respite care on measures such as stress reduction are unknown. Fourth, most of the studies have not included no-respite control
groups or other forms of control that would enable one to attribute stress reduction (or other changes) to the respite care services received. Intervening and third variables, such as the mere passage of time, changes in the family, and child maturation, could have had as much or even more impact on reported levels of parental stress. In light of these limitations, there is a clear need for additional research. Until such time when more data are available, we urge caution in advocating for any particular type of respite care without evaluating its effects on, appropriateness for, and acceptability to individual families.

References


CERTIFICATE CONFIRMING AUTHORSHIP CONTRIBUTION
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Does Respite Care Reduce Parental Stress in Families with
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As co-author of this paper, I, Professor Jeff Sigafoos confirm that Jeffrey Chan has made the
following contributions to this paper:
1. Conception and design of the research
2. Reading and review of the research literature
3. Analysis and interpretation of the review
4. Writing the paper and critical appraisal of content

Signed: 

(Date: 17/02/07)
CHAPTER SIX

Respite Care Service as a Support System for the Family

The previous chapters discussed the child and family characteristics that may predict the use and non-use of respite in the developmental disability area; and examined whether respite reduces parental stress in families who have children with developmental disability. There is further need for evidence in the developmental disability and respite literature regarding the benefits of respite and how respite ought to be delivered to maximize the potential impact on families who use respite. This chapter further examines relevant research that has been published since the articles in Chapters 4 and 5 were published, and the research presented in this chapter will reiterate some of the same issues reported earlier.

While there is a significant amount of research on respite in the developmental disability area, there is minimal evidence in the area of acquired brain injury and where carers of people with acquired brain injury may also require such a service. Furthermore there is no research in the area of respite that examines and compares the perspective of people who receive respite, their carers and that of service providers.

Respite Care in Acquired Brain Injury

The studies reviewed have clearly indicated the life-long strain and distress of caregivers and the individuals with brain injury (Hodgkinson et al., 2000; Koskinen, 1998; Marwit& Kaye, 2007; Stebbins & Leung, 1998; Rotondi et al., 2007; Winstanley et al., 2007). Koskinen (1998) argued that the family or carer should have the right to rest and vacation without feelings of guilt while caring for the person with brain injury. However, many of the needs of these individuals and their carers continue to be unmet (Pickelsimer
et al., 2007; Rotondi et al., 2007). There is now an increasing trend toward the provision of rehabilitation for the person with brain injury and severe disabilities within the home context and community setting (Brzuzy & Speziale, 1997; Cummins, 2001; Freeman, 1997; Minnes, Harrick, Carlson, & Johnston, 1998; Warden et al., 2000; Willer, Linn, & Allen, 1994). The benefits for rehabilitation within a home or community environment are obvious (Cummins, 2001) and include economic benefits for governments in terms of saving billions of dollars through the utilization of care within the family (Cummins, 2002; Post, 2007).

Given that there are benefits for the individual and governments in rehabilitation within the family or community context, the focus of rehabilitation should also include the family or carer (Koskinen, 1998). Cummins (2001) argued that, while there is an increasing trend toward encouraging family care for people with a severe disability, there is no corresponding concern in supporting families who care for the disabled family member at home. He also proposed that increased public expenditure needs to be directed to the care for people with severe disability. Winstanly et al. (2007) have also argued that resources such as respite and case management may help mitigate the consequences of the injury on carers and can lead to some positive outcomes.

Respite care refers to the use of an organised service that is developed to provide temporary relief from the care-taking responsibility associated with looking after a person with a disability (Chan & Sigafoos, 2000). Respite has been identified as one of the many support services to assist the family in the care of the individual with brain injury within the home and/or community setting (Hall et al., 1994; Kaplan, 1991; Knight et al., 1998).
There is a role for respite care services as a form of social and community resource support to the family’s adaptation to acquired brain injury. Respite care service is one of the many forms of social and community resource support systems that the family should be able to access to adapt to acquired brain injury, and yet there is a paucity of research and evidence available in the area of respite and acquired brain injury.

The focus of acquired brain injury research has tended to be on the medical rehabilitation of the individual, however there is now growing recognition that long-term care of these persons should also focus on their carers or family members (Friss, 1990; Tate et al., 2003; Winstanley et al., 2007). Friss (1990) reported that family of persons with acquired brain injury need a range of services and respite care is seen as one of the more important service that families require in order to assist them to care for the person with acquired brain injury in the long-term. Tate et al. (2003) reported continuing needs of people with traumatic brain injury 20 – 26 years post-trauma, with 73% having unmet needs such as work, social participation and domestic support. In the same study, 58% indicated a need for respite accommodation. The study clearly demonstrated the long-term needs of people with acquired brain injury and that respite is one of the many unmet needs.

In order to understand the importance of respite care in acquired brain injury, it is helpful to understand the much more extensive research available in developmental disability or aged care. While there is extensive research interest in respite care in the areas of developmental disability (Chan & Sigafoos, 2000, 2001; Olsen & Maslin-Prothero, 2001; Ridley, Chan & Roberts, 2004) and in aged care (Brown, McWilliam, Wetmore, Keast & Schmidt, 2000; Kosloski & Montgomery, 1995; Lawton, Brody & Saperstein,
There is likewise no research on mapping respite services that might be available to persons with acquired brain injury and their families or carers. Therefore, it is one of the aims of the thesis to gain this understanding and how research available in the various population groups (such as developmental disability, in aged care, mental health or persons with chronic conditions); and of varying age groups can inform respite services in acquired brain injury.

**Models of Respite Services**

There are varied models of respite service. Generally, the prevalent models of respite care can be described as either in-home or out-of-home services (AIHW, 2006; Friss, 1990; Friss-Feinberg & Kelly, 1995; Janicki, Krauss, Cotton, & Seltzer, 1986; Jeon, Brodaty & Chesterton, 2005; MacDonald et al., 2007; Olsen & Maslin-Prothero, 2001; Stancliffe, 1990; Upshur, 1983). According to Janicki et al. (1986) models of respite care developed for younger persons with developmental disabilities are also applicable to older adults with developmental disabilities. In-home respite services can include day programs, a personal care attendant, or child-minding services, family respite exchange programs, home-care or home health-aide programs (these services included assisting in the care of daily routines such as bathing, dressing or house-cleaning) and volunteer aides (Forde, Lane, McCloskey, McManus & Tierney, 2004; Janicki et al., 1986; Levy & Levy, 1986; Miller, 2002; Upshur, 1983). Out-of-home respite services can range from day programs or activity centres,
family respite exchange services, parent co-operative services, short-term respite centre-based services or institutional care (Janicki et al., 1986; Levy & Levy, 1986; Miller, 2002; Olsen & Maslin-Prothero, 2001; Upshur, 1983).

