CHAPTER NINE

A Profile of Respite Service Providers in New South Wales

This chapter describes the results of the survey focused on the perspective of respite providers in New South Wales and in Australian Capital Territory. It consists of a journal article currently in press. The respite providers in this study serve various types of children and adults with a disability not just persons with acquired brain injury, so this chapter presents a description of general respite provision in New South Wales, and not specific to acquired brain injury.

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Note:

Following a recent request from the editor and a reviewer’s comments, the title “A Profile of Respite Service Providers in New South Wales” will replace “Are Respite Service Providers Meeting the Needs of Carers and People with a Disability?” when the article is published.
A Profile of Respite Service Providers

ARE RESPITE SERVICE PROVIDERS MEETING THE NEEDS OF CARERS AND PEOPLE WITH A DISABILITY?

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Respite Care Services in Acquired Brain Injury

Abstract

Respite is one of the critical support systems for families and carers who support and care for a person with a life-long disability. This study examined the profile of respite services in the Australian state of New South Wales and explored respite providers' views on the factors influencing respite use, expectations of such a service and of delivering respite. Data were analysed from a 107-item survey questionnaire completed by 90 respite service providers who were members of the peak respite service association in New South Wales. A comprehensive profile of respite service providers is presented. A variety of respite services were provided to persons with different disability types in all age ranges and across varied geographical regions. The views of respite providers on factors influencing respite use and expectations of respite appear consistent with the research evidence on factors influencing some carers. There is strong argument for respite service funding to be flexible, responsive to the needs of carers and to be consumer-driven. Appropriate staff training remains an important issue. The findings suggest that many respite providers have significant experience in running a respite service. There is scope for respite providers to consider support for carers. The development of a tool to determine predictors of respite use and non-use may be beneficial for resource allocation and planning.
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Introduction

Caring for and supporting a person with a life-long disability can have an impact on the well-being and mental health of some family carers (Blacher, Neece & Paczkowski, 2005; Chan, 2007; Chan & Sigafoos, 2000; 2001; Plant & Sanders, 2007; Jeon, Brodaty & Chesterson, 2005; Jeon, Caenoweth & McIntosh, 2003; Savage & Bailey, 2004; Spector & Tampi, 2005). Informal (unpaid) caregiving is often provided on a continuing basis representing a significant social and economic contribution to the community (Jeon et al., 2007; Spector & Tampi, 2005). Some of these carers are also most vulnerable to health risks (Spector & Tampi, 2005). In their review of caregiving, Spector and Tampi reported that elderly spousal caregivers had a 63% higher 4-year mortality risk than non-caregivers, some carers also faced financial risk, such as job loss; and importantly, some carers suffered higher emotional strain than non-caregivers. The financial and health risks impacting on these carers often lead to caregiver depression that is becoming a major public health problem (Spector & Tampi, 2005).

Respite has potential to help alleviate caregiver stress and the burden of caring (Chan & Sigafoos, 2001). It is important to examine respite given the current trend toward caring for people with disabilities in the home (Australian Institute of Health & Welfare, 1997; Jeon et al., 2007). A review of respite services undertaken in 1998 by the then New South Wales Community Services Commission highlighted a service system in crisis, with a significant lack of respite; inequitable distribution of respite; respite not provided to those who need it most (e.g., individuals presenting with challenging behaviours); inadequate policy framework, planning and monitoring; and “blocked respite” (that is, where 40% of the 363 beds designated for respite were continuously occupied on average for 3.3 years) (Community Services Commission, 1998).

Further studies on respite needs in New South Wales (NSW) seem to indicate that there has not
been significant improvement in respite provision (Jeon et al., 2007; Marlowe, 1998; Parmeter, 1999). The findings of the studies were similar: (a) lack of information about respite services, (b) lack of service flexibility, (c) inadequate respite services, (d) need for trained staff, (d) lack of respite in rural areas and people from diverse cultural backgrounds; and (e) lack of specialist respite, such as mental health and for adults with developmental disability.

**Availability of respite**

The issue of lack of information about respite and its lack of accessibility to families is not peculiar to NSW, the issue is similar in other countries (Brown et al., 2000; Cotterill, Hayes, Flynn, & Sloper, 1997; Grant & McGrath, 1990; Haylock, Johnson & Harpin, 1993; MacDonald, Fitzsimons & Walsh, 2007; Robinson & Stalker, 1993; Salisbury, 1990; Treneman, Corkery, Dowdney & Hammond, 1997). In NSW, Marlowe (1998) found that 37% of families caring for a person with developmental disability did not know about respite and 51% of families used a family member or a friend to assist as a form of respite. In a study of 1,527 families who received Child Disability Allowance in Victoria, Australia; Hollingsworth (1992) found that 75% of these families had no access to respite for extended periods of time and approximately 25% were unaware of respite of any type.

Jeon et al. (2007) noted similar issues regarding lack of service flexibility and information for some older carers of people with a severe mental illness. People from diverse cultural and linguistic backgrounds may also be disadvantaged due to the lack of accessible information regarding the availability of such services (Cotterill et al., 1997; Jeon et al., 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 (MacDonald et al., 2007; Robinson, Jackson & Townsley, 2001). Robinson et al. (2001) 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. They expressed concern that in certain extreme cases, some of these children had to be accommodated in nursing homes for older people. MacDonald et al. (2007) found that children with intellectual disability who needed personal care and who have difficult behaviours did not use respite more than children without these needs. MacDonald et al. posit that it may reflect a lack of suitable respite than a lack of need to use respite by these families. Many of these studies focused on the views of carers and their concerns regarding respite.

Given the research was mainly from carers’ perspective, it would be appropriate to explore the state of actual respite provision in NSW. For example, it would be useful to determine the types or models of respite available, their accessibility to different disability groups, and whether the respite satisfies carers who use respite. A profile of respite providers will also be useful to examine whether there is a mismatch between views of some carers and that of respite providers.

Models of Respite Services

There are varied models of respite. Generally, the prevalent models of respite can be described as either in-home or out-of-home services (Friss, 1990; Friss-Feinberg & Kelly, 1995; Olsen & Maslin-Prothero, 2001; Stancliffe, 1990; Upshur, 1983). In-home respite can include activities conducted outside or in the home, personal care attendant, child-minding services, family respite exchange programs, home-care or home health-aide programs (these services include assisting in daily routines such as bathing, dressing or house-cleaning) and volunteer aides (Forde et al., 2004; Levy & Levy, 1986; Miller, 2002; Upshur, 1983).

Out-of-home respite 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 (Levy & Levy, 1986; Miller, 2002; Olsen & Maslin-Prothero, 2001; Upshur,
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1983). Other models of respite 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). While respite is traditionally defined as in-home or out-of-home service, it is critical to understand that the true intent of respite is to provide a break from caring or assistance to carers; and to alleviate the stress of caring (Chan & Sigafoos, 2001; Ridley, Chan & Roberts, 2004). Therefore, respite should be able to meet the needs of carers and as such, may take other forms as long as it provides a break from caring and alleviates the stress of caring (Ridley et al., 2004).

Caldwell and Heller (2003) explored the management of respite care and personal assistance services by 97 families of people with developmental disabilities. This is one of a handful of studies that focused on family-directed or consumer-controlled service provision. Such service provision can mean that the families are responsible for recruitment, hiring, training, scheduling, directing and negotiating wages of the staff they hire to provide the services. Caldwell and Heller (2003) found more control of the management of respite and personal assistance services was strongly associated with higher service satisfaction. 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%).

Frisse-Feinberg and Whitlatch (1998) also investigated consumer-directed respite in a population of families caring for a person with cognitive impairment. They compared the preferences for consumer-directed respite with agency-based respite in a sample of 168 caregivers. They found carers preferred a consumer-directed approach (68.5%) compared to use
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of an agency-based program (31.5%) for a range of reasons such as carers felt that their family member was safe (91.3%); 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”.

The studies by Caldwell and Heller (2003), and Friss-Feinberg and Whitlatch (1998) involved government funded services even though the service may be consumer directed. Are 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 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 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.

Predictors of Respite Use or Non-use

It is important to evaluate the reasons for the use and non-use of respite so that it informs policy development and resource planning. 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. Families may also request respite for other reasons such as special family circumstances (Upshur, 1982). Hence, requests for respite 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 a family event such as a night out)
involves proactive planning to reduce or prevent family stress (Neufeld et al., 2001; Salisbury & Griggs, 1983).

It is useful to examine the factors that relate to respite use and non-use, as they will have implications for the development of services, prioritisation of use, resource allocation and policy development. Chan and Sigatoos (2000) reviewed the child and family characteristics related to respite use in developmental disability services. Child-related characteristics associated with higher respite use include more severe disability, higher level of care required, presence of challenging behaviours and communication difficulties. On the family side, the factors related to respite use include greater family stress, less access to support services and family size.

Chan (2007) examined the perspectives of 85 carers of people with acquired brain injury (ABI). He found that marital status, severity of disability and level of dependency of the person with ABI predicted use of respite. These carers also rated the following factors as influencing their use of respite: (a) person with ABI need experience outside the carer, (b) day-day stress of carer, (c) stress level of a family member, (d) person with ABI need a break from carer, (e) level of severity of disability, (f) family need a break, (g) carer needs time with other members of family, (h) time for self, (i) dependency of the person with ABI and (j) poor health of carer or family. Chan (in press) explored the views of persons with ABI on respite and the factors that may influence their use of respite. The views of persons with ABI were similar to those of carers, that is, the factors that will influence their use of respite centered on the stress level of carer or family, level of dependency on carer, health of carer, family needing a break and person with ABI needing experience outside the carer. While both of these studies had a small sample size, the findings are important because these were the first studies in the area of acquired brain injury respite.
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The studies reviewed above focused mainly on families and carers, and did not examine respite providers. It is also important to examine the perspectives of providers. To date, there is no comprehensive map or profile of respite services in NSW. The purpose of this study is to profile respite service providers in New South Wales in terms of availability, models of respite care provided, and outcomes of respite. The study will also examine providers' perceptions of the reasons why carers require respite care, and by doing so, examine whether respite providers are meeting the needs of families identified in the studies mentioned.

Method

The current study is part of a larger study exploring respite from various perspectives (Chan, 2007). The results of this study represent the service providers' perspective on respite. Interchange NSW is the peak association in NSW of respite providers and maintains an active membership list. Surveys were mailed to all 110 member organisations of Interchange NSW, whose membership includes both government providers and local area (non-government) respite services. Some member organisations were based in the Australian Capital Territory that is located geographically within NSW. At the commencement of the study, the membership database of Interchange NSW was 110 active member organizations.

The study was approved by The University of Sydney Ethics Review Committee (Human Research) and used survey methodology. The questionnaire underwent three drafts involving consultations with some carers, expert clinicians and academics in the field of disability and in brain injury. The first draft of the survey was trialed on providers and carers of people with a disability. The survey questionnaire contained sections on demographic information, factors associated with respite use, expectations of respite, and satisfaction with respite services used by persons or carers (if the person or family has used such a service). The questionnaire also
included open-ended questions. The respondent was asked to rate on a 5-point Likert scale factors that may influence a carer to use respite (such as the level of severity of disability, stress level of carer or level of challenging behaviours), and carers’ expectations of respite services (such as having trained and qualified staff, having more respite or provide a homely environment) and the importance of perceived family needs (such as financial help, access to therapy services, or holiday scheme for the injured person), and to provide more information on challenging behaviours. A copy of the complete survey is available from the author.

Survey Process and Coding Reliability

Interchange NSW posted a copy of the survey to all of its 110 members. There were 2 survey mail-outs over a 3 month period. Two reminders to prompt members to complete and return the questionnaires were also advertised in the association’s newsletter. Ninety-three surveys were returned (85%) but three surveys were incomplete and as such, were not included in the analysis. Therefore, only 90 survey forms were analysed (82%). The responses to each returned questionnaire were coded for data entry. A doctoral student checked 20% of the returned questionnaires for correct coding of each response item and correct data entry into SPSS Version 11.5 (SPSS Inc., 2003). In all there were 107 items in the survey, with 100% inter-rater reliability for coding and 97% inter-rater reliability for data entry. Disagreements were resolved by checking all the responses with the data entry.
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Results

Characteristics of Respite Providers

Table 1 describes the demographic characteristics of respite service providers across New South Wales (NSW) and the Australian Capital Territory (ACT) representing a significant overview of “the state of respite services” in NSW.

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The majority of providers are non-government service organisations (78.9%) but Government funding (Federal and/or State Government) accounts for the total funding of 71.1% of respite services. Twenty respite providers (22.2%) indicated that they receive a mixture of Government and other source of funding. There is a reliance of a majority of providers on government funding. Many providers have extensive experience in terms of number of years of service provision. Nearly all providers (n = 81, 90%) had established their services for more than four years.

Respite services appear to be available across most geographical regions. Eighty-seven providers (96.7%) indicated that they provided services to people from English-speaking background (ranging from 29% - 100% of service users). Of these providers, 62 providers (71.2%) indicated between 80 – 100% of their services were mainly to people from English-speaking background. Seventy-one providers (78.9%) indicated they provided services to people from non-English speaking backgrounds (ranging from 1% – 27% of service users). Of these
providers, only six providers (7%) indicated between 50% - 71% of the services were directed to people from non-English speaking background (NESB).

Fifty-nine providers (65.6%) indicated that they provided services to Aboriginal and Torres Strait Islander people (ranging from 1% - 45% of service users). Of these providers, 56 provided between 1 – 10% of their services to people from Aboriginal and Torres Straits Islander background. Only one service organisation (1.1%) indicated 45% of its service was directed to people from Aboriginal and Torres Straits Islander background. Hence it is evident that majority of respite services are provided to people from English-speaking background followed by non-English speaking background. Given that about a quarter of the people with a disability are from NESB in NSW (Community Relations Commission NSW, 2003), the data suggests a low representation of services provided to NESB population group.

It appears that age is not an exclusionary factor and many of the services are provided to a mix of age groups. Table 2 describes the extensive experience in the range of disability types that service providers have. The evidence suggests that services provide respite to persons with intellectual disability, other developmental disability (e.g., autism, cerebral palsy or Down Syndrome), with acquired disability (e.g., brain injury) and to persons who have other conditions such as chronic health conditions or mental illness. However, a majority of the services catered to people with a developmental disability.

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Forty-one providers (45.6%) indicated that they had eligibility criteria for their respite service. Therefore, more than half of the providers did have a set of eligibility criteria for service entry. A few of these providers clarified their eligibility criteria, for example, those who have a primary diagnosis of mental illness; attention deficit disorder or dementia were not eligible for their respite service. A small number also indicated wheelchair access as another exclusionary criterion. One provider indicated that it did not cater to people with wheelchair access because the respite centre or house was not built with wheelchair access.

Models of Respite Service

Table 3 describes the various models of respite provision as reported by respondents. The results indicate the extensive range of models of respite across NSW that are not defined traditionally as in-home or out-of-home respite. A majority of these models could be described as ‘direct respite provision’ to the persons with a disability, such as ‘home-based’ respite (65.6%); ‘holiday camps or day excursions’ (62.2%); ‘emergency respite’ (60%); ‘out-of-home placement’ (58.9%) or ‘regular day programmes’ (36.7%). Only one service organization (1.1%) identified ‘foster-care’ as a model of respite.

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There are also respite services that focused on ‘family support’ (such as support groups) (15.6%) and training or teaching of families (10%). Other models of respite provision that benefit both the person with a disability and the carer or family member(s) are, for example, ‘use of volunteers’ (55.6%), and ‘information giving/resource sharing’ (38.9%). Financial assistance
may include providing the carer with some funding to purchase respite external to the provider. Equipment loan may include access to additional equipment (such as a wheelchair or specific medical equipment) to assist in continuing the care or provide a lesser stress and degree of caring; or counseling may be provided to some carers to alleviate the stress of caring (Ridley et al., 2004).

Respondents were also asked about the hours of respite provision. Sixty-five respondents (72.2%) indicated that they provided 24-hour respite care either in a ‘home-based’ or ‘out-of-home’ residential service. Eighty-eight respondents (97.8%) indicated that their service provided unplanned or crisis (such as a family emergency) respite. Therefore, nearly all respite provided 24-hour care and unplanned or crisis care that may require respite at short notice. The models of respite service provision are varied. There are also models that focused on carer or family needs, and services that might benefit both the person with a disability and the carer or family.

**Training of Respite Employees and Volunteers**

A small section of the questionnaire survey asked respite providers whether their employees and/or volunteers received any formal training in ‘disability in-service training’. ‘Disability in-service training’ is defined as any form of formal training provided, such as ‘in-service’ provided by the organisation, State Government competency-based training and/or accredited courses in disability (e.g., provided by Training and Advanced Education or TAFE centres or tertiary qualifications). Eighty-nine out of 90 providers responded to the question on training of their employees.

Eighty service providers (88.8%) indicated that their employees have formal training in disability in-service studies. Thirty-one respondents from these providers (34.4%) indicated that 100% of their employees have formal disability in-service training. A group of 17 providers
(19.1%) indicated that between 80 – 98% of their employees have formal disability in-service training. Eleven service providers (12.2%) indicated that between 15 – 40% of their employees have formal disability in-service training. Reasons why 9 providers (10%) did not respond to this question cannot be ascertained. It may be speculated that these providers comprised mainly of volunteers as may be the case in some rural and remote respite services, or that the question did not apply to them.