Other models of respite services that have been explored are leisure or weekend respite provision (Campbell, 1996, McGill, 1996), and hostel-based respite care for adolescents (Dossetor, Nicol & Stretch, 1993). McGill (1996) evaluated a summer holiday respite provision for families of children and young people with learning disabilities. The evaluation was based on a semi-structured interview procedure and a 3-point rating scale questionnaire conducted with 18 families who used the holiday respite scheme and 5 families who had not used the scheme. The children ranged from 6 to 18 years with an average of 13 years old, most of the children attended the holiday scheme for between 1 and 3 days in total. McGill (1996) found mothers who participated in the study found the holiday respite scheme useful and beneficial for all family members also. Campbell (1996) described the demand for additional respite services and the need for a variety of types of respite care following a postal questionnaire survey of 322 families of children with special needs in Fife in Scotland. Two most commonly requested services were a small homely respite centre and holiday play-schemes.

Caldwell and Heller (2003) explored the management of respite care and personal assistance services by 97 families of relatives with developmental disabilities. This is one of a handful of studies that focused on family directed or consumer controlled service provision to the person with developmental disability. Family-directed or consumer controlled service provision can mean that the families are responsible for the recruitment,
hiring, training, scheduling, directing and negotiating wages of the staff they hire to provide the services. Caldwell and Heller used several measures, such as caregiver satisfaction, caregiving self-efficacy, service satisfaction, community involvement of the person with developmental disability, employment of mothers and staff turn-over.

Caldwell and Heller (2003) found more control in the management of respite and personal assistance services was strongly associated with higher service satisfaction ($p < .05$). Having fewer unmet needs was also significantly associated with higher service satisfaction. More family control was also associated with increased community involvement for the person with developmental disabilities. Caldwell and Heller argued that this may be due to the fact that the families were hiring more qualified staff, or that they were also hiring other family members (52.6%) or friends (36.1%). Only 35% of the families experienced any change in staff during the previous year. More control was also related to increased employment of mothers, as the mothers were able to tailor the services to meet their specific needs.

While there appear to be benefits to the families in this model, it would have been interesting if the study had included health outcomes for both the caregiver and the person with developmental disability, and compared staff turn-over of family controlled services with that of disability respite agencies. It would also have been of interest to measure staff perception of workplace satisfaction. Despite the above criticism, the study presents an important shift from the traditional model of respite service delivery. A strong policy implication from the study by Caldwell and Heller (2003) is that it emphasises the need for
models of respite services to be flexible to meet the needs of both caregivers and people with disabilities.

Friss-Feinberg and Whitlatch (1998) also investigated consumer-directed respite services in a population of families caring for a person with cognitive impairment. They compared the preferences for consumer directed respite service with agency-based respite services in a sample of 168 caregivers. Friss-Feinberg and Whitlatch (1998) found more than twice as many caregivers were receiving respite service based on consumer-directed approach (68.5%) than from agency-based program (31.5%). The main reasons for the preference of using consumer-directed respite services were to ensure that their family member was safe (91.3%), and that there was reliable and trustworthy help (87.8%), with 79.1% wanting to be able to choose their own help and 59.1% wanting a home-care aide that “fit the household”. There were no significant differences found between both groups in terms of caregivers’ levels of depression. Comparisons between both groups on consumer satisfaction found more similarities than differences, that is, both groups were generally satisfied with the quality of care (Friss-Feinberg & Whitlatch).

The study by Caldwell and Heller (2003) examined a family controlled model of service delivery. Friss-Feinberg and Whitlatch (1998) compared preferences for consumer-directed and agency-based program respite service. Both studies involved government funded services even though the service may be consumer directed. The question needs to be asked whether families are willing to pay for respite services if there are minimal or no government funds for such a crucial service? Chiu, Tang, Shyu and Chang (1999) investigated the willingness of 174 families of patients following stroke, to pay for in-home
Respite services in Taiwan. They found that 42.5% of the families interviewed were willing to pay up to 50% of the family income for respite care. The willingness to pay for in-home respite services was strongly associated with family income and the more severe the physical dysfunction, the higher the willingness to pay for respite services. The study by Chiu et al. (1999) represents another model of respite service delivery that is a shift from the traditional government funded service.

Friss (1990) and Friss-Feinberg and Kelly (1995) described a Californian state-level approach to the provision of services to support family caregivers of persons with acquired brain injury and those with cognitive impairment. They described a statewide resource network called ‘Caregiver Resource Centers’ that provided a range of respite options and services that included information, advice and referral, and consultation and planning. A significant feature of the ‘Caregiver Resource Center’ was the wide range of respite options available. Another significant feature was the availability of respite for the caregiver to spend a weekend where the focus is not on the person with the disability but on the caregiver (Friss-Feinberg & Kelly, 1995). The research by Friss (1990) is one of the very few research reports specific to acquired brain injury.

Friss (1990) argued that families of people with acquired brain injury need a varied range of services. Respite is part of a system of long-term care, rather than as a discrete service. It is a service that is best used in conjunction with other services to reduce the stress and burden of caring. Friss reported that the top three needs of caregivers in a survey conducted in California were information (52%), respite care (36%) and emotional support (35%). Hence there is a demand for respite by families of people with acquired brain
injury. One could argue that the demand would be similar in New South Wales but the question needs to be asked is “How readily available is respite care in New South Wales?”

**Availability of Respite Services**

While there is general agreement on the need for respite services for families with children with developmental disabilities respite appears not be readily available to families who need such a service (Brown et al., 2000; Cotterill, Hayes, Flynn, & Sloper, 1997; Grant & McGrath, 1990; Haylock, Johnson & Harpin, 1993; Hughes, 2007; Jawed, Singer & Isralowitz, 1992; Jeon, Chenoweth & McIntosh, 2007; Robinson & Stalker, 1993; Salisbury, 1990; Spicer, 2007; Treneman, Corkery, Dowdney & Hammond, 1997). For example, Salisbury (1990) reported that 70% of mothers seeking respite in her study did not get their needs met by a respite program specifically designed to do so. Often carers relied on immediate family members, relatives and other social networks to provide respite (Salisbury, 1990). Families may also be reluctant to access respite for varied reasons, such as privacy, or the family may feel better equipped to care for their child (Grant & McGrath, 1990). In a study of the views of 33 parents of 4-year old children with cerebral palsy, Haylock et al. (1993) found that only 8 children had received respite care, although a further 7 more parents reported their need for such a service. Of the 8 children who received respite, only half of them received a respite service of their choice.

Another frequent finding in the research literature indicated that families often lack information regarding respite services (Halpern, 1985; Haylock et al., 1993; Jeon et al., 2007; Robinson & Stalker, 1993; Treneman et al., 1997). People from diverse cultural and linguistic backgrounds may also be disadvantaged due to the lack of information regarding
the availability of relevant support services, including respite (Cotterill et al., 1997; Niemeier & Arango-Lasprilla, 2007; Robinson & Stalker, 1993). The availability of respite appears to be more limited for families who have children with disabilities and complex health-care needs (Robinson, Jackson & Townsley, 2001) and for older carers of people with a severe mental illness (Jeon et al., 2007). Robinson et al. (2001) and Jeon et al. (2007) highlighted the lack of co-ordination and the poorly defined boundaries between health and social care that add to the difficulty of accessing respite services. Robinson et al. (2001) expressed concern that in certain extreme cases, some of these children had to be accommodated inappropriately in nursing homes for older people. Availability of respite is also influenced by lack of funding or the cost of services (Castellani, 1986), appropriate models of service delivery (Slater, 1986), and policy direction (Castellani, 1986).

Hollingsworth (1992) reported the findings of a survey on service needs that was completed by 1,527 families who received Child Disability Allowance in Victoria, Australia. The survey results reported that majority of the children (89.6%) had multiple intellectual or physical disabilities and a majority also reported the child’s disability severity level to be high (moderate 51.8%, severe 38.2% and profound 10%). The results of the survey indicated that there were substantial unmet needs for respite care, equipment and home-help services. For example, 75% of the families had no access to respite for extended periods and approximately 25% were unaware of respite services of any type. The satisfaction rate with respite care was the least satisfactory, with only 37.2% rating respite care received as good”, whereas 39.2% rated it as “poor” and 23.6% rated it as “fair”. Given the high number of children with severe disability, Hollingsworth (1992)
argued for the urgent need for respite and access to service information for families who have children with disability.

Brown et al. (2000) examined family physicians’ perceptions on how readily respite care was available to chronically ill older people, how easy it was to refer for respite care and the options available; in a local area in Canada. Brown et al. based their findings on 288 survey respondents (64.3% return rate). They found that 58.5% of respondents reported that out-patient respite care was available in their communities; however in-patient care was less available than out-patient care (40.7%). Most respondents agreed that respite care was valuable in long-term care, in decreasing caregiver stress, and in transitioning chronically ill older people from home to long-term care. Most of the respondents (76%) also agreed that respite care assisted chronically ill older people to remain at home. This study provided the perceptions from a family physician’s perspective.

It is important to note that medical professionals see the value and importance of respite, and if respite services are readily available; then appropriate referrals may be made for such a service. The study is also important because family physicians are often the first point of contact for the person with a disability or for the caregiver. Hence, if a respite service is required by a family caregiver, the family physician can make the appropriate referral. Information on the respite services therefore needs to be made more readily available not just to families but also to family physicians.

Predictors of Respite Use or Non-use

An overview of respite care in acquired brain injury was presented in the first section of this chapter. It was noted that very little is known of respite care in the field of acquired
brain injury, although the need for such a service is indicated. An overview of the models of respite care was presented to provide a broader understanding of respite care. The availability of respite services was examined in the context of the urgency and need for such a service for caregivers and the persons being cared for. In this section, it is important to evaluate the reasons for the use and non-use of respite so that it informs policy development and resource planning for such a service.

There are many varied reasons for the need for respite use. Abelson (1999) found that 65% of families cited emotional strain as a reason for respite use, 42% mentioned family emergency, 36% indicated the need to spend time with siblings and for vacation, 32% for shopping, and 27% reported employment reasons related to the need to use respite. Families may also request respite for other varied reasons such as special family circumstances (Upshur, 1982). Hence, requests for respite services may be planned or due to a family emergency (Abelson, 1999; Neufeld, Query & Drummond, 2001; Salisbury & Griggs, 1983; Upshur, 1982). Planned respite (for example, a planned family event such as a night out) demonstrates an action that is proactive to reduce or prevent family stress (Neufeld et al., 2001; Salisbury & Griggs, 1983). These studies provided valuable information on the use of respite, however the population studied was based on persons with developmental disability. There is a lack of such research in the area of acquired brain injury. McConkey (2005) investigated the characteristics of 1500 carers of adults with intellectual disability in Northern Ireland using information based on a standard proforma completed by service staff who knew the person with disability best. McConkey found that carers who were more likely to use respite were those whose relative with disability had high dependency needs, those who were rated as overactive, whose stress levels were
greater than average and whose household did not have two parent carers. McConkey also found that overall high dependency in person care predicted access to respite, domiciliary care and befriending services.

Families have reported varied reasons for the use of respite and therefore it is useful to examine the factors that relate to respite use and non-use, as it will have implications for the development for such a service, prioritisation of use, resource allocation and policy development.

Chan, Sigafoos, Watego and Potter (2001) conducted a qualitative study of 10 adults with intellectual disability in long-term respite care. They found that the characteristics were similar to those reviewed by Chan and Sigafoos (2000), in particular they found that challenging behaviour appeared to be a significant factor related to the use of respite. Another factor to consider is the lack of communication skills of the adults with intellectual disability. Furthermore the high level of care required by these persons may have contributed to the increased care demands and levels of stress (Chan et al., 2001). Chan et al. suggested that these factors may have contributed to the parents of these adults continuing to rely on respite on a long-term basis.