Forty-two providers (46.6%) indicated between 2 – 100% of their volunteers have formal disability in-service training. Volunteers may be used in providing direct respite (e.g., in rural areas) or in indirect respite care (e.g., driving a vehicle). Eight providers (8.9%) reported that 100% of their volunteers have formal disability in-service training. Three providers (3.3%) reported 80 – 90% of their volunteers have formal disability in-service training. Eight providers (8.8%) indicated between 50 – 69% of their volunteers have formal disability in-service training. The remaining 23 providers reported between 2 – 40% of their volunteers have formal disability in-service training.

Fees charged for respite services

Seventy service providers (77.8%) indicated that a service fee is charged for respite services. A minimum and maximum fee scale is indicated, however it is difficult to ascertain the mean or median range as many of the respondents did not indicate the schedule of fees as requested in the question. Based on the limited responses provided, the range of minimum fees might be from as little as $1 to $25 per respite service. The maximum fees that might be charged for respite service might range from as little as $2 to a limit of $75. Some of the respondents reported that service fees might be charged for other services or activities not covered by Government
funding, such as food on outings or an overnight respite stay, or activities related to a respite service (e.g., activities related to a day excursion).

Factors Reported to Influence Respite Use

Respite providers were asked to rate 19-items as to how important each factor or reason might have in influencing a carer’s decision to use respite. To rank these items by importance, raw ratings of quite important (4) and very important (5) were collapsed and the items with the highest frequency of these collapsed ratings were ranked as being most important. The results suggest that respite providers strongly rated factors that pertained to carers’ stress level and family-related concerns as their 10 most important factors that might influence carers’ use of respite. These factors were personal day-to-day stress level of carers (93.3%), poor health of carer/spouse/family member (93.3%), potential family break-up or other family problems (91%), stress level of carer/family members (90%), level of challenging behaviours of the person (90%), carers need time to spend with family (76.7%), dependency of person on carer/family (75.6%), family needs a break (74.4%), the person may need ‘experience outside carer/family’ (72.2%), and unexpected family situations; such as other family members needing medical attention (72.1%).

Reported Expectations of Respite Services

Respite providers were asked to answer a 24-item questionnaire specifically as to what items (expectations) they considered important in delivering outcomes for persons with disability and carers. The methodology used to rank the importance of the items was the same as the factors influencing respite use. The expectations of respite providers appeared to focused on what may be considered as ‘governance’ or ‘organizational’ issues. These ‘governance issues’ are recruiting appropriate staff and volunteers (94.4%), sufficient funding allocation (85.6%),
policies relevant to the work (85.6%), relevant training provided (84.4%) and ability of staff to manage and implement challenging behaviour management programs (82.2%). Another group of expectations might be termed as 'direct service delivery issues' such as increase frequency of services (84.4%), offer a wider range of activities (73.4%), meet cultural, religious and dietary needs of families or person with disability (72.2%) and providing a homely environment (71.1%).

Reported Difficulties of Respite Providers

Respite providers were asked to rate an 11-item questionnaire on factors that are most difficult or not a problem at all in providing services. The same methodology was used in ranking reported factors that influence respite use by carers. The following factors were rated by providers as 'some difficulty' to 'most difficulty' are the level of challenging behaviour (98%), level of medical or high health-care required (90%), severity of disability (82%), access to appropriate funding (80%), level of daily care or dependency (71%), meeting expectations of families (62%), lack of communication skills of the person with a disability (57%), working with families (51%), stress level of respite staff (47%), level of intellectual disability (42%), and working with other professionals (42%).

These factors were further analysed with the demographic characteristics of respite providers using a Fisher’s Exact test. The results indicate that there is evidence that providers of children’s respite are more likely to rate level of intellectual disability (p = 0.032) and stress level of respite staff (p = 0.036) as reported difficulties compared to other age groups. There is evidence (p = 0.016) that providers in adult respite are more likely to rate 'working with families' as difficult compared to other age groups. There is also evidence (p = 0.058) that the adult providers are more likely to rate 'access to funding issues' as a reported difficulty compared to other age
groups. It is difficult to speculate reasons for the evidence as respondents did not elaborate on the matter.

Relationship between Reported Predictors and Expectations of Respite Use and the Characteristics of Providers

This section examines the relationship between the demographic characteristics of providers and what respite providers report as factors that may influence carers use of respite and their expectations. The relationship was analysed using a Fisher’s Exact test. The results indicate few factors respite providers are more likely to rate as ‘important’ to ‘very important’ for carers accessing respite. There is evidence ($p = 0.052$) rural and country respite providers were more likely to rate the level of dependency (84%) as a factor for a carer to access respite as compared to city services (64%). It may be argued that some carers in such regions are isolated and may not have easy access to nearby informal network to alleviate the high level of dependency on the carer. There is evidence ($p = 0.040$) city and regional providers were more likely to rate ‘potential family break-up’ (100%) as a reason for accessing respite compared to rural and country towns (90%). Despite this factor being statistically significant, the difference in the proportion of providers rating ‘potential family break-up’ as ‘important’ to ‘very important’ is only a 10% difference and as such, may not hold clinical importance.

There is evidence ($p = 0.05$) that infants and toddlers (100%) and children (98%) need experience outside the family home as a reason for accessing respite compared to adults (86%). There is also evidence ($p = 0.015$) that adolescents (100%) need the same compared to adults (85%). There may be a variety of reasons to speculate for this reported factor, such as it may be argued that adults with a disability may already be in receipt of day programs or vocational placements, and would have had some experience outside the family home compared to very
young children and adolescents. There is evidence ($p = 0.025$) that respite providers that offer services to mixed age groups (94%) agree that carers need some time for self as a reason for using respite compared to those who offer respite to a specific age group (76%).

**How do Respite Providers obtain advisory feedback from stakeholders?**

Eighty-five providers (94.4%) responded to the question on how they went about seeking feedback from stakeholders. Their responses were analysed into themes and frequency counts. Service providers indicated varied ways in which they sought advisory feedback from stakeholders, such as regular satisfaction or evaluation surveys; community and service user consultations; informal and formal meetings; regular reviews (e.g., annual, quarterly, six-monthly); and quality assurance activities. The most common method service providers sought feedback was through satisfaction and evaluation surveys (76%). On a more personal basis, service providers also conducted home visits or made telephone contacts. A number of service providers (32%) ensured that carers or persons with disabilities were members of their management committees or advisory groups.

**What is an ideal respite service?**

Service providers were asked to comment on their ideal respite service. Seventy-five providers (83.3%) responded and the most common response was the importance of creating a flexible and responsive respite service (71%) that is individualized to the needs of the carer and person with disability. A flexible funding model (43%) was the next most frequent proposal mentioned by service providers. For example, flexible funding was proposed to provide paid carers instead of reliance on volunteers in the remote areas. Of the 32 respondents on the issue of flexible funding, 7 respondents indicated a need for more funding to increase the number of respite days for families who need it. Six service providers indicated the need to have a ‘one stop
shop* to provide a supplementary support services such as allied health services and a central site to co-ordinate respite services. Another group of 6 respondents expressed the need for more trained staff.

**Discussion**

The results of the study present the first comprehensive profile of respite services in New South Wales, Australia. Briefly, the findings suggest that many service providers have a significant experience in running a respite service. Most respite providers catered to a wide range of age groups. Respite appeared to be available in various geographical regions, however the study is unable to determine whether respite is readily available to all those who require it or how accessible the services are for carers. Respite services in New South Wales catered to people with a range of disability types and provided varied models of respite consistent with the research literature, such as home-based, residential care or holiday excursions. There is scope for further consideration of support for carers, for example, to alleviate feelings of guilt when placing a person with disability into respite (Ridley et al., 2004). Many respite providers indicated the importance of creating flexible and responsive services, and suggesting that there is scope for further innovation in respite care.

The results indicate a reliance on government funding (71.1%) even though the majority of respondents were non-government organizations. Adult respite providers indicate access to funding as a reported difficulty compared to other age groups. Two key issues need to be addressed in terms of reliance on government funding. First, there is merit in exploring other sources of funding for respite services such as user-pay, private sector funding or charity. While there were minimum and maximum fees charged to carers in NSW, other research has suggested
that some carers were willing to pay for respite services (Chiu et al., 1999). More research is needed on the interface between user-pay, government funding in terms of subsidies and private sector or charity funding. Second, the manner in which government funding is distributed to families and service providers requires further investigation. In considering a user-pay option it is critical to acknowledge that there will be carers who may not be able to pay for such a service as caring for a person with a disability can be an additional financial cost to the family (National Family Carers Voice, 2004). Creating flexible respite options and flexible funding models were reported by service providers as key features of an ideal respite service. Therefore it may be argued that respite providers do want to provide flexible services, as has also been expressed by carers (Jeon et al., 2007; Marlowe, 1998; Parmenter, 1999). It is not unreasonable or idealistic as such to consider making respite funding portable and consumer-driven or controlled (see Caldwell & Heller, 2003; Friss-Feinberg & Whiltatch, 1998).

While the results indicated that there is a range of respite models and many obtained advisory feedback, there was no mention of respite being consumer-driver or consumer controlled. A consumer-driven funding package would provide carers a sense of ownership and responsibility for managing the respite care required (Ridley et al., 2004). It would provide carers the opportunity to hire people or staff they trust, and the research attests to the benefits of a consumer-driven support system (Caldwell & Heller, 2003; Friss-Feinberg & Whiltatch, 1998). Funding portability is briefly defined as flexible packages that are given directly to the carer or family for a specified time period. Funding portability and consumer-driven funding will allow carers to make flexible choices and plan according to their needs (Ridley et al., 2004), and lead to greater carer satisfaction (Caldwell & Heller, 2003).
A majority of respite providers in the survey (88.8%) indicated that their employees have formal in-service disability training. While formal qualifications are not mandatory in NSW, the high proportion of services with workers who have formal training may be seen as a positive feature of respite services in NSW and compares favourably with respite services elsewhere (Salisbury & Griggs, 1983; Neef & Parrish, 1989, Upshur, 1982). Nearly half of volunteers appear to have some formal qualification. Appropriate training of respite workers, whether full-time employees or volunteers, can affect carers’ use or non-use of respite in two ways. First, carers may be more willing to seek services if they are confident that the respite worker is well-qualified to meet the needs of the person with disability. Second, they are more likely to use respite service if carers perceive the experience as positive and beneficial (Caldwell & Heller, 2003; Neef & Parrish, 1989). Neef and Parrish (1989) further argue that respite providers may be more likely to provide continuing respite services if they are confident that their training is enabling them to care appropriately and if their own experiences are positive. The importance of relevant training, recruitment of staff and volunteers, and skill in implementing challenging behaviour management were reported by providers as among the 10 most important expectations of respite. Providers also reported the level of challenging behaviour and level of health-care or medical needs of people with a disability as difficult compared to other factors. Hence further training in these areas is likely to be an important element in service provision.

Respite providers strongly rated factors that pertained to carers’ stress level and family-related concerns as their 10 most important factors that might influence carers’ use for respite service. These factors appear to be similar to those identified in previous reviews of research (Chan & Sigafous, 2000, 2001). These factors are also similar to the rating by carers’ of people with ABI (Chan, 2007) and what people with ABI (Chan, in press) consider as reasons for using
Respite. These factors are personal day-to-day stress of carers, poor health of carer, stress level of carer or family member, level of dependency of the person with a disability, family needing a break, and the need for experience outside the family or carer for the person with a disability. There is evidence that level of dependency, need for experience outside the family or carer, and potential family break-up are more likely to be rated by some respite providers as predictive of respite use by carers. However, there is a tendency for respite providers to assign same importance to different reasons for seeking respite. The level of challenging behaviour and high level of health-care or medical needs of people with disability seem to be a consistent theme for seeking respite (Chan, 2007; Chan & Sigafoos, 2000), coupled with the finding that respite is not necessarily readily available to some of these carers (MacDonald, 2007). It appears that respite providers do understand the needs of carers and are able to determine what factors may influence them to use respite. Predicting respite use or non-use by carers is useful in terms of planning of services, resource allocation, policy formulation and identifying carers or families most in need, and for respite to act as a preventative family support system rather than being crisis-driven. The development of a tool to assess the factors that influence carers' use of respite deserves further investigation.

This study had three main limitations. First, the survey was limited to one state (New South Wales) in Australia. Although it sampled the peak respite association in the state, generalization of the findings to respite providers in other states or countries might be limited. Furthermore, there might be other service providers who were not members of the peak respite association, such as government-run services and those who did not participate. Second, the findings represented the perspective of respite providers and as such, did not allow for direct comparison with people with disabilities and carers' perspective on key issues such as expectations of
respite. Third, the study was descriptive and so did not allow for statistical analysis of for
example, availability of respite. However, the study provided useful information and description
of the ‘state of respite service’ in New South Wales. To date, there had not been a
comprehensive description of respite services.

In summary, the study provides a comprehensive descriptive profile of respite services in
New South Wales and provides further information about the state of respite services there. The
data indicate that respite providers support funding being flexible, and services being responsive
to the needs of carers and be consumer-driven. Other research cited shows that there are benefits
to be gained for the carer and person with disability where services are consumer-driven. Further
discussion on fee-for-service respite needs to be considered in relation to how funding is being
allocated. Appropriate training remains an important issue, not just for carers but also for respite
providers. The implications of this study for policy development include the need to develop a
tool to assess the predictors of respite use or non-use. The potential of such a tool is to assist in
planning of future services and resource allocation to carers and families who most need it, and
to ensure that respite services act as a preventative measure rather than being crisis-driven.
### Demographic Characteristics of Respite Service Providers

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Frequency (n = 90)</th>
<th>Percentage %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type of Service Organization</td>
<td></td>
<td></td>
</tr>
<tr>
<td>State-Government</td>
<td>7</td>
<td>7.8</td>
</tr>
<tr>
<td>Non-Government</td>
<td>71</td>
<td>78.9</td>
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<tr>
<td>Private for-profit</td>
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<td>Other</td>
<td>11</td>
<td>12.2</td>
</tr>
<tr>
<td>Funding Source</td>
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<td></td>
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<tr>
<td>Government (Federal/State)</td>
<td>64</td>
<td>71.1</td>
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<tr>
<td>Charity/Non-Government</td>
<td>4</td>
<td>4.4</td>
</tr>
<tr>
<td>Mixed (Government and Other)</td>
<td>20</td>
<td>22.2</td>
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<tr>
<td>Other</td>
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<td>2.2</td>
</tr>
<tr>
<td>Number of Years in Service</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0 – 1 year</td>
<td>6</td>
<td>6.7</td>
</tr>
<tr>
<td>2 – 3 years</td>
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<td>2.2</td>
</tr>
<tr>
<td>4 – 6 years</td>
<td>16</td>
<td>17.8</td>
</tr>
<tr>
<td>7 – 10 years</td>
<td>15</td>
<td>16.7</td>
</tr>
<tr>
<td>more than 10 years</td>
<td>50</td>
<td>55.6</td>
</tr>
<tr>
<td>No Response</td>
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### Table 1.

**Demographic Characteristics of Respite Service Providers. (Contd).**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Frequency (n = 90)</th>
<th>Percentage %</th>
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</thead>
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<tr>
<td><strong>Geographical Location of Service</strong></td>
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<tr>
<td>Metropolitan Sydney</td>
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<td>30</td>
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<tr>
<td>Regional city/town</td>
<td>31</td>
<td>34.4</td>
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<tr>
<td>Country town</td>
<td>18</td>
<td>20</td>
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<tr>
<td>Rural and remote areas</td>
<td>12</td>
<td>13.3</td>
</tr>
<tr>
<td>Australian Capital Territory</td>
<td>2</td>
<td>2.2</td>
</tr>
<tr>
<td><strong>Ethnicity of Service Users</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>English-speaking background</td>
<td>87</td>
<td>96.7</td>
</tr>
<tr>
<td>Non-English speaking background</td>
<td>71</td>
<td>78.9</td>
</tr>
<tr>
<td>Aboriginal and Torres Strait Islander</td>
<td>59</td>
<td>65.6</td>
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<tr>
<td><strong>Age Groups of Service Users</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Infants/Toddlers</td>
<td>32</td>
<td>35.5</td>
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<tr>
<td>Children</td>
<td>47</td>
<td>52.2</td>
</tr>
<tr>
<td>Adolescents</td>
<td>41</td>
<td>45.5</td>
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<tr>
<td>Adults</td>
<td>58</td>
<td>64.4</td>
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<tr>
<td>Mixed Age Groups</td>
<td>38</td>
<td>42.2</td>
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</table>
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Table 2.
Number and Percentage of Respite Service providers that serve people with different types of disability.

<table>
<thead>
<tr>
<th>Type of Disability</th>
<th>Frequency (n = 90)</th>
<th>Percentage %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intellectual Disability</td>
<td>80</td>
<td>89</td>
</tr>
<tr>
<td>Physical</td>
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<td>78</td>
</tr>
<tr>
<td>Deafness/Hearing Impairment</td>
<td>54</td>
<td>60</td>
</tr>
<tr>
<td>Blindness/Visual Impairment</td>
<td>61</td>
<td>68</td>
</tr>
<tr>
<td>Autism</td>
<td>70</td>
<td>78</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>71</td>
<td>79</td>
</tr>
<tr>
<td>Down Syndrome</td>
<td>77</td>
<td>86</td>
</tr>
<tr>
<td>Fragile X</td>
<td>47</td>
<td>52</td>
</tr>
<tr>
<td>Brain Injury</td>
<td>52</td>
<td>58</td>
</tr>
<tr>
<td>Other Developmental Disability</td>
<td>68</td>
<td>76</td>
</tr>
<tr>
<td>Chronic health conditions</td>
<td>32</td>
<td>36</td>
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<tr>
<td>Multiple disabilities</td>
<td>69</td>
<td>77</td>
</tr>
<tr>
<td>Other Syndromes</td>
<td>56</td>
<td>62</td>
</tr>
<tr>
<td>Mental health/illness</td>
<td>37</td>
<td>41</td>
</tr>
<tr>
<td>Other</td>
<td>7</td>
<td>8</td>
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</table>
Table 3.