It appears that several factors listed above influence the use of respite care among families of children with developmental disabilities. Chan and Sigafoos (2000) argued that knowledge of these factors is important for disability service providers and funding agencies in order to effectively plan and organise respite care services that meet the needs of such families by planning ahead for respite and identifying families most in need for respite. In a more recent study, the characteristics of 108 children with a disability who
accessed respite in Northern Ireland were examined by McConkey, Nixon, Donaghy and Mulhern (2004). They found similar characteristics as those reviewed by Chan and Sigafoos (2000); that is, these children had challenging behaviours, communication difficulties, and were dependent on day-day care (technologically dependent children). Many of these families experienced a range of problems and half the children were placed in inappropriate placements, such as hospital or adult residential accommodation (McConkey et al., 2004).

While there is growing research in the area of predictors and non-predictors of respite in the population of developmental and intellectual disability, the same cannot be said for people with acquired brain injury. Friss (1990), however, did provide characteristics of brain injured adults and their caregivers who accessed respite in California. She reported that 53% were male and 47% were female, with the majority of users being older adults with brain injury aged 65 years and over (65%). The primary diagnoses reported by families were degenerative neurological conditions or dementing illness (55%), strokes (19%) and traumatic brain injury (16%).

Caregivers were mainly women (74%) and over half were middle-aged (52%). Most of the caregivers were spouses (37%) followed by adult children (32%). While Friss reported on the characteristics of users, her data did not specify these characteristics as predictors or non-predictors of respite use. It is envisaged that careful planning and appropriate resource allocation, and policy development in respite services will be able to identify families who most need respite (Hughes, 2007; Spicer, 2007), and who would be able to access the appropriate levels of respite in a timely manner. By doing so, the process for accessing
respite is carefully planned rather than reactive, that is, provided to families before they are close to breaking down.

**Benefits of Respite Care**

It is important to evaluate the effectiveness of respite care if government agencies and families are to put money aside for such a service. Chiu et al. (1999) reported that families are willing to pay for in-home respite services. It is generally perceived that there are benefits of respite care, however, little is known about its effectiveness. Hence, the purpose of this section is to review the benefits of respite care. There is an increasing level of research interest on the potential benefits of respite care in the developmental disability area (Chan & Sigafoos, 2001; Forde et al., 2004; MacDonald et al., 2007), in aged care (Kosloski & Montgomery, 1995; Mason et al., 2007; Perry & Bontinen, 2001; Strang, 2001) and in persons with complex health care needs (Miller, 2002; Olsen & Maslin-Prothero, 2001), but there is no research in the area of acquired brain injury.

Shu et al. (2002) surveyed 46 primary carers of children with intellectual disability in Taiwan over a 9-month period, using self-report Chinese Health Questionnaire. They found that primary caregivers showed a significant improvement in their mental health. Using a qualitative approach, eight carers and their families were interviewed regarding their expectations of respite, benefits and problems having experienced respite care for younger people with dementia (Parahoo, Campbell & Scoltock, 2002). The families interviewed expressed high satisfaction in their respite workers and benefited from the break from caring by attending to household chores or shopping. There was little evidence of the families using the break from caring to improve their social life or recreation (Parahoo et
al., 2002). Mason et al. (2007) reviewed the effectiveness of different models of community-based respite for frail older people and their carers. They found that the effects of respite on carers were small although many of the studies reported high levels of carer satisfaction of respite. They reported that there is no reliable evidence that respite that delays entry to residential care or adversely affects frail older people.

Similar studies on the benefits of respite care, using both quantitative and qualitative methodology report that respite care can be a moderator of parental stress and alleviate the stress of caring in the family unit (Ashworth & Baker, 2000; Conlin, Caranasos & Davidson, 1992; Deimling, 1992; Larkin & Hopcroft, 1993). Ashworth and Baker (2000) interviewed 23 carers regarding their experiences of respite care. An emerging theme of their study was that respite care offered ‘normality’ and ‘freedom’ for the carer, and that respite care enabled care to continue in the family home. Conlin et al. (1992) compared caregivers receiving respite care (n = 7) and those not receiving respite care (n = 8), using two instruments that measured mood and stress. They found that respite care significantly reduced stress among caregivers who used the service.

According to Chan and Sigafoos (2001) (see Chapter 5), several of the studies they reviewed had significant limitations, particularly related to the reliance on indirect measures of stress reduction and associated benefits, such as increased coping or improved quality of life. The extent of the benefits of respite use may also vary from one family to another (Chan & Sigafoos, 2001; Olsen & Maslin-Prothero, 2001). Most of the studies, for example, relied on self-reported stress and reports of improved coping.
The use of respite may not always be beneficial, if for example, access to it is difficult or the services provided do not meet the expectations of the families and hence it may be more stressful when respite is used. The extent of stress reduction may depend heavily on the type, extent, and quality of services provided as well as other recipient and family variables (Chan & Sigafoos, 2001). The effect of respite on carers in the studies reviewed is inconclusive. Given the limitations of the studies on the benefits of respite care in developmental disability, Chan and Sigafoos (2001) argued that the general positive effect of reduction in parental stress appears to be sufficient evidence to warrant the use of respite services.

In a study of the impact of respite use on nursing home placement, Kosloski and Montgomery (1995) found that the use of respite may act as a potential delay or decrease the likelihood of nursing home placement over a 12-month period in 126 aged participants in the study. Like Chan and Sigafoos (2001), and Kosloski and Montgomery (1995), Mason et al. (2007) argued that further studies are needed to understand what makes respite care an attractive form of assistance to caregivers and argued for better quality evidence to inform current practice and policy in respite.

Nicoll, Ashworth, McNally and Newman (2002) postulated that social support is an important factor in carer’s satisfaction with respite service in dementia care. While it was a pilot study with a limited sample (18% return rate, n = 26), Nicoll et al. (2002) suggested that social support during respite care may have provided the carer with a sense of returning to normal life, whereas support during caring may have been a means to share emotional or physical burden of caring, leaving the carer to enjoy the respite break.
Therefore, the issue may not simply be the access to respite but how carers use the respite break along with the support it brings (Chan & Sigafoos, 2001; Ridley et al., 2004).

In a descriptive study of 17 wife and daughter carers supporting an older relative, Salin and Astedt-Kurki (2007) found that while respite provided opportunities for carers to look after their own health, carers in this study experience emptiness and guilt during respite use. The relationship of the care-recipient is seen as “burdensome” and the carers acted out of obligation. Therefore, while there may be benefits to be derived from respite, it is important that service providers address the guilt experienced by carers when they use respite.

These findings indicate a further need to explore the benefits of respite use. There have been no studies to date to determine whether respite care as a support service can alleviate some of the distress and stress the family or carer experienced in the care of the person with brain injury. However, this issue was not the focus of this thesis as there are no studies to date to map out the needs for respite care by these families or carers, let alone explore its potential benefits, and addressing the guilt of carers when they access respite.

What do families look for in a Respite Service?

While there may be a need to further examine the potential benefits of respite, there is a high level of unmet demand for respite use currently (Australian Institute of Health & Welfare, 1997; Community Services Commission, 1998; Kersten, McLellan, George, Mullee & Smith, 2001). According to the Australian Institute of Health and Welfare (1997), there will be continued unmet demand for respite services in the future. It is definitely a need identified by families who care for a person with a disability, including
those with acquired brain injury. However, availability of respite care does not necessarily translate to use of the service if the services do not meet the needs of families or if families were unaware of the existence of respite. In order for a respite service to be effective it has to meet the needs of families (Chan & Sigafoos, 2001; Jeon et al., 2007). Jeon et al. (2007) examined how older carers of people with a severe mental illness access respite in New South Wales using a semi-structured interview methodology. They found that respite needs to involve a concerted effort of carers, health professionals and service providers. They recommended better information and co-ordination, and that respite services must be flexible and appropriate to the population they serve.

Hence Kersten et al. (2001) and Jeon et al. (2007) argued that caregivers’ needs must be assessed appropriately and services need to be flexible and specific to the needs of caregivers. There is no evidence in the current literature on respite care that clearly articulates the expectations of families and caregivers of a respite service. The expectations of families of respite services are important because of the potential influence on both benefits and use of respite. If respite services fail to meet caregiver expectations, then the use of respite may in fact work to the detriment of the caregiver, as it may contribute to the caregiver’s already heightened stress level. Studies of the potential benefits of respite need to examine whether respite care providers and services meet the expectations and needs of families and caregivers.

Damiani, Rosenbaum, Swinton and Russell (2004) conducted a cross-sectional study and interviewed 468 caregivers of children with cerebral palsy in Ontario. Caregivers were asked about their knowledge and experience of respite use or non-use, financial
implications of respite use, and barriers to respite use. Damiani et al. (2004) found that majority of the caregivers were female (94.4%). This finding is similar to other reviews and studies in respite care (Chan & Sigafous, 2000; Neufeld, Query & Drummond, 2001). Mothers were the primary caregivers in this study (89.7%). Of the 468 caregivers interviewed, 46% reported use of formal respite services with a reported total of 389 episodes of respite use (Damiani et al., 2004). Of interest to the study by Chiu et al. (1999), Damiani et al. (2004) found that 40.7% of the families had to pay for respite services out of their own pocket and the amount they had to pay limited the amount of respite they used. Nearly all the caregivers (> 90%) who had used respite services agreed that the services were beneficial for the caregiver and children and the main reason for using respite care was to get a break from caring.

Many caregivers (63%) stated that they found it difficult to access respite services (Damiani et al., 2004). The study revealed five most commonly cited barriers to formal respite use: respite resources were limited (50%), respite services difficult to arrange (47%), the services their family needed were difficult to find (44%), concern about the quality of care (29%) and lack of information regarding respite care services (11%). The study also revealed that caregivers who had received support from health or social professionals were more likely to have used respite service in the past year than those who had not.

Damiani et al. (2004) suggested several strategies to assist families who require respite care services, such as: informing families of the benefits of respite care; encouraging health professionals to increase information to families; service providers should target respite
information to caregivers with less developed informal support networks; ensuring quality care through worker training programmes; increasing quality through continual quality assessments of their services and including families in decision-making. Damiani et al. also suggested that families should not feel guilty when accessing respite to help maintain their own physical and mental health. Families need to be educated that caring for their own well-being is important and would enable them to cope better in the care of the disabled family member.

In a similar study, Neufeld et al. (2001) examined perceptions of primary caregivers of children with chronic medical conditions and/or life-long disability with regards to respite use and barriers to respite care. They used a questionnaire designed for the study of 299 families and received a response rate of 21% (n =57). Neufeld et al. (2001) found all of the carers were female (76% identified themselves as the child’s mother, followed by 18% as foster mother and 6% as grandmother). The majority of the respondents indicated they were also caring for other children in the household (44% indicated 2 other children in the household and 40% indicated three or more children). Respondents’ mean age was 41 years (range of 28 – 60 years) and 93% stated that they had completed high school and/or a trade school.

In terms of respite use, 73% used some form of in-home respite and/or regular in-home baby-sitting (55%) (Neufeld et al., 2001). According to Neufeld et al., in-home care can range from occasional use of less than once a month to daily use, totaling 40 hours per week. Access to group-home respite (26%) ranged from 4 to 30 days per year and institutional respite care (13%) ranged from 2 days per year to 1 weekend per month plus 2
weeks per year (Neufeld et al.). The study also noted that camps appear to be a source of respite care for older children (40%) that may range from 1 to 2 weeks in summer, and day camp use may range from 5 days per camp to 8 weeks of day camp. Neufeld et al. (2001) noted that 26% of respondents rarely used respite services (less than monthly and less than 15 days per year; 26% occasionally used respite (monthly to less than weekly of up to 30 days per year, and 34% used respite frequently (more than twice a week).