Models of Respite Service.

<table>
<thead>
<tr>
<th>Models of Respite Services</th>
<th>Frequency (n = 90)</th>
<th>Percentage %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home-based</td>
<td>59</td>
<td>65.6</td>
</tr>
<tr>
<td>Out-of-home placement (e.g., residential care)</td>
<td>53</td>
<td>58.9</td>
</tr>
<tr>
<td>Foster-care</td>
<td>1</td>
<td>1.1</td>
</tr>
<tr>
<td>Holiday camps, day excursions</td>
<td>56</td>
<td>62.2</td>
</tr>
<tr>
<td>Use of volunteers</td>
<td>50</td>
<td>55.6</td>
</tr>
<tr>
<td>Regular day programmes</td>
<td>33</td>
<td>36.7</td>
</tr>
<tr>
<td>Financial assistance</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>Equipment loan</td>
<td>14</td>
<td>15.6</td>
</tr>
<tr>
<td>Service co-ordination/case management</td>
<td>28</td>
<td>31.1</td>
</tr>
<tr>
<td>Counseling</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>Family support (e.g., support groups)</td>
<td>14</td>
<td>15.6</td>
</tr>
<tr>
<td>Information giving/resource sharing</td>
<td>35</td>
<td>38.9</td>
</tr>
<tr>
<td>Training or teaching of families</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>Training of volunteers</td>
<td>33</td>
<td>36.7</td>
</tr>
<tr>
<td>Emergency respite (e.g. home-based or ‘out-of-home’)</td>
<td>54</td>
<td>60</td>
</tr>
<tr>
<td>Other services</td>
<td>12</td>
<td>13.3</td>
</tr>
</tbody>
</table>
A Profile of Respite Service Providers

References


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Respite Care Services in Acquired Brain Injury

A Profile of Respite Service Providers


A Profile of Respite Service Providers


CHAPTER TEN

Carers’ perspective on respite for people with acquired brain injury

This chapter explores the perspectives of carers of persons with acquired brain injury regarding respite. It is the first study that examined the perspectives of carers regarding respite in the brain injury literature.

Jeffrey Chan

Office of the Senior Practitioner

Carers' perspective on respite for persons with acquired brain injury

Jeffrey Chan

Persons with acquired brain injury require continuing care and support in various aspects of their lives. Although the care and support are predominately provided by family members, little is known about the respite that these carers require to continue the care on a daily basis. This study aims to address the lack of data on respite care and people with acquired brain injury from the perspective of carers. Survey methodology was used to gather information from carers who were members of a peak brain injury association in New South Wales, Australia. The responses of 85 carers were analysed using logistic regression and frequency counts. The characteristics of carers were consistent with the research literature on respite and acquired brain injury, with carers being mainly female and there being a reliance on an informal network to assist in the care. Carers also reported that caring prevented them from obtaining gainful employment. Several factors were significantly associated with the use of respite, these were carers' single marital status, and the person with acquired brain injury's severity of disability, high level of dependency and number of days spent in coma. Carers also reported other factors that might influence them to use respite and they identified their expectations of respite. This study highlights carers' perspective on respite that is an under-researched area in acquired brain injury and reiterates ongoing need for respite.


Les personnes ayant une lésion cérébrale secondaire nécessitent des soins permanents et soutien dans divers aspects de leur vie. Malgré le manque de données sur les soins de soutien, les caractéristiques des soins de respite sont bien documentées. Cette étude a pour objectif de combler ce vide d'informations. Les réponses de 85 personnes aux soins de respite pour personnes ayant une lésion cérébrale secondaire ont été analysées en utilisant une méthode de régression logistique et des analyses de fréquences. Les caractéristiques des personnes soignées par les soins de respite étaient conformes à la littérature sur les soins de respite et l'acquisition de l'acquis lésionnel. Les facteurs liés au sexe, à la dépendance et à la durée de l'hospitalisation ont été identifiés. Les soignants ont également signalé d'autres facteurs qui affectaient leur prise de décision en matière de soins de respite, notamment leur besoin de soutien pour poursuivre leur activité professionnelle. Ce travail a pour but d'évaluer la perspective des soignants en ce qui concerne les soins de respite.
Introduction

Acquired brain injury (ABI) not only impacts the person but also on the family or carer (Florian et al., 1999; Wood and Vorderkot, 1997; Wake et al., 1998; Perfetti et al., 1999; Harris et al., 2001; Nabors et al., 2002; Colantonio et al., 2004). Many of these families’ needs go unrecognized and unmet (Socio et al., 1995). Families and carers require ongoing help to cope with caring and continuing the rehabilitation process within the community context (Socio et al., 1995; Hodgkinson et al., 2000; Keutzer et al., 2002; Smith et al., 2006). Appropriate family or carer support can mitigate the problems experienced by carers caring for a person with ABI and appropriate intervention should consider the needs of carers first before identifying the models of service delivery (Keutzer et al., 2002; Smith et al., 2006).

What are the needs of carers?

Socio et al. (1995) noted that family members continue to provide ongoing support to the person with ABI in the absence of continuing professional treatment programs. They found that on average 55% of needs were perceived as being met. They reported that 30% of families reported emotional support as important but unmet. The authors noted differences in role of carers and related dependency issues. For example, spouses 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, Socio et al. (1995) reported that a spouse having no joint carer may have more unmet needs which result in greater demand for respite care. They found that behaviour problems were especially predictive of relatives’ unmet needs, including respite.

Stebbins and Leong (1998) explored longer term changes in family needs after brain injury (e.g. strokes, motor-vehicle accidents or epilepsy). They found that carers experienced changing and expanding needs over time. Family needs changed from focusing on acute medical and professional supports during the first 2 years to an expanded range of needs such as community supports, financial resources, caregiver supports and health information. Carers support included respite care and nursing or day care for the person with brain injury. Another finding was an increasing level of unmet needs over time. They suggested the possibility of a relationship between unmet needs and stress and burden in family members caring for a person with brain injury.

Similarly, Hodgkinson et al. (2000) identified that use of services by people with traumatic brain injury remained high for many years after injury. They identified services often used by Australians with such injury were medical and allied health services (61%), transport (46%), financial services (58%), legal matters (49%), and vocational services (40%). Other needs included accommodation, day activity programs and home support. Hodgkinson et al. (2000) also found that psychological

Con la lesión cerebral secundaria, y reitera la necesidad de los cuidadores de tener relevo en sus labores.

Les personnes souffrant de traumatisme cérébral acquis nécessitent des soins et une assistance continue dans tous les aspects de la vie quotidienne. Bien que ces soins et cette assistance soient principalement fournis par les proches, il existe peu d’informations sur le soin/épargne, dont ces personnes peuvent avoir besoin pour continuer à pratiquer les soins au quotidien. Cette étude se proposait de combler certaines lacunes en termes d’informations sur le besoin de relâche des personnes à charge de patients souffrant de traumatisme cérébral acquis. La méthodologie adoptée pour l’enquête a consisté à recueillir des informations des soignants membres d’une association de soutien aux victimes de traumatisme cérébral des nouvelles Galles du Sud, en Australie. Les réponses de 85 soignants ont été analysées en employant la régression logistique et les décimales de fréquence. Les caractéristiques présentées par les soignants correspondaient aux données issues de la recherche sur les soins de relâche et le traumatisme cérébral acquis. Les soignants étaient principalement des personnes s’appuyant sur un réseau de soutien officieux. Les soignants ont également précisé que le fait d’avoir à dispenser ces soins les empêchait d’occuper un emploi rémunérateur.

Plusieurs facteurs étaient associés aux besoins de soins de relâche, en particulier le cérébral des soignants et la sévérité du handicap de la personne souffrant d’un traumatisme cérébral acquis, le haut degré de dépendance et le nombre de jours passés dans le coma. Les soignants ont également signalé certains autres facteurs pouvant influer sur le besoin de relâche et ont identifié leurs attentes à cet égard. Cette étude met en relief les perspectives des soignants vis-à-vis des soins de relâche.

disability may be a better predictor of service use than physical and cognitive disability alone. This study provides significant documentation of service utilization by people with ABI at different times postinjury and highlights their ongoing needs. Although the study reports service utilization, it did not evaluate whether minimal use or none of services might be because of the fact that these services were not known by or to families or persons with ABI or simply unavailable. Minimal use might also be because of the fact that there is a lack of a service such as respite or day activity programmes (Priss, 1990).

The studies reviewed have clearly indicated the life-long strain and needs of carers (Kaskinen, 1998; Stebbins and Leung, 1998; Hodgkinson et al., 2000). Kaskinen (1998) argued that the carer should have the right to rest or go on vacation without feelings of guilt. Following discharge from inpatient rehabilitation settings, there is now an increasing trend towards the provision of rehabilitation for the person with brain injury and severe disabilities within the home context and community setting (Willer et al., 1994; Beatty and Speziale, 1997; Ficenec, 1997; Minnes et al., 1998; Warden et al., 2000; Cummins, 2001). The benefits for rehabilitation within a home or community environment include economic benefits for governments through the utilization of care within the family. Cummins (2001) argued that though there is an increasing trend towards encouraging family care for people with a severe disability, there is no corresponding support for families to continue the care at home.

Respite has been identified as one of the many support services to assist the family in the care of the person with ABI within the home and/or community setting (Kaplan, 1991; Hall et al., 1994; Knight et al., 1998; Nabors et al., 2002). Respite care refers to the use of an organized service that is developed to provide temporary relief from the caretaking responsibility associated with supporting a person with a disability (Chan and Sigafos, 2000). A role for respite care services as a form of social and community resource support to the family’s adaptation to ABI exists, and yet there is quite limited research and evidence available in the area of respite and ABI.

Benefits of respite care

Considerable research is done on the benefits of respite care in the developmental disability area (Chan and Sigafos, 2001; Fonds et al., 2004), in aged care (Lawton et al., 1989; Kolski and Montgomery, 1995; Perry and Bontinen, 2001; Strang, 2001; Nicoll et al., 2002) and in persons with complex health care needs (Owen and Muldoon-Postden, 2001; Miller, 2002), but there is little research in the area of ABI. In a review of studies that evaluated the effects of respite care services on families of children with developmental disabilities, Chan and Sigafos (2001) found that respite care is related to significant reductions in parental stress for most parents, in the short term at least. Parahoo et al. (2002) found that families expressed high satisfaction with their respite workers and used the break from caring to attend to household chores or shopping. Little evidence of the families using the break to improve their social life or recreation, however, was found (Parahoo et al., 2002). Similar studies on the benefits of respite care, using both quantitative and qualitative methodology, report that respite care can be a moderate of parental stress and alleviate the stress of caring in the family unit (Conlin et al., 1992; Deimling, 1992; Larkin and Hopcroft, 1993; Ashworth and Ruzoe, 2000). The use of respite may not always be beneficial, e.g., if access to it is difficult or the services provided do not meet the expectations of the families. In such cases, 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 and Sigafos, 2001).

The use of respite may delay or decrease the likelihood of nursing home or other institutional placements (Kolski and Montgomery, 1995; Chan et al., 2001). Like Chan and Sigafos, Kolski and Montgomery argued that further studies are needed to understand what makes respite care an attractive form of assistance to carers. The issue may not simply be the access to respite, but how and what carers do with the respite break along with the support it brings (Chan and Sigafos, 2001; Ridley et al., 2004). These studies did not specifically include people with ABI, which underlines the fact that 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 carers experience in the care of the person with brain injury. Understanding the predictors of respite use and nonuse can assist in identifying the carers who need respite, so that these carers can be granted greater access to presumably benefit more.

Predictors of respite use

McConkey (2003) investigated the characteristics of 1500 carers of adults with intellectual disability in Northern Ireland. McConkey found that carers who were more likely to use respite were those whose relative with disability had high dependency needs, those who were raised as siblings, whose carer stress levels were greater than average and whose household did not have two parent carers. McConkey also found that overall high dependency in personal care predicted access to respite, domiciliary care and befriending services. Families have identified varied reasons for the use of respite, and therefore it is useful to examine the factors that relate to respite, use and nonuse, as it will have implications for service development, prioritization of use, resource allocation and policy development.
Chan and Sigafoos (2000) reviewed the child and family characteristics related to respite use in developmental disability services. They found that on the child side, the characteristics include severity of disability, level of care required, presence of challenging behaviours and communication difficulties. On the family side, the factors include greater family stress and lesser access to support services. They found no conclusive evidence to suggest whether a larger or smaller family size was a reliable predictor. The presence of challenging behaviour appears to be more associated with respite use in the developmental disability research and will be investigated in this study.

In one of the very few studies of respite and ABI, Friss (1998) did provide characteristics of brain-injured adults and their carers who accessed respite in California. She reported that 53% are male and 47% are female, with the majority of users being older adults with brain injury aged 65 years and over (65%). The primary diagnosis reported by families was degenerative neurological conditions or dementia (55%), strokes (19%) and traumatic brain injury (16%). Carers were mainly women (74%) and over half were middle aged (52%). Most of the carers were spouses (37%) or adult children (32%). Although Friss reported on the characteristics of users, her data do not specify these characteristics as predictors or non-predictors of respite use.

What do carers look for in a respite service?

Kersten et al. (2001) argued that carers’ needs must be assessed appropriately and services need to be flexible and specific to the needs of carers. No evidence is found in the current literature on respite care and ABI that clearly articulates the expectations of families and carers of a respite service. These expectations are important because of their potential influence on the benefits of the use of respite. If respite services fail to meet such expectations, then the use of respite care may in fact work to the detriment of the carer, as it may contribute to the carer’s already heightened stress level. Studies into the potential benefits of respite need to examine whether respite care providers and services meet the expectations and needs of families and carers.

Many carers (63%) stated that they found it difficult to access respite services (Buchanan 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 carers were more likely to have used respite service in the past year if they had received support from health or social professionals.

In a similar study, Neufeld et al. (2001) examined perceptions of primary carers of children with regards to respite use and barriers to respite care. Neufeld et al. noted the use of a range of respite models, such as inhome respite (73%), regular inhome babysitting (55%), group-home respite (26%), camps (40%) and institutional respite care (13%). No relationship was found between the use of respite services and the child’s age. There was no association between amount of respite care used and perception of an adequate break, and that many primary carers who actively used respite care services did not perceive it as an adequate break. Their concern centred on the lack of qualified carers, adequate funding, increased access to services and increased frequency of respite services (Neufeld et al., 2001).

The aims of this study were to obtain a profile of carers who use or do not use respite, to describe the persons with ABI being cared for, to explore the factors associated with respite use or nonuse, to describe carers’ expectations of respite and to identify other support services that they might require in the ongoing care of the person with ABI. The data gathered were based on the information provided by carers.

Method

This study is part of a larger study exploring respite from the perspective of carers and persons with ABI. The results of this study represent the carers’ perspective on respite. The carers were recruited from the membership database of the New South Wales (NSW) Brain Injury Association. The Association is the peak advocacy organization of persons with brain injury and their families in the Australian state of NSW. The study was approved by The University of Sydney Ethics Review Committee (Human Research) and used survey methodology. The questionnaire underwent three drafts involving consultations with carers, expert clinicians and academics in the field of disability and brain injury.

The survey questionnaire contained sections on demographic information, factors associated with respite use, expectations of respite services and satisfaction with respite services used by persons or carers (if the person or family has used such a service). The questionnaire also included openended questions. The respondent was asked to rate on a five-point Likert scale factors that influence use of respite (such as the level of severity of disability, stress level of carer or level of challenging behaviours), expectations of respite services (such as having trained and qualified staff, having more respite service or provide a homely environment) and the importance of perceived family needs (such as financial help, access to therapy services or holiday scheme for the injured person), and to provide more information on challenging behaviours. Those who have used respite before were asked to rate their level of satisfaction with...
the respite use and whether they had been able to access sufficient respite.

For privacy reasons, the survey questionnaires (n = 260) were mailed directly to the NSW Brain Injury Association for distribution to its membership. A total of 101 surveys were returned (39%) and 85 (33%) of the 101 carers’ responses that were correctly completed were analysed. The responses to each returned questionnaire were coded for data entry. To ensure the reliability of data analysis, 20% of the data was checked by a doctoral student for correct coding of questionnaire response items and correct data entry into SPSS Version 11.5 (Chicago, Illinois, USA). In all there were 133 items in the survey, with 99% interrater reliability for coding. Interrater reliability on data entry was 83%. Disagreements were resolved by checking all the responses with the data entry.

Results

Demographic characteristics of carers

Table 1 describes the demographic characteristics of carers of persons with ABI. Several respondents had not specified their gender. Thus, it is difficult to ascertain the accuracy of the number of female and male carers, but the available results indicate that nearly all of the carers were females, comprised mainly of mothers (61.2%) and wives (12.9%). This is also consistent in the research evidence in brain injury (e.g., Perlese et al., 1999) and in respite care (Chun and Sigafoos, 2000). The primary carer tends to be over-65s (e.g., parents, spouses, partners or siblings). Other carers identified in the survey questionnaire include grandparents or friends. The age range of carers is 18-75 years, with a median age of 53 years. It can be surmised that majority of carers are female and young to middle-aged adults.

Almost all of the carers (91.8%) were from an English-speaking background. This is not reflective of the diverse cultural and linguistic population of NSW and reflects an under-representation of people from a culturally and linguistically diverse background relative to their numbers in the general population of the state. Nearly half of carers (44.7%) indicated that looking after a person with ABI prevented them from gaining employment.