Central to the study, Neufeld et al. (2001) examined carers’ experience of whether they were receiving adequate breaks. They found that 77% identified limited breaks as inadequate regardless of the level of care the child required. They also found that there was no association between amount of respite care used and perception of an adequate break. The lack of people or agencies to provide care for their child was the most frequently identified reason given as a barrier to respite. It was interesting to note that 74% of those who required high level of care identified the lack of people or agencies to provide care as a barrier compared to 67% in moderate and 63% in intensive levels.

Seventy-one per cent of respondents indicated that they would make one or more specific changes to services that they currently use if given the opportunity to do so, 33% cited concern regarding the lack of qualified staff and the need to educate staff. Twenty per cent specified the need to increase access to care, and 18% indicated a wish to increase their respite use (Neufeld et al., 2001). Less frequently identified changes included increased short-term emergency care (8%) and reimbursement for family carers (2%). Analysis of open-ended questions appeared to provide evidence of satisfaction with the current use of respite service.
The results of the study indicated that many primary carers who actively used respite care services did not perceive a break from caregiving. Their concerns centred on the lack of qualified carers, adequate funding, increased access to services and increased frequency of respite services (Neufeld et al., 2001). A primary limitation of the study was the small sample size for generalization to the larger population of primary caregivers. As in most of the studies reviewed on respite, further research into the benefits of respite is required along with expectations of respite use by families (Chan & Sigafoos, 2001; Ridley et al., 2004).

Hence part of this research will explore the expectations of families with regards to respite and what service providers think of families’ expectations. It could be argued that part of the mismatch between what respite service provider providers and families’ expectations may contribute to the lack of use of respite and negatively impact the potential benefits of respite.
CHAPTER SEVEN
Respite Care in New South Wales and Carers’ Profile

Respite Use in New South Wales

This thesis research was conducted in New South Wales (N.S.W.), hence this chapter focuses on respite in N.S.W. In December 1998, the Community Services Commission in N.S.W. published a report on the efficiency and efficacy of the existing centre-based respite care system for people with intellectual disabilities. The N.S.W. Community Services Commission was a statutory organisation that advocated and monitored community services across the state, and acted on behalf of families and/or individuals on the complaints made against any community service agency or organisation. The report entitled “Respite Care – a system in crisis” (Community Services Commission, 1998) highlighted the inadequacy of respite care and the systemic problems that existed in the N.S.W. government run respite services. In N.S.W., the government run respite services catered to children and adults with developmental disability.

It was a significant report in that for the first time in the state of New South Wales, a systematic and comprehensive evaluation of respite care was undertaken using quantitative data. It was a massive report which has led to a discussion paper (Ageing and Disability Department, 1999) and formation of committees at state level in the Ageing and Disability Department, and the Department of Community Services. The major findings of the report which are of interest to this present study are: (a) a significant lack of respite services and specialist “respite only” services, (b) inequitable distribution of respite services across the state, (c) the continuous occupation of respite beds and the occupancy of such beds by
long-term respite users, for example, 40% of the 363 beds designated for respite were continuously occupied on average of about 3.3 years (this is defined as “blocked respite” by the Department of Community Services and Ageing and Disability Department), (d) inadequate policy framework, planning and monitoring, (e) failure of the respite service to conform to the country’s Disability Services Act, (f) a high rate of the respite users present with challenging behaviour and yet only 42% received a behaviour management program, and (g) the majority of the long-term respite users did not receive other critical services, such as access to advocates or a guardian, or had an adequate plan to exit them to more appropriate placements.

The report strongly recommended that the then Minister of Community Services address the concerns as a matter of high priority and establish a taskforce of experts, relevant representatives, and a taskforce of relevant decision-makers. Both the Ageing and Disability Department, and the Department of Community Services initiated a series of measures to investigate the concerns and develop strategies. It is important to note that the great majority of the long-term respite users described in this report did not strictly fall within the definition of respite use. The discussion paper developed by the Ageing and Disability Department (1999) in response to the Community Services Commission’s report defined respite care according to the definition used in the present study which has common agreement in the literature on respite, that is, respite is “short-term”, “time-limited”, may be “planned” or “unplanned” in order to “assist in supporting and maintaining the primary caregiver’s relationship” and providing a “positive experience” for the person with a disability. Given this definition of respite and the fact that the majority of the “respite” users were long-term, the report by the Community Services Commission
(1998) was therefore not strictly about respite. Parts of the report were best described as permanent out-of-home placements rather than respite, although the respite user may have first accessed the service as a respite.

In response to the N.S.W. Community Services Commission Report, the Department of Community Services drafted an internal document “DoCS Respite Services Plan 2000” (1999) which discussed the problems and offered practical solutions. The document indicated that the state department has 69 respite service outlets which provided 359 respite beds across the state in the various regions and institutional settings (Large Residential Centres). Of the 69 service outlets, 45 were community-based, 13 were group homes for permanent clients with an emergency respite bed (generally in rural areas), and 11 were located in institutional settings. The report highlighted various factors which have been perceived or reported to impact on the respite services offered by the department. The factors outlined inconsistencies with respite practices, systems and policies, and external factors beyond the control of the department such as an increase in adults with intellectual disability who are homeless.

There were three other descriptive studies on the respite needs of families conducted in New South Wales (Jeon et al., 2007; Marlowe, 1998; Parmenter, 1999). Two of the studies focused mainly on people with developmental disability (Marlowe, 1998; Parmenter, 1999), and the study by Jeon et al. (2007) focused on people with mental illness. The review of Jeon et al. (2007) has been discussed in earlier sections. As such, the studies by Marlowe (1998) and Parmenter (1999) are reviewed here. Marlowe (1998) conducted a telephone survey of 45 families and an initial focus group for The Spastic Centre of New
South Wales in a Sydney metropolitan region. The findings of the study indicated that generally families did not know about respite (37%) and a majority of the families used a family member or a friend as a form of respite (51%). According to the families surveyed, there was a lack of appropriate respite services and a lack of information given to families regarding respite availability (Marlowe, 1998). Marlowe also reported that families usually used respite as a last resort, families with children who presented with challenging behaviours and aged parents most needed respite. Other findings included the need for flexible respite options and approachable staff.

Parmenter (1999) examined respite options for families using focus groups (n = 4) and surveys (n = 63) which were made up of service providers, families and service users. Similar findings to Marlowe’s (1998) study were reported by Parmenter (1999). Parmenter (1999) reported the need for respite options to be flexible and individualised to cater to each family’s needs; there was a need to make respite options simpler and more accessible; and the concerns of rural and remote communities were also identified. Other findings included a need for respite for people with developmental disability over the age of 18 years; a need for trained staff and volunteers; and the inability of service providers to identify the needs of families.

The studies reviewed so far focused on developmental disability in N.S.W. and there is no research to date on acquired brain injury. There is no information available regarding the needs of people with acquired brain injury for respite. Furthermore these studies did not provide a comprehensive profile of respite services in N.S.W. This thesis aims to address the lack of information in the area and to compare this to perspectives of respite by
service providers, people with acquired brain injury and their carers. Therefore it is important to map and describe respite services in New South Wales generally, and its availability to persons with acquired brain injury. An understanding of the issues of respite providers is important in terms of policy development and planning.

The literature reviewed in this thesis has highlighted the impact of acquired brain injury on the person and carer. Some of the studies suggested that support services, such as respite may have positive effects on carers and on the person (Chapters 2, 3 and 5). There is substantial research on respite in the developmental disability, aged care and mental health literature (Chapters 4, 5 and 6). However there is a paucity of research on respite in acquired brain injury. To date there has been no research that explores the perspective of persons with acquired brain injury and their carers regarding respite. It is pertinent to understand the perspective of consumers of respite given the potential role respite play as a support system for persons with a disability and their carers, and to ensure that support services such as respite are meeting the needs of the person and the career.

There is an urgent need to understand respite services in acquired brain injury. To address the gap in the literature, it is important to explore the profile of persons with acquired brain injury and their family or carers who use or do not use respite, and whether the profile is similar to respite in developmental disability; and to understand the potential factors that may influence the use or non-use of respite. A comparison of the perspectives of persons with acquired brain injury, their carers and service providers regarding respite can inform planning, policy development and resource allocation. This research attempts to address the gap in the respite and acquired brain injury literature.
CHAPTER EIGHT
Aims of the Study and Overview of the Methodology

The reports on the crisis in the Department of Community Services respite care system in New South Wales mostly relied on research in developmental and intellectual disability. Little is known of the met and unmet needs of respite care services in the population of acquired brain injury. Hence there is an urgent need to understand the extent of the met and unmet needs for respite services in this population.

Aims of the Research Project

1. To identify the profile and characteristics of families and individuals with acquired brain injury who use and/or do not use respite services.
2. To identify the potential predictors of families and persons with acquired brain injury who use and/or do not use respite services.
3. To map and describe the respite services available in New South Wales for people with acquired brain injury.
4. To compare the perspectives of respite by service providers, persons with acquired brain injury and their carers.

Research Questions

1. What are the respite services that are available and currently used by persons with acquired brain injury and their families in New South Wales?
2. What is the profile of the persons with acquired brain injury and families who use or do not use respite care services in New South Wales? Is the profile similar to that of respite users with developmental disability?
3. What are the potential predictors of use of non-use of respite care services by people with acquired brain injury? Are the predictors similar to those for respite users/non-users with developmental disability?

4. What are the concerns and issues faced by respite care providers?

5. Are respite services meeting the expressed needs of carers in New South Wales?

Overview of Method

The present study used a survey methodology so as to reach a broad base of the various stakeholder groups and to provide a comprehensive profile of respite providers in New South Wales. Survey methodology would also allow for analysis of the potential factors that may influence respite use or non-use. Previous studies tended to focus on one group of stakeholders (e.g. carers or providers only). An extensive review of the literature covering respite in various population groups, such as developmental disability; aged care and in mental health informed the development of the survey. Experts in the field of respite and acquired brain injury also provided advice and input on the development of the survey. A draft survey was trialed on a small group of carers before the final survey questionnaire was agreed upon. Further details are presented in the published articles in the next three chapters.

Participants

Summary

There were currently 114,685 people with acquired brain injury in New South Wales. Of these, nearly half (i.e., 54,035) were defined as having a severe-profound level of disability. These persons were the ones who require some level of support and who were
therefore the target population for this study. To contact these individuals, the membership database of the NSW Brain Injury Association was utilised. The NSW Brain Injury Association is the peak advocacy organisation of individuals with brain injury and their families in NSW. The participants were recruited from the membership database of the NSW Brain Injury Association. Interchange Respite Care NSW is the peak respite service association in NSW and maintains an active membership list. Both organisations were considered representative of the groups they served. The surveys were mailed to the members of the NSW Brain Injury Association and Interchange Respite Care NSW. Due to privacy reasons, both organisations directly mailed the survey questionnaires to their members.

**Participants**

Three groups of participants were identified for this study, persons with acquired brain injury, family members or carers of people with brain injury, and respite service providers.

(a) Persons with acquired brain injury and families caring for these individuals. The individuals were from all age groups as long as the participants met the criteria in the definition for acquired brain injury. Membership of the association tends to be people with traumatic brain injury and this may bias the results of the study. At the period of the survey, the NSW Brain Injury Association membership database consisted of 260 members, comprising of both persons with brain injury and their families or primary carers. The membership database was unable to delineate between membership of person with brain injury and membership by the family or primary carer.
(b) Respite care providers were recruited from the NSW peak respite organisation, Interchange Respite Care NSW whose membership included both government respite organisations and local area respite services. At the commencement of the study, the membership database of Interchange Respite Care NSW was 110 active member organizations of respite.

_Ethics_

The study was approved by The University of Sydney Ethics Review Committee (Human Research). The Executive Officers of the NSW Brain Injury Association and Interchange Respite Care NSW were contacted formally by telephone, followed by a formal letter. The letter was essential to obtain the respective association Boards’ approval. A meeting was held with the respective Executive Officers to explain and clarify the purpose and scope of the study. There was no direct access to the membership database of the associations for privacy reasons. A sample of the survey questionnaires was provided to the Executive Officers of the associations. The front page of the survey provided a brief introduction of the study, including the purpose of the study and definition of respite, and who should complete the survey. To satisfy consent issues, the introduction highlighted the fact that the survey was voluntary and independent of whether the participants were receiving a respite service or not, and assured potential respondents of the confidentiality of the survey. Consent to participate in the survey was assumed by the fact that the respondents have completed and returned the surveys. The Executive Officers were also informed that translation of the survey into other languages was available upon request.
Design

Three population groups were surveyed, persons with brain injury, a family member or primary carer from the NSW Brain Injury Association; and respite service providers who are members of Interchange Respite Care NSW.