Fifty-one carers (60%) indicated that a variety of people were involved in the care of the person with ABI. The carers who responded to this question reported that family members such as spouses or partners (n = 78); siblings (n = 11), grandparents (n = 1) or other relatives (n = 9) were involved in care. Three respondents mentioned friends as a group also involved in care and two respondents mentioned a paid carer or nanny at their own expense. Fourteen respondents reported ‘other’ persons were involved and some had specified neighbours and volunteers. The results suggest a reliance on an informal support network, especially that of family members to assist in the care of a person with ABI.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N (n=65)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Male: 47, Female: 19*</td>
</tr>
<tr>
<td>Age range</td>
<td>18-75 years</td>
</tr>
<tr>
<td>Marital status</td>
<td>In a relationship: 62 (93.9%)</td>
</tr>
<tr>
<td>Education level</td>
<td>Less than Year 10 School: 14 (21.5%), School Certificate/Certificate Year 10: 10 (15.3%), High School Certificate/Certificate Year 12: 11 (17.2%), Trade/TAFE/Vocational Diploma: 16 (24.6%), Other: 27 (41.5%)</td>
</tr>
</tbody>
</table>

*The gender of primary carers in an estimate as described in the table as ‘other’ gender was difficult to study on several respondents had not identified ‘gender’ when completing relationship status to the person with ABI.

Characteristics of persons with acquired brain injury as reported by carer

Sixty-six carers (77.6%) indicated that the person they were caring for had sustained a traumatic brain injury and 17 carers (20%) reported nontraumatic brain injury. Three carers did not indicate the type of brain injury. Fifty-one carers (60%) indicated that the person had spent more than 7 days in a coma, 12.9% indicated the person had spent between 1 and 7 days in a coma, 8.2% indicated between 1 and 23, and 4.7% indicated less than 1h in a coma. Twelve (14.1%) required the question was not applicable. Carers indicated 11.8% of the persons with ABI that they were caring for as having a

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profound level of disability, 47.1% as having a severe level of disability, 23.5% as having a moderate level of disability, 8.2% as having a mild level of disability and 9.4% as being independent. In terms of levels of disability, the results indicate a high proportion of severe to profound disability.

Level of dependency was based on the definition proposed by the Australian Institute of Health and Welfare (1999): ‘total dependency’ indicates the need for 24-h care, ‘moderately dependent’ is defined as ‘where personal help or supervision is required some- times’, ‘somewhat dependent’ is defined as ‘where no personal help or supervision is required but difficulty performing one or more tasks’, ‘mildly dependent’ is defined as ‘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 difficulty or cannot easily pick up an object from the floor’ and independent ‘not requiring personal care’. Carers rated 23.5% (n = 29) of the persons with ABI they were caring for as being totally dependent, 37.6% (n = 32) as being moderately dependent, 20% (n = 17) as being ‘somewhat dependent’, 9.5% (n = 5) as being ‘mildly dependent’ and 9.4% (n = 8) as being independent; there were three nonresponses (3%).

Access to other support services
Fifty-five carers (64.7%) accessed a wide range of support services at the time of the survey, and many of the carers were using more than one support service. The support services accessed were case management (33.9%), medical support (23.5%), speech pathology (18.9%), physiotherapy (16.5%), occupational therapy (14.1%), recreational support (14.1%), special education (11.8%), return to work or employment support (11.8%) and behaviour management support (5.9%). ‘Other’ services (18.8%) included social and peer support groups.

Access to respite care
Forty-one (48.2%) carers indicated that they have used respite before and 36 (82.8%) out of the 41 provided more information on their access to respite in a snapshot 1-year period. Table 2 presents the snapshot period of respite use. The purpose was to ascertain the use of respite in a given period and to determine the most recent use of respite by carers, given that some carers might have used respite many years ago. On average, each carer had used respite 3.5 times in the past year. It is important to note that a carer might have accessed more than one type of respite services.

Demographic characteristics as predictors of respite
This section examines the relationship between the use of respite and the demographic characteristics of carers. ‘Use’ of respite was defined as having accessed the service at the time of the survey or before. ‘Nonuse’ was defined as not having accessed respite at any time. The relationship was analysed using logistic regression. The results are presented as an odds ratio, 95% confidence interval (CI) and probability (P) value. The P value is for the test using the likelihood ratio. The univariate relationships are presented. The relationship between respite use (Maner Survey Section A, Question 14 ‘Have you used respite care service before?’) and the demographic characteristics of carers and those of persons with ABI that were significant or showed evidence of a relationship were as follows:

- Carer single status vs. marital status (odds ratio 3.87, CI 1.39–10.82, P = 0.007);
- More than 7 days in coma vs. less than 7 days in coma (odds ratio 5.58, CI 1.60–18.4, P = 0.006);
- Total and moderate dependency vs. somewhat, mild, and independent (odds ratio 0.16, CI 0.05–0.40, P < 0.001).

The results indicate that if a carer was single they were 3.9 times as likely to be using respite care as carers who were married. Strong evidence which states that if a person being cared for were in a coma for more than 7 days then the carer was 3.5 times as likely to use respite as carers of persons with less than 7 days in a coma is found. A strong evidence is also found to indicate that greater level of dependency (total and moderate) was a predictor of respite use (P < 0.001) with those with total or moderate dependency being 84% more likely to use respite. Although not statistically significant, there is some evidence that severity of disability was also related to respite use with carers supporting a person with severe and profound disability were being more likely to use respite than those with mild and moderate disability (severe and profound disability vs. not known, mild and moderate disability) (odds ratio 2.5, 95% CI 1.0–6.6, P = 0.06).

Analyses using logistic regression between actual respite use and other demographic factors (such as age, education level or employment status) that might influence a

Table 2: Respite use in a snapshot period of 1 year (n = 36)

<table>
<thead>
<tr>
<th>Type of respite</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emergency respite</td>
<td>6</td>
<td>16.7</td>
</tr>
<tr>
<td>Planned respite</td>
<td>23</td>
<td>66.4</td>
</tr>
<tr>
<td>Used both emergency and planned respite</td>
<td>3</td>
<td>13.9</td>
</tr>
<tr>
<td>Types of respite</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Funding packages</td>
<td>5</td>
<td>13.9</td>
</tr>
<tr>
<td>State Government respite service or unit</td>
<td>8</td>
<td>22.2</td>
</tr>
<tr>
<td>In-home care (eg. attending care)</td>
<td>13</td>
<td>36.1</td>
</tr>
<tr>
<td>Non-Government respite service</td>
<td>15</td>
<td>41.7</td>
</tr>
<tr>
<td>Private (for profit agency)</td>
<td>5</td>
<td>13.9</td>
</tr>
<tr>
<td>Private (not for profit)</td>
<td>2</td>
<td>5.6</td>
</tr>
<tr>
<td>Help from relatives/friends</td>
<td>10</td>
<td>27.8</td>
</tr>
<tr>
<td>Currently using respite</td>
<td>21</td>
<td>58.3</td>
</tr>
</tbody>
</table>

Carers may have used more than one type of respite so percentages add to more than 100%.
care's use of respite, and expectations of respite were conducted. No significant association was found between those factors and respite use.

Factors reported to influence respite use
Carers were asked to rate on a five-point Likert scale how important certain factors (such as the level of challenging behaviour, carer stress level or severity of disability) might influence their use of respite. No significant association between carers' importance ratings of factors reported to influence respite and actual respite use was found. Carers reported, however, that the 10 most important factors that may influence their decisions to use respite care were: personal needs experienced apart from carer (78.9%), personal daily/day stress of carer (69.9%), stress level of family members (64.7%), person may need a break from carer or family (63.5%), family needs a break from person (62.4%), level of severity of disability (58.9%), carer needs time to spend with spouse or family (57.6%), carer needs time for self (56.5%), dependency on person care (51.8%) and poor health of carer or family member (51.8%). Overall, carers considered factors to influence respite use that related to the stress and needs of carers or family, and to the disability needs of person.

Types of challenging behaviours demonstrated by persons with acquired brain injury as reported by carers
Although there was no statistically significant association between actual respite use and the level of challenging behaviour, and the fact that the level of challenging behaviour was not rated by carers as among the ten most important factors or reasons influencing respite use, this factor was further investigated because the level of challenging behaviour appears to be significantly associated with respite use in the developmental disability literature. Furthermore, challenging behaviour is a consequence of ABI as a result of funeral lobe damage in most cases. Carers who reported challenging behaviour as a factor further elaborated on the types of challenging behaviours. Fifty-nine carers (81.2%) provided further information on the types of challenging behaviours they experienced as demonstrated by the person they were caring for. The types of challenging behaviours were verbal aggression (66.7%), physical aggression, alcohol and other drug use (18.8%), inappropriate sexual behaviour (15.9%), self-harm (15.9%), property damage (14.5%), police or criminal justice involvement (14.5%), and absconding (11.6%). A carer might be experiencing one or more types of challenging behaviours of the person whom they are supporting. The types of challenging behaviours reported were chronic, and it can be speculated that the behaviours presented may contribute to carer stress and "burden" of caring.

Further analysis using logistic regression was conducted to explore the relationship between challenging beha-

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the importance of various forms of respite as part of the overall mix of support and information services that carers need.

Discussion

One primary aim of the study was to describe the characteristics of carers of persons with ABI and to ascertain the level of support, in terms of respite care available to them and their carers. The results were consistent with the research on respite care and ABI, in that there were several characteristics of carers and persons with disability that were ‘predictive’ of respite use (Piris, 1990; Chan and Sigafuso, 2000; McConkey, 2005). The majority of carers of persons with ABI were mainly women and relatively young (Piris, 1990; Hall et al., 1994; Petless et al., 1999; Chan and Sigafuso, 2000; Harris et al., 2001; Damiani et al., 2004; McConkey, 2005). Caring for a person with ABI may prevent a carer from obtaining gainful employment (44.7%). The data suggest that most of the caring was done by at least two persons, with 72.9% of carers reported to be in a relationship and many carers were also reliant on an informal network of other people being involved (60%). Family members were the predominant informal network who assisted in the care. The majority of the persons being cared for had a high level of dependency and high severe disability.

The data indicate that there are continuing demands on carers with more than half of them (64.7%) will accessing a wide range of support services, 45.8% had used respite in the past (before the snapshot year of survey) and another 58.3% were currently using respite at the time of the survey. The snapshot year was defined as a calendar year at the time of the survey. The needs for ongoing support and care of persons with ABI have long-term impacts on carers (Stebbins and Leung, 1998; Hodgkinson et al., 2000). Given the high level of dependency and severity of disability reported in this study by carers, and a reliance on informal network to assist in the care; there is strong argument that there is a high level of unmet need for formal respite (Serio et al., 1995; Stebbins and Leung, 1998; Hodgkinson et al., 2000). This conclusion is supported by the fact that majority of carers reported that they require regular schemes for the person with ABI, respite services outside the home and club activities. The people involved in the informal network of caring for a person with ABI are usually unpaid and as such, represent a huge saving in terms of government expenditure (Cummings, 2001).

As indicated by carers in this study, one appropriate step to address the gap is to increase respite funding and allocation for persons with ABI. In order for respite to be effective in alleviating carer stress, it would be prudent to incorporate the expectations of carers regarding respite care. The results of this study present a preliminary way forward to meet carers’ respite needs. Respite needs to provide a wider range of services for carers and persons with ABI, such as holiday schemes and activities or clubs that are available throughout the week. Availability is important so that carers do not become more stressed in having to arrange and locate respite. Having trained and qualified staff is important so that carers can be assured of the quality of care provided (Damiani et al., 2004). Having qualified staff with support from senior management and relevant policies is important to carers to ensure that there is appropriate governance that meets legislative requirements and duty of care. A positive experience with respite care will help ensure that carers continue to use the service.

It is crucial that carers who access respite use the time for themselves without feelings of guilt. Further research is required to measure the benefits of respite over time and ensure that carers use the ‘time away from caring’ productively for themselves (Chan and Sigafuso, 2000; Ridley et al., 2004). Premeasurement and postmeasurement of immediate respite use, and over time in critical domains such as health, personal well-being, family well-being, and levels of stress and anxiety are useful in knowing whether respite benefits the carer. Understanding the predictors of respite use is critical in developing the appropriate respite service that will promptly identify carers who need respite most.

The data in this study have identified characteristics that had a significant relationship to respite use. The evidence is clear that single carers may find care more ‘burden-some’ (Serio et al., 1995) and so uses respite more. Other factors that appeared to influence respite use included level of disability (severe and profound), total and moderate dependency, and the number of days in care. These factors relate to the overall level of care required and may, as such, impact on the stress level of the carer. Carers rated similar factors as influencing respite use, but indicated personal stress level and needs of other family members were also important. The importance of these factors strengthens the argument for respite providers to pay attention to potential predictors of respite use. The preliminary findings on the factors that have influenced respite use could assist in developing appropriate policies and guidelines on respite prioritization and resource allocation for government and respite organizations. These may prevent unnecessary carer distress, potential family breakdown and inappropriate institutional placements (Kaski and Montgomery, 1995; Chan et al., 2001).

The results also suggest that respite service providers should provide a range of services in addition to respite (Piris, 1990; Serio et al., 1995; Hodgkinson et al., 2000). Carers in this study reported the need for other support services such as case management, medical and other health-care advice, need for more information and help
about other services, help in planning the future, and training on how to manage challenging behaviours. It is not always possible to provide all the information in a single document, but respite services must also meet cultural and religious differences (Costerhill et al., 1997).

Management of challenging behaviour needs to go hand in hand with respite care. Even though carers did not indicate the level of challenging behaviour as one of the top 10 most important factors influencing respite use and logistic regression analysis did not indicate any significant relationship between actual respite use and level of challenging behaviour, 81.2% of carers in this study elaborated on the types of challenging behaviour they experienced in the care of the person with ABI, such as verbal and physical aggression, self-injury or inappropriate sexual behaviour. One can speculate that the reason for not identifying challenging behaviour as a factor is the acceptance that the behaviour is a consequence of brain injury and might be interpreted as a 'medical problem' resulting from brain injury. The level of challenging behaviour is a factor that influences respite use among people with developmental disability (Chan and Sigfusson, 2000). Aggressive behaviour is not uncommon in brain injury (Bagley et al., 2008; Winkler et al., 2006). The level of challenging behaviour in this study was also significantly related to other factors that in turn were reported to influence respite use, such as medical problems, potential family breakdown and difficulties relating to the person with ABI. That is, challenging behaviour was a secondary predictor of respite use. These factors may add to carer stress and need for a break from caring. Winkler et al. (2006) reported that interventions to minimize the level of challenging behaviour can facilitate successful integration into the community. One can also argue that intervention in challenging behaviour may alleviate carer stress. Hence, given the level of challenging behaviours experienced by carers, future research should consider this as a potential factor in respite provision for people with ABI.

This study has a few limitations. First, the small sample size limits generalization of the findings to carers and ABI population generally. Second, the findings are also likely to reflect respite service provision in NSW. Third, the findings are based on the perspectives of carers and it would be useful to make comparisons of the findings with that of persons with ABI and respite care providers (Chap. in preparation). The comparison may highlight areas of similarities or differences and hence evaluate the importance of respite care in ABI from multiple perspectives. Fourth, this study was confined to members of the NSW Brain Injury Association. The findings of this study were, however, similar to the research on respite and ABI in general.

Given the limitations of this study, the findings demonstrate a need for respite for persons with ABI. Many carers are reliant on an informal network to assist in the care and that the level of care required is high. Carers in this study have articulated their expectations for respite and ongoing support needs that are strongly supported by other studies. Carers urgently need respite so that they can continue the care of the person with ABI.

Acknowledgement
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References
Respite Care Services in Acquired Brain Injury


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CHAPTER ELEVEN

What Do People With Acquired Brain Injury Think About Respite Care and Other Support Services?

This chapter presents the findings of the study focused on the perspective on respite and other support services by people with acquired brain injury. It is the first study that examined the perspective of people with acquired brain injury on respite provision.

Jeffrey Chan

Office of the Senior Practitioner

International Journal of Rehabilitation Research, 2008, 31:3-11
What do people with acquired brain injury think about respite care and other support services?

Jeffrey Chan

Little is known about the need for continuing support services, such as respite for persons with acquired brain injury (ABI). This study focuses on the views of people with ABI on respite and support services. In particular, the study aims to identify the characteristics of persons with ABI who were using or not using respite, to explore the factors influencing respite use and to determine expectations of respite and need for other support services. Survey methodology was used to gather information from members of a peak brain injury association in New South Wales, Australia. The characteristics of participants with ABI appeared consistent with the current literature in the area. Several characteristics were found to be significantly related to respite use; these were level of severity of disability, overall dependency of person with injury and number of days in coma. The factors that influenced respite use appeared to be similar to those reported in the developmental disability literature and in a study of respite from the views of carers of people with ABI. Some of these factors included the stress level of the carer and severity of disability. Other factors existed that influenced use of other support services. Persons with ABI indicated reported several expectations of respite, for example, they preferred a wider range and more flexible respite options, and more trained and qualified staff. They also reported lack of sufficient respite. Respite service planning and allocation need to consider the views of people with ABI and to respond to the inequities in respite service delivery.


Poco se conoce sobre la necesidad de contar con servicios de apoyo continuado, tales como los servicios de descanso, para personas afectas de lesión cerebral secundaria (LCS). Este estudio se centra en las opiniones de personas afectas de LCS que hacen uso de los servicios de descanso y de apoyo. En particular, el objetivo del estudio es determinar las características de las personas con LCS que hacen, o no, uso de los servicios de descanso, así como explorar los factores que intervienen en el desempeño de estos servicios y para determinar las expectativas y necesidades relacionadas con otros servicios de apoyo. Como método se empleó una encuesta destinada a recolectar información aportada por miembros de una importante asociación de lesión cerebral de New South Wales, Australia. Las características de los participantes afectos de LCS parecía ser consistente con lo descrito en la literatura especializada actual sobre este tema. Se halla que varias características estaban significativamente relacionadas con el uso de los servicios de descanso; estos fueron: el grado de discapacidad, la dependencia genérica de la persona afecta en lesión cerebral y el número de días en estado de coma. Los factores que determinaron el uso de los servicios de descanso parecieron ser similares a los informados en la literatura especializada sobre las discapacidades del desarrollo y en un estudio sobre los servicios de descanso desde la perspectiva de los cuidadores de personas afectas de LCS. Entre estos factores se encontraron el grado de tensión psicológica del cuidador y el grado de...
Introduction

Nearly 2% of the Australian population is reported to have acquired brain injury (ABI) (Australian Institute of Health and Welfare, 2003). Overall, 81% of people with ABI reported injury or accident as the main cause. People with ABI face lifelong disability and experience difficulty in community integration (McCabe et al., 2007). The disabling conditions of people with ABI in Australia are defined at four levels of handicap, namely profound, severe, moderate, and mild (Fortune and Wen, 1999).

The levels of handicap 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 and Health, 1994). Although there has been an approach to care and coordination of service to people with ABI and their families over the years, much of the rehabilitation process has tended to focus on physical rehabilitation (Cope et al., 2005). Persons with ABI continue to experience significant long-term problems (Florian et al., 1989; Koskinen, 1998; Perlext et al., 1999; Hoofien et al., 2001; Taitz et al., 2003; Colantonio et al., 2004; Corrigan et al., 2004; Onsworth et al., 2004).

The long-term problems experienced by these individuals impact on every facet of their lives. It is also known that the support needs of these individuals are varied and long term (Hoofien et al., 2001; Corrigan et al., 2004; Onsworth et al., 2004, Pickelsimter et al., 2007). Furthermore, the impacts on the family or carer (Florian et al., 1989; Wade et al., 1996; Perlext et al., 1999). The impact of ABI is costly in terms of not only lives lost but also in terms of health care expenditures and productivity losses for the community (Max et al., 1991). Max et al. (1991) developed an economic model to determine the lifetime cost of all head injuries in 1985 in the USA. They found that the lifetime associated cost with all head injuries resulting in death or hospitalization is estimated at $57.8 billion. More than 65% of the total cost is accrued among
those who survived a head injury. Therefore, from these studies the logical conclusion is that ABI is clearly a significant problem that has many negative consequences for the person, his or her family, and society at large. Hence, there is a need for research on aspects of service provision, such as the use of respite and other support services. Furthermore, there is a need to discuss social policy and resource allocation for persons with ABI to support their needs and those of their carers (Goodall et al., 1994; Vaughan and King, 2001). Few studies have investigated the provision of support services for the family or carer while the person with ABI lives at home or in the community (Fiorian et al., 1989; Pryor et al., 2002). Most of these are focused on counselling, stress management, and support networks (Witter et al., 1990; Kaplan, 1991; Ciccarino and Kreutzer, 1997), not respite.

Respite refers to the use of an organized service that is developed to provide temporary relief from the caregiving responsibility associated with looking after a person with a disability (Chan and Sigfusson, 2000). Respite has been identified as one of the many services needed to assist the family to continue the care within the home and/or community setting (Kaplan, 1991; Hall et al., 1994; Kitchen and O’Hara, 1998; Marsh et al., 1998; Tate et al., 2003). Respite could also be considered as a government strategy to prevent early out-of-home placement for people with disabilities (Australian Institute of Health and Welfare, 1997). Hence, respite can be a form of social and community resource support to the family’s adaptation to ABI. Fries (1990) reported that families of persons with ABI need a range of support services and respite care is one such service. Tate et al. (2003) reported that 75% of people with traumatic brain injury (TBI) at 20–26 years posttrauma continued to have unmet needs, and 85% had used a service in relation to their injury in the previous 12 months. In the same study, 58% indicated a need for respite accommodation.

Although there is extensive research interest in respite care in the areas of developmental disability (Chan and Sigfusson, 2000, 2001; Olsen and Maclin-Porter, 2001; Ridley et al., 2004), in mental health (Jean et al., 2005; Jean et al., 2007), and in aged care (Lawton et al., 1989; Kosinski and Montgomery, 1995; Brown et al., 2000; Perry and Rostin, 2001; Straet, 2001), it has received little attention in the ABI area. Chan (2007) investigated the views of carers of ABI on respite and noted the need for ongoing need for respite. Although there is acknowledgement that respite can act as a preventative strategy for reducing out-of-home placements for people with disabilities, the unmet demand for respite by people with ABI in Australia remains high (Australian Institute of Health and Welfare, 2002). Moreover, it is not clear whether available services are targeted towards those with the greatest need (e.g., the most severe disability). Although insufficient provision of such services is doubtless one factor contributing to the shortfall in respite, it is highly likely that persons with ABI hold views about the nature of such services that influence their willingness to use available respite services. Research evidence is, however, not available regarding the types of respite that people with ABI prefer.

The fundamental tenet in contemporary service provision is for persons with disabilities to participate in the decisions that affect their lives, including decisions about support services. Little is known about how respite is actually being meeting the needs of persons with ABI. More importantly, little is also known about the views of persons with ABI regarding respite. Therefore, the aims of the study were to (a) describe the profile and characteristics of persons with ABI who use and/or do not use respite, (b) identify the potential predictors or factors influencing respite use or nonuse by persons with ABI, (c) describe the expectations of respite services from the perspectives of persons with ABI, and (d) identify other service needs that persons with ABI might report that they have.

Methods

This study is part of a larger study that investigated respite services from the perspective of people with ABI, carers, and respite service providers (Chan, 2007). The results of this study are from the perspective of people with ABI. The database did not permit delineation of membership between members who were carers and persons with ABI and the actiology of the injury. The sections in the survey were the same as with the larger study (Chan, 2007). Assistance to the person with ABI to complete the survey could be noted. For reasons of privacy, the survey questionnaires (n = 260) were mailed directly to the New South Wales (NSW) Brain Injury Association for mailing to its members. Of 260 surveys mailed, 75 (29%) surveys for people with ABI were returned. Only 62 (24%) were, however, analysed as incomplete surveys were not included in the analysis. It is important to highlight that although it appears to be a low return rate, the membership database of the NSW Brain Injury Association was unable to differentiate carer members from persons with ABI, so it is not known how many of the 260 surveys reached people with ABI, but it seems clear that it was far fewer than 260. Furthermore, membership of persons with ABI and carers at the time of survey was reported to be similar, that is, around 130 people with ABI or fewer (D. Frith, personal communication, June 8, 2006). As such, it is difficult to ascertain the precise number of members of the association who were persons with ABI and therefore not possible to provide a definitive response rate, but the results are representative of people with ABI. To ensure the reliability of data analysis, 20% of the data were checked by a doctoral student. Reliability of data was

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checked for correct coding of questionnaire response item and accurate data entry with SPSS Version 11.5 (Chicago, Illinois, USA). Four errors in coding with 96% interrater agreement and six errors in data entry with 94% interrater agreement were found. Consensus ratings were used to correct coding of items where there was disagreement.

Results

Table 1 describes the demographic characteristics of respondents with ABI. More than half of the respondents (44.5%) received varying levels of assistance or facilitation from carers to complete the survey questionnaire form. The degree of assistance to complete the form is unknown. The remaining 22 respondents (35.1%) completed the survey questionnaire forms without assistance. The demographic characteristics are shown in Table 1, which reveals that they were typically middle-aged men of English-speaking background who were married or in a relationship, unemployed, and with varied levels of education.

Fifty respondents (80.6%) indicated they sustained TBI (e.g., motor vehicle accident or other types of injury to the head) and 19.4% specified they sustained non-TBI (e.g., stroke, alcohol-related or hypoxia at birth). The number of years since injury ranged from 1 to 50 years with a median of 14 years. Thirty-five respondents (56.5%) indicated that they had spent more than 7 days in coma, seven respondents (11.3%) had spent between 1 and 7 days in coma, six (9.7%) were in coma between 1 and 23h, and four (6.5%) had been in coma for less than an hour. The remaining 10 respondents (16.6%) did not complete the questionnaire as it was not applicable to them or they were unable to recall. Therefore, more than two-thirds of the respondents had been in coma for more than a day and slightly more than half had been in coma for longer than 7 days.

Table 2 presents the level of disability and current overall level of dependency of respondents. Respondents were asked to rate the level of disability as told to them by a medical specialist. They were also asked to self-rate their current experience of overall dependency as defined in the questionnaire.

The definitions for level of dependency as used in the questionnaire were based on the Australian Institute of Health and Welfare (1999). Five levels of current dependency, ranging from total dependency to independent living, were defined as follows. ‘Total dependency’ indicates the need for 24-h care, ‘moderately dependent’ was defined as ‘where personal help or supervision is required in some tasks’, ‘somewhat dependent’ was defined as ‘where no personal help or supervision is required but has difficulty performing one or more tasks’, and ‘mildly dependent’ is defined as ‘where no personal help or supervision is required and there is no difficulty in performing specified tasks, but the person needs an aid or has a mild mobility difficulty or cannot easily pick up an object from the floor’. ‘Independent’ was defined as ‘not

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Number of persons with ABI (%)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education level</td>
<td>Less than year 10 School</td>
<td>21 (9.5)</td>
</tr>
<tr>
<td></td>
<td>Scholarship certificate/completed year 10</td>
<td>39 (19.4)</td>
</tr>
<tr>
<td></td>
<td>High school certificate/completed year 12</td>
<td>6 (2.9)</td>
</tr>
<tr>
<td></td>
<td>TAFE/Diploma/Technical diploma</td>
<td>17 (7.9)</td>
</tr>
<tr>
<td></td>
<td>University qualifications</td>
<td>7 (3.2)</td>
</tr>
<tr>
<td></td>
<td>No response</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Geographical location</td>
<td>Metropolitan</td>
<td>48 (22.6)</td>
</tr>
<tr>
<td></td>
<td>Regional or rural</td>
<td>22 (10.7)</td>
</tr>
<tr>
<td></td>
<td>Remote or very remote areas</td>
<td>5 (2.2)</td>
</tr>
<tr>
<td></td>
<td>Other (e.g., ACT)</td>
<td>2 (0.9)</td>
</tr>
<tr>
<td>Living arrangement of person with ABI</td>
<td>Alone without support</td>
<td>4 (0.5)</td>
</tr>
<tr>
<td></td>
<td>With my family who support me</td>
<td>18 (8.5)</td>
</tr>
<tr>
<td></td>
<td>With my family who receive help</td>
<td>3 (1.5)</td>
</tr>
<tr>
<td></td>
<td>Shared accommodation with paid carers</td>
<td>5 (2.3)</td>
</tr>
<tr>
<td></td>
<td>Alone with support from paid carers</td>
<td>4 (0.4)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Level of disability</th>
<th>Persons with ABI (%)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>8</td>
<td>17.9</td>
</tr>
<tr>
<td>Moderate</td>
<td>15</td>
<td>33.3</td>
</tr>
<tr>
<td>Severe</td>
<td>28</td>
<td>60.0</td>
</tr>
<tr>
<td>Not known</td>
<td>4</td>
<td>8.4</td>
</tr>
<tr>
<td>Current overall level of dependency</td>
<td>Totally dependent</td>
<td>16 (25.9)</td>
</tr>
<tr>
<td></td>
<td>Moderately dependent</td>
<td>23 (37.1)</td>
</tr>
<tr>
<td></td>
<td>Somewhat dependent</td>
<td>11 (17.7)</td>
</tr>
<tr>
<td></td>
<td>Mildly dependent</td>
<td>3 (4.8)</td>
</tr>
<tr>
<td></td>
<td>Independent</td>
<td>8 (12.9)</td>
</tr>
<tr>
<td></td>
<td>No response</td>
<td>0 (0.0)</td>
</tr>
</tbody>
</table>
requiring personal support and supervision'. Nearly all the respondents with ABI (98.6%) self-rated themselves to be 'totally dependent' to 'somewhat dependent' based on these definitions.

It is interesting to note that the self-rating of a high level of dependency is similar to the results regarding number of days people with ABI were in coma. Logistic regression was used to examine the relationship between level of dependency and number of days in coma by classifying the variables into two groups: total and moderate dependency together and somewhat, mild and independent as another; versus less than 24 h as a group, and more than 1 day in coma, and more than 7 days as another. The results indicate that respondents were four times more likely to be totally or moderately dependent if they were in coma for more than 7 days (odds ratio 4.0; confidence interval CI 1.2-14.0; \( P = 0.024 \)). Available research evidence is consistent with this finding and indicates a correlation between number of days in coma and level of dependency (Doyle et al., 2001; Egh et al., 2002).

Access to other types of support services (including respite)

Forty-three persons with ABI (69.4%) indicated they were receiving support services at the time of the survey and 19 persons (30.6%) were not receiving any services. Table 3 presents the types of support services currently received by respondents. It is important to note that a person with ABI might have been accessing more than one support service. Respondents were continuing to use support services, with case management, medical and physiotherapy support being the three main types of service being accessed. This was followed by 'other' and respite services (19.4%). 'Other' support services included peer support and training in independent living skills. Although respite were not used by the majority of respondents, it seems that it is still an important service as it was the fifth highest support service accessed by respondents. Traditionally, recreation and peer support are not perceived as respite. Services such as recreation and peer support, however, could be defined as respite by the research literature reviewed or at least can be considered to have a 'respite effect'.

The relationship between use of support services (including respite) and demographic characteristics

The sample size for respite use was too small for any meaningful analysis. As such, respite and use of other support services were combined to determine the relationship between the use and nonuse of support services (e.g., medical, allied health, return to work) including respite, and demographic characteristics of persons with ABI (e.g., sex, age, marital status, education level, employment status). The coding for the dependent variable, receipt of support service including respite was 1 = access and 0 = no access, that is, 'Yes' or 'No'. The demographic data were either pooled together or collapsed into groups. For example, the results on overall level of dependency were collapsed into three groups (comprising of total/moderate dependency, somewhat/ mildly dependent and independent). Full-time and part-time employment was grouped versus unemployed and student status. The univariate relationships are presented and only demographic characteristics that were significant are reported. The variables that were significantly related to the person's access to support services including respite under univariate analysis were:

1. Received help in completing survey (odds ratio 5.66; 95% CI: 1.76–18.23; \( P < 0.003 \)).
2. Employed/student status versus full-time/part-time employment (odds ratio 7.09; 95% CI: 1.79–28; \( P < 0.004 \)).
3. More than 7 days in coma versus less than 1 h in coma (odds ratio 14.30; 95% CI: 1.26–164.35; \( P < 0.034 \)).
4. Severe disability versus mild disability (odds ratio 10.00; 95% CI: 1.69–93.31; \( P < 0.029 \)).

The results indicate that if a respondent had assistance to complete the survey, they were 5.7 times as likely to be receiving support services. If the respondent was unemployed or a student, they were 7.1 times as likely to be receiving support services. Being in coma for more than 7 days and severe level of disability were significantly related to access to support services including respite.

The multivariate relationship between overall level of dependency and use of support services, including respite, was analysed using logistic regression with both forward and backward selections, which resulted in the same model, with a single predictor variable: total/moderate dependency versus independent (odds ratio 20.8; 95% CI: 3.2–130.0; \( P < 0.001 \)).

Table 3: Types of support services currently used

<table>
<thead>
<tr>
<th>Type of service</th>
<th>Received by persons with ABI (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respite service</td>
<td>19 (6.4)</td>
</tr>
<tr>
<td>Special education</td>
<td>4 (0.8)</td>
</tr>
<tr>
<td>Recreational support</td>
<td>11 (17.3)</td>
</tr>
<tr>
<td>Case management/Service coordination</td>
<td>30 (22.3)</td>
</tr>
<tr>
<td>Return to work and employment support</td>
<td>7 (11.3)</td>
</tr>
<tr>
<td>Speech pathology</td>
<td>6 (9.7)</td>
</tr>
<tr>
<td>Occupational Therapy</td>
<td>5 (8.1)</td>
</tr>
<tr>
<td>Physiotherapy</td>
<td>13 (19.4)</td>
</tr>
<tr>
<td>Behaviour management support</td>
<td>4 (6.5)</td>
</tr>
<tr>
<td>Medical support (e.g. attendance at clinic)</td>
<td>18 (29.5)</td>
</tr>
<tr>
<td>Other</td>
<td>14 (22.6)</td>
</tr>
</tbody>
</table>

Abb: acquired brain injury.

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that they were unable to access sufficient respite service at any time. Further analysis was undertaken regarding the perception of whether they were receiving sufficient respite (i.e. from those who were using respite) and demographic characteristics. Fisher’s exact test was the appropriate test used given the small sample size. The only significant relationship was the number of days in coma versus less than 7 days in coma. The number of days in coma related to whether the respondents perceived that they were receiving sufficient respite ($p = 0.033$). That is, 45% of the respondents who were in coma for more than 7 days perceived that they were receiving sufficient respite compared with 8% of those who were in coma for less than 7 days, suggesting that people with more severe disability were more likely to consider that they received enough respite. This may indicate that respite services were more readily available to people with more severe disability.