Procedure

Development and Design of the Survey Questionnaire

Three survey questionnaires were developed and designed to collect data from the identified population groups. The questionnaires were developed after an extensive review of the literature to identify the critical factors in respite care services (Chan & Sigafoos, 2000) (Chapter 4). The initial drafts of the survey questionnaire were provided to various professionals with expertise in the area of respite services, service delivery and disability. These professionals included two senior clinical practitioners in disability from disability services that was then part of the Department of Community Services, a university professor of special education with expertise in the area of challenging behaviours and disability, the state project officer of respite services from the Department of Community Services, and the executive officer of Interchange Respite Care NSW. Changes were made to the initial drafts following comments and feedback on the questionnaire surveys.

A second draft of the questionnaire surveys was then designed. The survey questionnaires were trialed on 20 families who supported and cared for a person with a disability, including some with brain injury. The surveys were distributed at random to families in a child-care and disability facility by an officer from the Department of
Community Services. The facility received funding from the Department of Community Services. The families were requested to complete the survey questionnaire and to provide feedback or comments on the design of the questionnaire, and the time it took to complete the questionnaire. Comments on the questionnaires were incorporated in the third draft.

The third draft was circulated to four individuals with expertise in the area of brain injury for their comments and suggestions for improvement. The individuals were the clinical nurse consultant in brain injury, a university professor of rehabilitation studies, carer of a person with brain injury, and the executive officer of a non-government respite agency that catered only to individuals with brain injury. Their suggestions and comments were incorporated in the final survey questionnaires.

**Description of the Survey**

There were three types of survey questionnaires designed to collect data from the person with brain injury (Appendix A), the family member or carer of a person with brain injury (Appendix B), and a respite service provider (Appendix C). The survey questionnaires shared several common sections. The sections were demographic information, factors influencing respite, expectations of respite services, and satisfaction with respite services used by persons or carers (if the person or family has used such a service) and respite service provider’s perceptions of how satisfied they were with the services they provided. The questionnaires also included open-ended questions. The estimated time for completion of the questionnaires was about 30 minutes.

The first questionnaire (Appendix A) was aimed at persons with brain injury. Section A of the person questionnaire was designed to provide descriptive information on the person
(e.g., age, gender, level of brain injury severity, type of brain injury, etc.). If an individual with brain injury required assistance to complete the survey this was noted in survey, it may also be completed by a family member or carer (e.g., for a child with brain injury or a person with brain injury who was unable to complete the survey for various reasons). The person with brain injury was asked to rate on a 5-point Likert scale factors that influence use of respite, expectations of respite services and the importance of family needs. Those who have used respite before were asked to rate their level of satisfaction with the respite use. They were also asked whether they have been able to access sufficient respite. The survey contained a total of 93 items.

The second questionnaire (Appendix B) was aimed at the primary carer or family member of a person with brain injury. The questionnaire was designed to provide descriptive information on the person with brain injury and the primary carer. The carer questionnaire was similar to that for persons with brain injury except for questions that pertained to the primary carer, such as whether looking after the person with brain injury had prevented the carer from seeking employment. Additional sections in the questionnaire included questions for those who had used respite services before, further information on types of challenging behaviours and an estimation of the types of respite the primary carer would access. The survey for family or primary carer had 113 items.

The third questionnaire (Appendix C) was aimed at respite service providers. One of the purposes of this questionnaire was to map the respite services that were available in NSW and how many actually provided a service to people with brain injury. The questionnaire was designed to provide descriptive information on the respite service, the
model(s) of service, the issues and concerns that the service providers had, and their perception of the reasons why families used respite. The questionnaire also contained open-ended questions on the provider’s ideal model of respite service and how they sought feedback from consumers. The survey for respite service providers had 107 items.

In summary, there were 3 types of survey questionnaires aimed at the person with brain injury, a family member or primary carer of a person with brain injury, and a respite service provider. The questionnaires contained several common items and some items specific to the population group being surveyed. There were also open-ended questions to provide the respondent with the opportunity to make comments or add other information not found in the surveys.

Survey Process

*NSW Brain Injury Association.*

As mentioned at the time of the study, there were 260 members of the NSW Brain Injury Association. The survey questionnaires for both the person with brain injury and the family member or carer were paper-clipped together and 260 copies of each questionnaire were given to the NSW Brain Injury Association. The association then mailed the surveys to their members directly. The surveys were mailed twice over a three month period. An advertisement was placed in the NSW Brain Injury Association newsletter prior to the mail-out. The purpose was to introduce the study to the members of the association. A reminder letter to return the survey questionnaires was also mailed to 260 members of the association. At the time of the survey, the association was unable to distinguish family or carer membership from persons with acquired brain injury. It is important to highlight that
at the time of the survey the actual number of persons with acquired brain injury who were members was around 130 or fewer (D. Frith, personal communication, June 8, 2006).

Interchange Respite Care NSW Association.

At the time of the study, there were 110 respite service provider services or agencies that were members of the association. A hundred and ten copies of the survey questionnaire were given to the Interchange Association for postage to its members. There were two survey mail-outs to members of the association over a 3 month period. Two reminders to prompt members to complete and return the questionnaires were also advertised in the association’s newsletter.

Data Analysis

The data on questionnaires were analysed using SPSS Version 11.5 (SPSS, Inc.) and SAS Version 8 (SAS Institute) statistical package using frequency counts, chi-square, independent t-tests, collapsed variables and/or logistic regression tests where appropriate. The data were graphed to reveal trends and patterns in relation to the aims and research questions. Other issues emerged from open-ended questions of the questionnaires; these issues was analysed into themes or categories of concerns. The interpretation of the results involved visual analysis of the graphed data. The data from the measurement of benefits of respite (i.e., instruments tracking changes in stress and anxiety) were based on t-test analyses. Descriptive statistics (mean and standard deviation and range) were presented in Table format.