Factors reported to influence respite use

From a list of 19 items, respondents were asked to rate on a five-point Likert scale how important certain factors (such as the level of challenging behaviour, carer stress level, or severity of disability) might be in influencing their use of respite. The 10 most important factors thought to influence respite use were: caregiver needs own time (74%); stress level of carer (73%); level of severity of person with disability (69%); unexpected situations, for example, other family member needing medical attention (69%); person with ABI needs break from carer (69%); poor health of carer, spouse or family member (68%); carer needs time to spend with spouse and/or family (68%); person with ABI needs experience outside carer or family (68%); personal day-to-day stress level of carer (64%); and dependency of person on carer (63%). The results indicate that respondents considered factors that related to stress level and needs of carer and/or family members, and their disability needs as most important.

The relationship between factors reported to influence respite and access to support services was investigated using logistic regression. The factors that were rated as important to very important were coded and analysed. No relationship existed between access to support services (including respite) and any of the factors reported to influence respite use. Although not significant, there was some evidence for level of challenging behaviour (odds ratio 0.35; 95% CI 0.11–1.00; $p = 0.09$). The result indicates that there were fewer odds of receiving a support service if the person had challenging behaviours, but this trend did not quite attain statistical significance.

Expectations of respite

Respondents were asked to rate on a five-point Likert scale how important certain expectations of respite were to them from a list of 24 items. The 10 most important expectations were: offer wide range of activities (66%); have trained and qualified staff and/or volunteers (82%); provide a homely environment (82%); sufficient funding for respite allocation (81%); recruit appropriate staff and volunteers (81%); a more flexible respite service (79%); have emergency beds or funds readily available (79%); a wider range of services for families (77%); and respite services close to home (77%). The results indicate that the expectations of respite by persons with ABI related to direct service delivery and how those services meet their personal needs and preferences. Organizational or ‘government’ expectations related to training, recruitment, and funding were rated as less important.

Satisfaction with respite services

People with ABI who have used respite services previously ($n = 57$) were asked to rate their level of satisfaction with respite services, either provided by government ($n = 36$) or non-government organizations ($n = 27$) on a five-point Likert scale of ‘very dissatisfied’ to ‘very satisfied’. Nearly all respondents (80%) found government respite to be satisfactory to very satisfactory (very satisfied 27%; quite satisfied 30%; satisfied 23%). More than half of the respondents (65%) found non-government respite to be satisfactory to very satisfactory (very satisfied 44%; quite satisfied 15%; satisfied 22%). In general, it can be argued that most respondents were satisfied with respite from government and non-government organizations. Still there is a need to understand a small proportion of those who were not satisfied with government (20%) and non-government (35%) respite. None of the respondents provided further information on their satisfaction or dissatisfaction with respite services to explain the reasons for their (dis)satisfaction.

Ten most important other support needs identified

Respondents were asked to rate on a five-point Likert scale how important support needs were from a list of 20 items. The 10 most important needs were: more information and help about other services (85.5% of respondents rated this item as ‘quite’ to ‘very’ important); case management (75.9%); medical or health care advice (71%); help in planning services for the future (69.4%); holiday schemes (64.5%); respite services at home (61.3%); help in school and employment (58.1%); for me to socialize with other people with ABI (55.7%); transport (57.4%); and therapy services (56.5%). Most persons with ABI want many services as important, indicating that they require a number of continuing services. In relation to respite-type services, persons with ABI indicated a strong preference for holiday schemes and respite at home.

Discussion

This is the first study that presents the perspective of persons with ABI on respite. A key aim of the study was to describe the characteristics of persons with ABI who
were accessing or not accessing respite and/or other support services. The study demonstrated the continuing need for support services including respite. The data characteristics of the study sample were consistent with the Australian research on people with ABI (Australian Institute of Health and Welfare, 2003; Chan, 2007) regarding several demographic characteristics such as sex, age, and type of injury sustained. Men (69.4%) accounted for the majority of respondents and were mainly young to middle aged (median age 38 years). Nearly all of them (80.6%) were TBIs. Findings are consistent with the Australian prevalence rate of ABI-related disability, which is higher for males (1.5%) than females (0.9%) (Australian Institute of Health and Welfare, 2003). Males accounted for 70% of TBI and 60% of individuals with TBI were people of working age (i.e., aged 15–64 years) (Fortune and Wen, 1999). The majority of the respondents (91.9%) was reported as being from an English-speaking background, which is similar to the Australian study (84% reported as being born in an English-speaking country) (Australian Institute of Health and Welfare, 2003).

Many of the participants continued to live with their family who supported them and relied on their families to support them (Chan, 2007). This finding is consistent with the trend in Australia where increasing numbers of people with disabilities are living in a family home (Australian Institute of Health and Welfare, 2003). In Australia, 85% of people with ABI lived in households rather than in supported accommodation (Australian Institute of Health and Welfare, 2003). More than half of the participants reported a high level of disability and overall dependency level, and the results of both these variables were similar to the number of people who reported that they had been in coma for more than 7 days. The majority of Australians with ABI (73.4%) reported a severe or profound level of dependency (Australian Institute of Health and Welfare, 2003). It is interesting to note that majority of people with ABI (71.8%) in this study continued to be in a relationship, whereas other studies reported breakdown of relationships (Perlitz et al., 1999). This may reflect an overrepresentation of people with ABI who had someone to help them complete the study in the study.

The support needs of people with ABI are long term, with 69.4% indicating that they were still accessing support services many years postinjury (median number of years postinjury was 14). Of those who were accessing support services, 19.4% were currently using respite. The finding is similar to the study by Chan (2007), who found that 80.6% of carers were accessing respite. Slightly more than half of the respondents (53%) reported that they were unable to access sufficient respite service at any given time. Of those 53%, only 8% who were in coma for less than 7 days felt they were receiving enough respite, whereas 45% of those who were in coma for more than 7 days perceived that they were receiving sufficient respite. This difference may indicate that respite services are rationed, with a larger amount of respite being granted to those with more severe disability (although the survey did not evaluate this issue directly). The fact that the majority of respondents reported that they were receiving insufficient respite echoed many of the findings on the continuing unmet needs of people with ABI as a result of the long-term impact of their disability (Fortune and Wen, 1999; Hoofnagle et al., 2001; Tate et al., 2003; Colantonio et al., 2004; Corrigan et al., 2004; O’Neill et al., 2004; Chan, 2007; Picklesimer et al., 2007). Hence, the data reiterate the findings of previous studies showing the need for continuing support services for people with ABI long after discharge from rehabilitation into the community. This study is the first in the ABI literature that examined the unmet need for respite as perceived by the people with ABI. Slightly more than half the respondents stated that they were unable to access sufficient respite.

Given the high level of overall dependency and high level of disability in more than half of the respondents, respite may well be an unmet need that should be addressed urgently (Chan, 2007). Fortune and Wen (1999) found that people with ABI generally had insufficient access to a range of services, including respite. The respite literature in developmental disability reveals that the stress level of carers is an important factor in predicting respite use or nonuse (Chan and Sigafoos, 2000).

The expectations of respite reported by persons with ABI are useful when considering guidelines for respite service delivery. The expectations of respite are similar to carers’ views (Chan, 2007). Respondents indicated the need for a wider range of respite, a service that is close to home and more flexible services. They also placed importance on having qualified respite staff. Respite service providers and organizations need to consider these expectations so that care and service delivery take into account consumers’ personal preferences. The need for respite care to be close to home is a particular concern for persons with ABI.

Respite service planning needs not only be sensitive to the cultural and religious beliefs of recipients of respite (Cottrell et al., 1997), but also needs to provide equity of service to diverse cultural groups. Very low representation of people from non-English-speaking background or indigenous Australians among participants in this study was observed, with the majority of the respondents (92%) in this survey being from English-speaking background, even though translation from the English-language survey into other languages was available when it was requested. Although challenging behaviour had no significant association with respite use (albeit not statistically

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significant), there was evidence that a nonsignificant trend \( (P = 0.06) \) that a person with challenging behaviors would be less likely to receive support services and respite.

Little is known about the benefits and impact of respite on recipients, that is, for people with ABI. Slightly more than half of the respondents in the study indicated a need to have a break from the carer or family (69.4%) and the need to have some experience outside the carer or family (60%). Future research should examine and measure the impact of respite on the recipients of respite care. Inappropriate, poor-quality and insufficient respite can negatively impact on the quality of life of people receiving such care (Consellet al., 1997).

Sixty-one percent of respondents indicated respite as one of 10 most important support services they require, and 53% indicated that they were unable to access sufficient respite. Respite is an emerging support need in the field of ABI. Hence there is a need to increase the awareness of and information on respite services to persons with ABI and their carers (Sample and Langlois, 2005). Improving access to information about respite and other related support services is essential so that people with ABI and their carers can be linked to appropriate services (Sample and Langlois, 2005). The need for more information and help about other services was rated as the most important other support service by 66% of the respondents in this study. The lack of awareness of and difficulty in accessing respite service information are not peculiar to the field of ABI (Consellet al., 1997; Treneman et al., 1997). It appears that although respite is an important support service for the person, it may not be widely known and accessed (McConkey, 2005). Therefore, it can be surmised that the need for respite is growing as more people find out about this service.

Several limitations in this study have been observed. First, the sample size \( (n = 62) \) was too small and the response rate was too low to allow for generalisation of its findings. Second, the study is limited to NSW and hence the findings need to be carefully considered it generalizing it to other localities because access issues or lack of information may differ from state to state, or from country to country. Self-selection of respondents meant that the sample could well have been biased towards (a) people with mild disability who could complete the survey independently, and/or (b) people with live-in carers (e.g., family) who could help them complete the survey. A further limitation was that there were no objective data about the amount of respite use, only participants’ reports of use or nonuse were available. Analysing the amount of respite actually used will be important in future studies of respite and people with ABI. Despite its limitations, this study is the first of its kind in the respite and brain injury literature to consider what persons with ABI need and expect from respite and other support service providers.

The study highlights three key issues that merit further investigation. First, development of a measurement tool that reliably ‘predicts’ need for respite use to assist in allocating respite resources fairly. Certain characteristics of persons with ABI were significantly related to respite and support services in this study. Similarly, the perception of persons with ABI of factors influencing respite use provides the preliminary framework for future research to aid service planning and development, resource allocation and policy development. Second, increased provision of respite is needed to address the unmet need for respite identified in this study. Increasing awareness and information about support services such as respite available to various groups of people with ABI is important for appropriate linkages to services to take place. Third, researchers should examine the impact of respite in terms of benefits experienced by persons with ABI and its impact on their quality of life. Although respite seems to provide relief from caring and mediate stress level of carers, little is known about its impact on recipients (Chan and Sigafoos, 2001). This impact needs to be evaluated in terms of its immediate effect (i.e., after receipt of respite) and over a period of time to understand the longitudinal effects of respite on the quality of life for the person. The paucity of such studies highlights the importance of considering the perspectives of people with ABI in service planning and development.

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References


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CHAPTER TWELVE

Summary of the Findings of the Study

While respite is well researched in the area of developmental disability, in aged care and mental health; there is minimal research in the area of acquired brain injury. Prior to the current research, there is no profile of respite service provision in New South Wales and whether it is meeting the needs of carers. There is also no research to date on the perspectives of persons with acquired brain injury and their families or carers regarding respite. To address these questions, survey methodology was used to gather data from persons with acquired brain injury and carers who were members of a peak brain injury association in New South Wales, and from respite providers who were members of the peak respite association. The results of the study are presented in the preceding chapters (Chapters 9, 10 and 11) that have been published or are to appear in the international peer-reviewed journals indicated. These three chapters present separately the findings concerning respite providers (Chapter 9), carers (Chapter 10) and people with acquired brain injury (Chapter 11). In this chapter, the key results of the study in the preceding chapters are drawn together and compared. This chapter also presents other results that did not appear in the published papers.

The relationship between characteristics of persons with acquired brain injury and carers, and respite provision

The characteristics of persons with acquired brain injury and their carers who participated in this study appear consistent with research in the acquired brain injury literature. For example, the majority of carers of people with acquired brain injury were
women (74.0%) and the majority of people with acquired brain injury were males (69.4%) (AIHW, 2003; Damiani et al., 2004; Harris et al., 2001). The results of the study reiterated previous findings that the needs of people with acquired brain injury post-injury and their carers were long term with 64.7% of carers (Chapter 10) still accessing a range of support services (48.2% has accessed respite in the past year). The majority of people with acquired brain injury (69.4%) indicated that they were still accessing support services many years post-injury (median number of years was 14) (Chapter 11).

Several characteristics of persons with acquired brain injury were found to be significantly associated with the use of respite. There was a significant relationship between respite provision and being in coma for more than 7 days. If a person being cared for were in coma for more than 7 days then the carer was 5.5 times as likely to use respite as carers of persons with less than 7 days in a coma (Chapter 10). Similarly, persons with acquired brain injury were 14.5 times as likely to access other support services (including respite) if they had been in a coma for more than 7 days (Chapter 11). There was strong evidence that greater dependency level (total and moderate versus mild) was related to respite use as reported by carers (Chapter 10). Likewise, if a person with acquired brain injury received help in completing a survey, they were 5.7 times as likely to be receiving support services including respite (Chapter 11). The level of severity of disability was significantly related to access to support including respite among persons with acquired brain injury (Chapter 11) and there was some evidence that severity of disability was also related to respite use, with carers supporting a person with severe and profound disability being likely to use respite than those with mild and moderate disability (Chapter 10).
Comparison of the Ten Most Important Factors Influencing Respite Use.

Table 12.1 describes and compares the 10 most important factors or reasons reported by respite providers, persons with ABI and carers to influence respite use. There were 19 factors that each participant group had to rank, so inclusion of the same factor in the top 10 by several groups represents between group agreement, even if the rank order within the top 10 differs somewhat from one group to another. These factors were developed from the literature review and feedback on the trial questionnaire. There is no research to date in the respite literature and particularly, in the area of acquired brain injury that compares three stakeholder groups’ perspectives on the reported factors influencing respite use.

People with acquired brain injury reported two factors equally in the 10 most important factors, they were family needs a break (63.0%) and dependency on carer (63.0%). These factors are included in the comparative data as they appear as common factors among the three respondent groups.
Table 12.1.

Comparison of the 10 Most Important Factors Influencing Respite Use.

<table>
<thead>
<tr>
<th>Rank</th>
<th>Respite Provider (%)</th>
<th>Person with ABI (%)</th>
<th>Carer (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Personal day – day stress level of carer (93.3)</td>
<td>Carer needs own time (74.0)</td>
<td>Person with BI need experience outside carer (72.9)</td>
</tr>
<tr>
<td>2</td>
<td>Poor health of carer, spouse or family (93.3)</td>
<td>Stress level of family member/carer (73.0)</td>
<td>Personal day – day stress of carer (67.1)</td>
</tr>
<tr>
<td>3</td>
<td>Potential family break-up or other family problems (91.0)</td>
<td>Level of severity of person with disability (69.0)</td>
<td>Stress level of family members/carers (64.7)</td>
</tr>
<tr>
<td>4</td>
<td>Stress level of family members/carers (90.0)</td>
<td>Unexpected situations, e.g. other family members needing medical attention (69.0)</td>
<td>Person with BI may need a break from family/carer (63.5)</td>
</tr>
<tr>
<td>5</td>
<td>Level of challenging behaviours (84.4)</td>
<td>Person with BI may need a break from family/carer (69.0)</td>
<td>Family needs a break from person with BI (62.4)</td>
</tr>
<tr>
<td>6</td>
<td>Need some time to spend with spouse/family (76.7)</td>
<td>Poor health of carer, a spouse or family (68.0)</td>
<td>Level of severity of disability (58.8)</td>
</tr>
<tr>
<td>7</td>
<td>Dependency of person (level of care required) (75.6)</td>
<td>Carer need some time to spend with spouse/family (68.0)</td>
<td>Need some time to spend spouse/family (57.6)</td>
</tr>
<tr>
<td>8</td>
<td>Family needs a break from person with BI (74.4)</td>
<td>Person with ABI need experience outside carer/family (68.0)</td>
<td>Need some time for self (56.5)</td>
</tr>
<tr>
<td>9</td>
<td>Person with disability needs experience outside carer (72.2)</td>
<td>Personal day – day stress level of carer (64.0)</td>
<td>Dependency of person with BI on carer (level of care required) (51.8)</td>
</tr>
<tr>
<td>10</td>
<td>Unexpected situations (72.1)</td>
<td>Dependency of person on carer (63.0)</td>
<td>Poor health of carer, a spouse or family member (51.8)</td>
</tr>
</tbody>
</table>

Comparison of the results indicates that there are 6 factors common across the 3 respondent groups. Table 12.2 presents the common factors reported by the groups.
Table 12.2.

**Common Factors Influencing Respite Use Among Service Providers, Persons with ABI and Carers.**

<table>
<thead>
<tr>
<th>Factor</th>
<th>Respite Provider % (Rank)</th>
<th>Person with ABI % (Rank)</th>
<th>Carer % (Rank)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal day-day stress</td>
<td>93.3 (1)</td>
<td>64.0 (9)</td>
<td>67.1 (2)</td>
</tr>
<tr>
<td>Poor health of carer</td>
<td>93.3 (2)</td>
<td>68.0 (6)</td>
<td>51.8 (9)</td>
</tr>
<tr>
<td>Stress level of family member/carer</td>
<td>90 (4)</td>
<td>73.0 (2)</td>
<td>64.7 (3)</td>
</tr>
<tr>
<td>Dependency on carer</td>
<td>75.6 (7)</td>
<td>63.0 (10)</td>
<td>51.8 (9)</td>
</tr>
<tr>
<td>Family needs a break</td>
<td>74.4 (8)</td>
<td>63.0 (10)</td>
<td>62.4 (5)</td>
</tr>
<tr>
<td>Person with disability need experience outside carer or family</td>
<td>72.2 (8)</td>
<td>68.0 (8)</td>
<td>72.9 (1)</td>
</tr>
</tbody>
</table>

The results suggest a degree of agreement among the three participant groups. The factors influencing respite use appeared to be similar to those reported in the developmental disability literature, such as personal day-day stress level of carer and dependency of the person on the carer (Chan & Sigafoos, 2000). Some differences in the ranking order are noted. Differences in the ranking of the common factors reflect each group’s differing perspective. While carers and respite providers appeared to agree that personal day-day stress as most important (carers rated it as second most important and respite providers rated it as the most important), people with acquired brain injury rated it as ninth most important. This may reflect that the stress of the day-day caring role was more evident for the carers than for the person with acquired brain injury.
Comparison of the 10 Most Important Expectations of Respite Use.

Table 12.3 describes and compares the 10 most important expectations of respite use by the 3 respondent groups from a list of 25 potential expectations of respite.

Table 12.3.

Comparison of 10 Most Important Expectations of Respite Services.

<table>
<thead>
<tr>
<th>Rank</th>
<th>Respite Provider (%)</th>
<th>Person with ABI (%)</th>
<th>Carer (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Recruit appropriate staff and volunteers (94.4)</td>
<td>Offer wider range of activities for person with disability (86.0)</td>
<td>Sufficient funding allocation for respite (85.9)</td>
</tr>
<tr>
<td>2</td>
<td>Sufficient funding allocation for respite (85.6)</td>
<td>Have trained and qualified staff and volunteers (82.0)</td>
<td>Recruit appropriate staff and volunteers (85.9)</td>
</tr>
<tr>
<td>3</td>
<td>Policies relevant to respite (85.6)</td>
<td>Provide a homely environment (82.0)</td>
<td>Offer wider range of activities for person with disability (83.5)</td>
</tr>
<tr>
<td>4</td>
<td>Relevant training for staff and volunteers (84.4)</td>
<td>Sufficient funding allocation for respite (81.0)</td>
<td>Have trained and qualified staff (82.4)</td>
</tr>
<tr>
<td>5</td>
<td>Increase frequency of respite for families who need it (84.4)</td>
<td>Recruit appropriate staff and volunteers (81.0)</td>
<td>Provide a homely environment (82.4)</td>
</tr>
<tr>
<td>6</td>
<td>Respite staff who can manage or implement challenging behaviours program (84.4)</td>
<td>A more flexible respite service (79.0)</td>
<td>Policies that are relevant to family needs (77.6)</td>
</tr>
<tr>
<td>7</td>
<td>Support for staff from senior management or organization (82.2)</td>
<td>Have emergency beds of funds readily available (79.0)</td>
<td>Support for respite staff from senior management or organization (76.5)</td>
</tr>
<tr>
<td>8</td>
<td>Offer wide range of activities for person with disability (73.4)</td>
<td>Have a mixture of male and female staff (79.0)</td>
<td>A more flexible respite service (75.3)</td>
</tr>
<tr>
<td>9</td>
<td>Meet the family’s cultural, religious or dietary needs (72.2)</td>
<td>A wider range of services for families (77.0)</td>
<td>A wider range of services for families (75.3)</td>
</tr>
<tr>
<td>10</td>
<td>Provide a homely environment (71.1)</td>
<td>Respite service close to home (77)</td>
<td>Respite service close to home (75.3)</td>
</tr>
</tbody>
</table>
Table 12.3 indicates that there are 5 common expectations of respite services reported by the respondent groups. The common expectations were recruiting appropriate staff and volunteers, having sufficient funding for respite, having trained and qualified staff and volunteers, offering wider range of services to person with disability, and providing a homely environment. Three expectations that respite providers did not anticipate would be rated as highly by carers and persons with ABI were offering a more flexible respite service, offering a wider range for families and a respite service close to home.

The results suggest that generally respite providers appeared able to recognize many of the expectations of persons with ABI and carers. By the same token it appears that carers appeared able to understand the needs of service providers because carers were also able to consider expectations of service providers on ‘governance’ issues, such as support for respite staff from senior management or the organization (respite providers 82.2%, carers 76.5%) and relevant policies to either the service or families (respite providers 85.6%, carers 77.6%).

Comparison of Other Support Needs of Persons with ABI and Carers

Table 12.4 compares the 10 most important other support needs as reported by persons with acquired brain injury and carers. The 10 most important factors were drawn from a list of 20 potential support needs based on the literature review and feedback on the trial of the draft questionnaire.
### Table 12.4.

#### 10 Most Important Other Support Needs According to Persons with ABI and Carers.

<table>
<thead>
<tr>
<th>Rank</th>
<th>Person with ABI (%)</th>
<th>Carer (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>More information and help about other services (85.5)</td>
<td>Case management (72.0)</td>
</tr>
<tr>
<td>2</td>
<td>Case management (75.8)</td>
<td>Holiday schemes for person with ABI (67.0)</td>
</tr>
<tr>
<td>3</td>
<td>Medical or health care advice (71.0)</td>
<td>More information and help about other services (67.0)</td>
</tr>
<tr>
<td>4</td>
<td>Help in planning services for my future (69.4)</td>
<td>Medical or health care advice (66.0)</td>
</tr>
<tr>
<td>5</td>
<td>Holiday scheme for person with ABI (64.5)</td>
<td>Help in planning services for future of person with ABI (65.0)</td>
</tr>
<tr>
<td>6</td>
<td>Respite services at home (61.3)</td>
<td>Help in school or employment (61.0)</td>
</tr>
<tr>
<td>7</td>
<td>Help in school and employment (58.1)</td>
<td>Respite services outside home (60.0)</td>
</tr>
<tr>
<td>8</td>
<td>For me to socialize with other people with ABI (59.7)</td>
<td>Therapy services (60.0)</td>
</tr>
<tr>
<td>9</td>
<td>Transport (57.4)</td>
<td>Clubs or activities outside school or work hours (55.0)</td>
</tr>
<tr>
<td>10</td>
<td>Therapy services (56.5)</td>
<td>Training on how to manage challenging behaviours (49.0)</td>
</tr>
</tbody>
</table>

Persons with acquired brain injury and carers appeared to agree on the need for common services (for carers, it is based on the anticipated service needs of the person they are caring for). Both respondent groups reported requiring continuing services such as more information and help about other services, case management or service co-ordination, help in planning future services, and medical or health-care advice. Issues specific to the person with acquired brain injury included respite care in terms of holiday schemes, and clubs or activities outside school or work hours. Persons with acquired brain injury
indicated a preference for respite at home, whereas carers indicated outside the home environment.

*Can Respite Providers Meet the Needs of Persons with Acquired Brain Injury and their Families or Carers?*

The study provides a first comprehensive descriptive profile of and information on respite services in New South Wales. The results indicated that the majority of respite providers were non-Government service organizations (78.9%), followed by 12.2% of these service organizations that are identified as ‘Other’ (i.e., defined as a mixture of charity/private and Government funding), 7.8% identified as Government service organizations, and only 1.1% identified as a private-for-profit respite service provider. Although the majority of respite service providers were non-Government service organizations, Government funding (Federal and/or State Government) accounted for 71.1% of the funding of respite services. Respite in New South Wales is provided to all age groups and is available in most geographical regions. Respite services typically serve a wide range of disability types, such as, persons with developmental disability (e.g., autism, cerebral palsy or Down syndrome), with acquired disability (e.g., brain injury) and persons who have other conditions such as chronic health conditions or mental illness. There was only one brain-injury specific respite service. Hence it is common for people with acquired brain injury to be receiving respite from a provider who catered to a wide range of disability types.

There is also a variety of respite models being provided that are consistent with the research evidence, such as ‘home-based’ respite (65.6%); ‘holiday camps or day
excursions’ (62.2%); ‘emergency respite’ (60.0%); ‘out-of-home placement’ (58.9%) or ‘regular day programmes’ (36.7%). Only one service organization (1.1%) identified ‘foster-care’ as a model of respite service. Models of respite that focused on family support include ‘family support’ (such as support groups) (15.6%) and training or teaching of families (10.0%). Other models of respite service provision that benefit both the person with a disability and the carer or family member(s) are ‘use of volunteers’ (55.6%), ‘information giving/resource sharing’ (38.9%); ‘training of volunteers’ (36.7%); ‘service co-ordination/case management’ (31.1%); ‘loan of equipment’ (15.6%); ‘financial assistance’ (10%); and ‘counseling by trained professionals’ (10.0%).

An additional question was asked of respite providers in the study specific to services to persons with acquired brain injury that was not reported in Chan (in press) (Chapter 11). Fifty-five service providers (61.0%) responded to a question that specifically asked whether the service provided respite to people with acquired brain injury over the past year. Of these providers that had provided respite to people with acquired brain injury, only 10.1% of respite was provided to people with acquired brain injury over the past year. Only one provider indicated its respite was specific to people with acquired brain injury. Only 12 persons with acquired brain injury (19.4%) accessed respite services at the time of the survey during a 12-month snapshot year.

**Brief Analysis of Respondents’ Responses to an Open-ended Question**

Twenty carers (23.5%) responded to the final open-ended question in the survey, on any other issues or concerns on which they might wish to elaborate. Given the small number of responses, some of the responses were collapsed into a broader theme on
'general respite' issues. There were 13 comments regarding respite, mostly the comments (n = 8) related to ‘unavailability of respite’. The comments are as follows:

When we required respite 10 years ago there were none available or no information around………very limited for mild ABI…more so in the country.

It has been a battle to have a service provided that is reliable. It had been the cause of so many bad feelings within the family.

I wish I had been able to receive funding earlier prior to 2002 as it would take some pressure away from being a full-time carer.

I would find trying to find appropriate respite services in the city extremely difficult as they are non-existent in the district and rural areas.

Other issues raised by carers included the need for more information and increasing the types of respite service available. There were two responses regarding the future of the person with ABI from an aged carer. An example of a response on the anxiety about the future is best summarized in the following quote from an aged carer:

We wonder where in the country do our sons and daughters go when we die…we know nursing homes for young people with ABI are not the answer.

Carers of persons with acquired brain injury have highlighted a lack of the availability of respite in this study. Respite is also one of a range of unmet needs in Australia for carers supporting persons with life-long disability (AIHW, 2002; AIHW, 2007; Hughes, 2007; Spicer, 2007). Therefore the lack of respite for people with acquired brain injury is in the
context of a general shortfall of respite services regardless of the disability type. Although there is an apparent lack of respite service specific to acquired brain injury, it may be argued that non-specific respite provision can meet the needs of persons with acquired brain injury and their carers. This argument is based on the extensive experience of providers; the wide variety of respite models; the training provided to staff and the commitment to flexible respite options. The results indicated that many respite service providers have many years of service provision in the industry. Nearly all respite service providers (n = 81, 90%) have established their services for more than four years and half of respite service providers have been in service for more than 10 years (55.6%). Furthermore, there appear to be some common expectations of respite among persons with acquired brain injury, carers and respite providers. It appears that respite providers do understand and can anticipate and share the expectations of respite of persons with acquired brain injury and their carers. Hence it can be argued that respite providers in New South Wales can meet the needs of persons with acquired brain injury and their carers. Even so, training specific to acquired brain injury is highly recommended to respite providers to better equip staff. Further discussion of the implications of the study on practice, service delivery and research will be presented in the next chapter.
CHAPTER THIRTEEN
Discussion and Conclusion

This study provides the first comprehensive mapping of respite services in New South Wales. It is the first study that examines respite services in the area of acquired brain injury and more importantly, it presents the perspectives on respite of persons with acquired brain injury and carers. In the previous chapter these perspectives were compared with respite providers’ views. The findings of the study have important implications for the resiliency model of family adaptation, policy development, practice and service provision, and research. The potential implications of the study are discussed in this section. Many of the implications proposed go beyond the research data to take account of the current service delivery and policy environment in Australia.

Implications for the Resiliency Model of Family Adaptation

The findings of the study have several implications for the resiliency model of family adaptation (Kosciulek, 1993) described in Chapter 3. The model recognised that families did not only deal with the catastrophic event of the acquired brain injury and its impact, but also deal with a series of pile-up stressors, such as the severity of disability following the injury or the level of care required; and that these stressors are experienced over a period of time. Kosciulek (1993) proposed three potential resources available to the family to adapt to the stressor of acquired brain injury. They are the resources available to the family, the family working as a cohesive unit, and community resources. It was proposed that respite as a community and social support can play a role in acting as a
buffer against the continuing demands of acquired brain injury, and as a positive family adaptation to a catastrophic event.

The findings of the present study confirm previous research and the resiliency model regarding the continuing and long-term needs of people with acquired brain injury and their carers; particularly for respite (Chan, 2007; Hodgkinson et al., 2000; Serio et al., 1995; Stebbins & Leung; 1998). There is a lack of appropriate service and support for persons with acquired brain injury after their rehabilitation (Pryor et al., 2000). Many people with acquired brain injury in this study (69.4%) indicated that they were still accessing support services many years after their injury (Chapter 11). Of those accessing support services, 19.4% were using respite (Chapter 11). Similarly, carers of people with acquired brain injury indicated that they were still accessing a range of support services (64.7%), with 58.3% of them still accessing respite at the time of the study (Chapter 10). Hence according to the model and as shown in the present study, families not only deal with the catastrophic event but experience the impact over time.

The findings of the study also confirmed that families have to deal with certain “pile-up stressors”, factors such as severity of disability, length of time spent in coma and the level of dependency of the person with a disability (Chapters 10 and 11). In this study, these factors were associated with the use of respite. The findings of the study from the 3 participant groups further confirm the model regarding several common factors that might influence use of respite. The common factors related to personal day-day stress of the carer and dependency of the person on the carer.
Respite is discussed in the earlier chapter as a community resource and social support that families can draw upon to better adapt to the acquired brain injury (Kosciulek, 1993). It is important to highlight that the findings of the present study do not provide evidence that respite may reduce family stress or act as a resource to positive family adaptation over time. However, the findings of the study do highlight potential factors that may better inform future research into the area of respite: several demographic factors associated with respite use, reported factors that might influence respite use and expectations of respite. These may provide guidance in planning responsive community resources and social supports to enable positive family adaptation to acquired brain injury. The findings of the study also provided information regarding other support services that people with acquired brain injury and their carers require, such as more information; case management or service co-ordination (Chapters 10 and 11). Such information assists in defining the types of resource and social support required by families to positively respond to the demands of acquired brain injury. How families can be better supported in caring for a person with acquired brain injury is discussed in implications for policy development and practice.

Implications for Policy Development

There are strong arguments for the economic benefits to governments through the provision of care and support provided within the family (Cummins, 2001; Jeon et al., 2007). Given the benefit that governments derive from families continuing the care and support to persons with acquired brain injury, it is critical for a government-led policy of increasing respite to families of persons with acquired brain injury. The implications for policy development will focus on unmet respite needs and several ideas for policy
Meeting Unmet Respite Needs

According to the Australian Commonwealth State and Territory Disability Agreement (CSTDA) 2004 – 2005 report on types of services funded, there are 143 respite service outlets and 4,129 service users of respite (with all types of disability) in New South Wales (each ‘outlet’ represents one location but several outlets can be provided by the same provider) and 709 respite service outlets across Australia (AIHW, 2007). Funding for respite across Australia makes up 8% ($196.7 million) of the total CSTDA funding for disability services reported to be $3.6 billion. Funding for respite services in New South Wales is $65.6 million. It is important to note that these figures pertain to services that are funded by Commonwealth and State governments under the CSTDA. It does not reflect other private services, such as for-profit organizations or local community co-operatives. Nor does it include community services funded under the federal Home and Community Care (HACC) program.

There was an increase in the number of service users who accessed respite from 9,141 to 11,103 service users nationally for the period 2004 - 2005. The CSTDA report also indicated that 53% (n = 84,964) of service users (users of all types of disability services) depend on an informal carer and 9% of these carers are aged 65 years and above. As such, there is clearly still a reliance on informal carers to fulfill the role of care-giving and support. According to the Australian Institute of Health and Welfare (2007), a
A conservative baseline estimate of the number of people with unmet demand for accommodation and/or respite services in 2005 is 27,800. Unfortunately no data are available to show how many persons with acquired brain injury are represented among the number of service users accessing respite, but it seems reasonable to assume that people with acquired brain injury are proportionally represented among the 27,800 who need but do not receive accommodation and/or respite services.

Despite the increase in the number of service users accessing respite, respite continues to be an unmet need for persons with acquired brain injury (AIHW, 2002; Chan, 2007; Pickelsimer et al., 2007; Rotondi et al., 2007) and for people with other types of life-long disability (AIHW, 2007; Hughes, 2007; Spicer, 2007). There is only one acquired brain injury specific respite in New South Wales and only 10% included persons with acquired brain injury in their service (Chapter 9). While there is an apparent lack of respite for persons with acquired brain injury, it is not within the scope of this study to argue for respite specific for people with acquired brain injury. Rather it can be argued that there ought to be proportionate allocation of respite for people with acquired brain injury within existing respite services by increasing the funding, resource allocation and models of respite services. Creating respite services specific to particular diagnostic groups (for example, specific to people with autism or progressive neurological conditions) may not necessarily translate to access and equity. For example, a carer in a particular geographical area may have to travel further to access a diagnostic specific respite service. Instead the focus should be on increasing capacity and resource allocation of existing respite services to meet the unmet respite needs of persons with acquired brain injury and their families.
Funding flexible respite

There is evidence that respite may delay or circumvent admissions to out-of-home accommodation or other institutional placements (AIHW, 2002; Chan et al., 2001; Koloski & Montgomery, 1995). As such, increased respite for persons with acquired brain injury would enable families to continue the care at home. The development of such a policy could also consider a fee-for-service model as some families appear to be willing to pay for such a service (Chiu et al., 1999). A fee-for-service respite for those who can afford it may generate new services and reduce the waiting list for those who need respite. It may also potentially reduce the competition for limited respite services for carers who really need respite and who cannot afford to pay for it. This is not to suggest that all respite services are turned into a user pays model. Consideration of a fee-for-service respite model ought not to penalize carers who may be unable to afford such a service (Damiani et al., 2004; Spicer, 2007).

Spicer (2007) argued that carers supporting persons with life-long disability already incur increased expenditures related to the disability. Hughes (2007) further elaborates the financial strain of caring. The lack of money and the expenses incurred as a result of caring for a person with acquired brain injury are stressors for carers (Douglas & Spellacy, 2000). Therefore a fee-for-service respite model may present an additional difficulty for such families and carers. As such, a consideration of government policy could include a subsidy to respite providers so those families who may not be able to afford a full fee-for-service respite. The potential of such a scheme is that it will encourage families to seek or purchase respite when required. Government subsidy for respite may generate interests in
the non-government sector such as local community support groups or charities to increase the capacity and availability of respite; particularly in rural and regional areas.

**Funding Portability**

A further consideration for policy is funding portability (Ridley et al., 2004). This approach provides the control of how and when a carer would like to expend funding on respite. Control of the funding by carers may lead to greater service satisfaction (Caldwell & Heller, 2003; Chan & Sigafoos, 2001; Ridley et al., 2004). Family-directed or consumer-controlled service provision is also associated with greater community involvement by the person with a disability (Caldwell & Heller, 2003). Funding portability allows opportunities for carers to choose the types of respite that better suit their needs and those of the person with an acquired brain injury, such as purchase of holiday schemes, and clubs or activities outside school or work hours. Funding portability addresses the expectations of persons with acquired brain injury (79.0%) and their carers (75.3%) for a more flexible respite service (Chapters 10 and 11).

Funding portability also permits carers to access respite service within or outside their geographical area or residence. For example, a carer may be able to purchase respite closer to a grandparent’s or parent-in-law’s home for a period of time, or purchase the service of local community agencies or an informal network. The concept of funding portability could be used by carers to purchase respite directly from people the carer trusts or they may recruit directly (such as friends and neighbours), and as such may alleviate the stress of carers and persons with acquired brain injury as they become confident in their choice of respite providers. This may be particularly important for carers in rural and regional areas.
where availability and access for respite may be limited. For example, a carer in a rural area may use the funding allocated to bring another family member or friend to the rural area to provide respite.

Funding portability also addresses reported expectations of persons with acquired brain injury (77.0%) and carers (75.3%) for a wider range of respite services (Chapters 10 and 11). Funding portability also introduces another innovative feature of respite services, that is, “banking” the allocated respite hours to when respite is most needed by the carer and family. Instead of an allocated time and date for respite, the carer may choose to “bank” or save the respite hours. This concept also allows the carer to use respite when it is most required or suitable rather than be controlled by an allocated respite date and time. It provides the carer greater flexibility to manage her or his schedule. Carers, persons with disability and respite providers highlight the importance of a flexible respite service (Chan, 2007; Chan, in press; Jeon et al., 2007). Funding portability provides for greater flexibility for carers and persons with acquired brain injury.

There is a need for research on respite funding allocation for individual families and persons with acquired brain injury, to underpin an equitable allocation for families and persons with acquired brain injury. The findings of this study in terms of predictors of respite use and non-use may form part of the research. For example, the study indicates that certain person and family characteristics predict respite use or non-use (Chapters 10 and 11; Chan & Sigafoos, 2000). Such information should guide the development of the criteria for priority funding and resource allocation.
It is not within the scope of this study to discuss in detail the appropriate funding models for respite, such as whether it should be based on means-testing of family income or on a needs-based criterion. There are several factors that may form part of the criteria for respite funding and resource allocation. These include equity of access, prevention of potential family breakdown, prevention of early or unplanned permanent out-of-home accommodation placements, encouraging return to employment or studies for the carer and person with acquired brain injury, and promoting the well-being and health of the carer and person with acquired brain injury to circumvent potential health breakdown as a result of caring. Whatever the respite funding model may be based on, funding portability for the carer and care recipient appears to be a practical solution that better suits the needs of the person.

Shared Understanding of a Partnership in Care and Support

It is also pertinent to have a common understanding of the dimensions of care and support from the perspective of carers and persons with acquired brain injury (Dowse, Gill, Webb & Moore, 2003). This research has described the important expectations of respite from three different perspectives, carers; people with acquired brain injury and providers. The common perspectives on the various factors of respite use and expectations of respite could inform the initial development of a shared understanding of care and support. Such an approach in strategic policy direction may remove the stigma of “burden” of care and work toward a shared understanding of care and support (Brown, 2007; Dowse et al., 2003).
The concept of a shared understanding of care and support also means considering carers and persons with acquired brain injury as partners in the provision of respite. A consumer-provider partnership for policy direction has benefits for the carer-caregiving relationship, such as potentially leading to higher service satisfaction and less stress experienced when accessing respite (Caldwell & Heller, 2003; Chan & Sigafoos, 2001). Furthermore, a consumer-provider partnership presents carers and persons with acquired brain injury as proactive participants in addressing their needs, rather than passive recipients of respite. Such a concept builds on the family/carer’s strengths and well-being that in turn can facilitate family resilience in the face of acquired brain injury as a stressor (McCubbin & McCubbin, 1996).

Such a consumer-provider partnership echoes previous Commonwealth government national policy on services for people with acquired brain injury that seeks to include the participation of consumers in the planning, monitoring and evaluation of services (Commonwealth Department of Human Services and Health, 1994). This policy direction also implies that respite services are co-ordinated across various service sectors to facilitate flexibility of service, an issue that will be elaborated in the next section. Social policy in the area of respite needs to focus on enabling a positive carer-care recipient relationship in the home and where there are adequate community resources that carers can rely on.

**Summary**

In summary, in the context of the Australian service delivery and policy environment, the first policy implication of the study is to address the unmet needs of carers and people with acquired brain injury, in terms of access, equity and availability. The policy of
funding portability and its merits have been discussed, specifically for carers. The notion of funding portability is consistent with the findings of this study where persons with acquired brain injury, their carers and respite providers considered as important for respite services to be flexible and innovative. There is a need for respite policy to embrace carers’ perspectives on respite and this shared understanding of care-giving and support ought to guide policy development. This policy direction reiterates previous Government national policy on services for people with acquired brain injury.

Implications for Practice and Service Provision

The present study shows that there are several consistent key elements among the three stakeholder groups that are pertinent to respite practice and service provision. The key findings are flexibility, responsiveness, for respite practitioners to be adequately trained, and where the perspectives of carers and persons with acquired brain injury are included in planning and service provision. The implications for an integrated approach to practice and service provision are discussed and a “spa model” of respite is proposed.

An Integrated Practice-Oriented Framework

An integrated practice-oriented respite framework that embraces the evidence discussed in this study is proposed which uses the available evidence to develop and plan services that are responsive to the expressed needs of the consumers, rather than separately developing each of the individual findings to a particular aspect of respite (Montoro-Rodriguez, Koloski & Montgomery, 2003). The study has highlighted certain carer and person characteristics that influence respite use; there are several common factors that all
respondent groups reported to influence respite use; and several shared expectations among the three participant groups in the study. Such information enables the development and planning of respite services and practice that best meet the needs of all parties (Montoro-Rodriguez et al., 2003). This study has also reviewed the respite literature and identified the issues relating to the impact of caring for a person with acquired brain injury presenting with life-long disability (Chan & Sigafoos, 2001; Chan et al., 2001; Ridley et al., 2004; Spicer, 2007).

The proposed “Spa Model of Respite” will translate the policy implications into practice and service delivery. Furthermore, the “spa model” of respite can play a part in facilitating family resilience and regenerate families’ internal strength and internal locus of control; that is, to focus on family time, routines and well-being in the face of acquired brain injury as a stressor (McCubbin & McCubbin, 1996). A carefully planned “spa model” of respite as a community resource available to the carer/family that views them as partners in the shared care and support builds upon the family’s own personal resources. The family or carer’s personal resources include the skills and knowledge acquired from education and training and well-being that draws upon the positive aspects of caring can create better adaptation to the stressor of acquired brain injury (McCubbin & McCubbin, 1996).

The “spa model” views respite as not simply an isolated episode in a family’s life and time as a “break from caring”. In this context, respite is seen as a responsive and quality social support system that seeks to restore and regenerate family well-being and resilience; where care and support become a positive experience for the carer and person; and hence
scaffolds positive family adaptation to acquired brain injury (Kosciulek, 1993). This model translates policy implications into practice and service delivery, that is, a significant shift from a “burden of caring” model to a positive caregiver-care recipient relationship, and where care and support is a partnership with the provider and aligned with government policy. The following sections will elaborate how the key findings of the study apply to practice and service delivery that will enhance family resilience. It is also acknowledged that the findings of the data do not directly provide the evidence for the implications for practice and service provision. Many of the implications are inferred, taking into account related research and the Australian policy and service development context.

The “Spa Model” of Respite

The proposal is for a “spa model” consisting of a “one-stop shop” respite service. The concept of a “spa” today is to promote the physical and mental well-being for the person who accesses a spa treatment, and includes services to reduce stress and to encourage a positive lifestyle through advice, consultancy or individual programs to suit the needs of the person. The concept of a “one stop shop” is where such services and programs are available in a single service agency or provider, rather than for the person having to seek a service or programs at different locations.

Herman and Marcenko (1997) suggested that when access to respite is problematic or when the interaction with the staff is difficult, use of the respite service may use up more time and energy leading to more rather than less stress for the family. Therefore, access to respite should not be a stressful experience for carers to begin with. Carers need to feel confident and stress-free when trying to organise respite. This means that the entire
experience of accessing respite should be stress-free from the moment a carer thinks he or
she needs respite. Furthermore, carers already experience feelings of guilt when accessing
respite which adds to their stress (Damiani et al., 2004; Neufeld et al., 2001; Ridley et al.,
2004). The “spa model” of respite aims to provide the focus on well-being and is
consistent with the reported needs of carers and persons with acquired brain injury, rather
than simply a ‘break from caring’.

The “Spa Model”: Accessible Information

In the findings of the present study and throughout the literature review carers have
voiced their need for accessible information regarding respite and that such information is
an important starting point in their consideration of respite (Chan, 2007; Chan, in press;
Cotterrill et al., 1997; Jeon et al., 2007; McConkey, 2005; Sample & Langlois, 2005).
McConkey (2007) argued that while respite is an important service for the person it may
not be widely known and accessed. The need for more and better information hence is a
critical factor in promoting the awareness for such a service among carers and people with
acquired brain injury. Information needs to consist of not only the availability and
accessibility of respite but also what types of respite are available (such as in-home respite
or holiday camps), and how convenient it is for carers to contact the respite service.
Information should not only be in print media but also could be in various formats, such as
audio and computer web-based systems. Information also ought to be available in local
and community services.

Accessible information needs to consider the needs of diverse cultural, religious and
linguistic groups (Chan, in press; Cotterrill et al., 1997; Niemeier & Arango-Lasprilla,
The present study (Chan, in press; [Chapter 9]) found that the majority of the respite services in New South Wales tended to cater to people from an English-speaking background. People from diverse cultural and linguistic backgrounds may not necessarily be able to navigate the complex social system (Montoro-Rodriguez et al., 2003; Niemeier & Arango-Lasprilla, 2007). Niemeier and Arango-Lasprilla (2007) clearly outline the need for rehabilitation professionals and services to be sensitive to the needs of people with traumatic brain injury from ethnically diverse backgrounds. It is important for information about respite to be delivered in a manner that treats the carer and the person with acquired brain injury as a “spa customer” with the intent of alleviating stress and promoting carer-care recipient well-being. That is, information provided needs to highlight the benefits of respite for the carer and respite recipient.

The “Spa Model”: Training and Learning Development of Respite Practitioners

Appropriate training and learning development of respite practitioners to promote the concept of a “spa model” is critical. People with acquired brain injury have strongly indicated the importance of having trained and qualified staff or volunteers (82%) and recruiting appropriately trained staff and volunteers (81%) (Chan, 2008). Similarly, carers have reported as important their expectations of recruiting trained staff and volunteers (85.9%) and having trained and qualified staff and volunteers (82.4%) (Chan, 2007). Respite providers have also reported similar expectations in recruiting and having trained staff and volunteers (Chan, in press). Having trained and qualified staff can provide carers and people with acquired brain injury with the confidence about the quality of the respite
service, and the knowledge of the quality of staff and volunteers can be a welcome relief for carers (Chan & Sigafoos, 2001).

It is not within the scope of this study to provide detailed recommendations on the training curriculum for respite practitioners, as the study did not specifically address training needs of respite. However, using an integrated practice-oriented framework (Montoro-Rodriguez et al., 2003), it is reasonable to provide some guidance on training based on the findings of the study. In addition to general training that may be required for respite employees, the following specific training topics are offered as guidance for implications for practice.

First, carers and respite providers have identified the level of challenging behaviour as influencing respite use (Chan, 2007; Chan, in press). Chan (2007) found that the level of challenging behaviours is a secondary predictor of respite use. As such, it is appropriate that respite practitioners are provided training in how to support persons presenting with challenging behaviours and to be able to implement behaviour support programs across various settings. There are ample behaviour support training programs in the disability literature that respite providers can access. Addressing the level of challenging behaviour may potentially alleviate the stress of carers who will view such training and skills of staff as an additional competency to the overall qualification of staff.

Secondly, stress-related factors were reported by all three participant groups to influence respite. Hence consistent with the concept of a “spa model”, that is, to alleviate stress and promote well-being; it is important that respite practitioners be afforded training in how to support and respond to the stress of carers and persons with acquired brain
injury. Training should not be limited to simply dealing with carer and person stress, but to provide a “spa model” atmosphere of well-being in the respite service. This proposal will be further expanded in the later section on flexibility of respite services. It is also appropriate that respite practitioners themselves are afforded opportunities to promote their own well-being as part of promoting a safe workplace. Such a model that aims to alleviate the stress of carers and promote well-being builds on the idea of harnessing the altruism of carers and promoting the “joy of caring”; and the shared understanding of care and support.

Thirdly, training specific to the psycho-social and health-care needs of persons with acquired brain injury is recommended. Training needs to consider the impact of acquired brain injury on the individual and carers, and their unmet needs (such as the importance of community integration and being able to respond to the mental health needs of carers and persons with acquired brain injury). Development of specific training for staff need not be the primary responsibility of respite providers. It is reasonable for respite providers to link their training requirements to specific acquired brain injury services and the New South Wales Brain Injury Association that have a role in education and training. This proposal is not intended to add to the responsibility and burden of respite providers by requesting them to develop training specific to acquired brain injury.

*The “Spa Model”: Flexible and Responsive Respite Services*

The findings of the study highlight the need for flexible and responsive services reported by all participant groups. For example, when asked to comment on the ideal respite service; the most common response of respite providers was the importance of creating a flexible and responsive respite service (n = 53, 70.6%), that is individualised to
the needs of the carer and person with disability. A flexible funding respite model (n = 32, 42.6%) was also mentioned by service providers (Chan, in press) as important. Carers and persons with acquired brain injury highlight the need for a variety and range of respite services that take into account their personal preferences and needs; such as being closer to home and providing a ‘home-like’ respite environment. The views expressed by the participant groups in the study are consistent with the concept of the “spa model” of respite, that is, the promotion of family/carer well-being and focusing on the caregiver-care recipient relationship instead of the “burden of caring”. Hence flexible and responsive respite is a shift from the traditional understanding of either an ‘out-of-home’ facility or ‘in-home support’.

In terms of practice and service provision, it is important to review how respite funding is being allocated. As a policy implication, funding portability is proposed so that families/carers and respite providers can use available funding in a way that best suits the needs of the person and his or her carer. As such, it is reasonable for flexible funding to be applied to a wide variety of related costs, such as the ‘wear and tear of vehicles on dirt road’ by carers in rural and remote areas who often have to travel great distances to access services. As noted in the literature review, carers often incur increased expenditure in caring for a person with a life-long disability (Douglas & Spellacy, 2000; Hughes, 2007; Spicer, 2007), alleviating the financial strain would thus achieve the intent of respite. Furthermore, funding for ‘wear and tear’ of vehicles may also mean carers could use their vehicles on family outings and as such, serve a respite function and keep the family unit cohesive.
Flexible funding also gives carers control over purchasing services instead of relying on existing respite services or volunteers. This idea of flexibility suits both city and rural carers. For example, it is appropriate for a carer to use the flexible respite funding to pay for an air fare of a family member to care for the person at home rather than accessing ‘out-of-home’ respite. The benefits of such an informal use of respite include the fact that the carer is confident of the care being provided because it is someone the carer trusts. It potentially reduces the stress for the carer and the person as the care is being provided in the familiar home situation, and provides a vacancy in the ‘out-of-home’ respite for another person with a disability who may require it. Flexible and portable funding also allows carers to ‘bank’ or save their respite allocation for when they might need it most. For example, it allows carers to seek employment or meet their employment requirements; undertake personal development such as further studies; or when other family events require their participation. Hence the family unit or carer continues the rhythm of life routines and maintains locus of control (McCubbin & McCubbin, 1996).

The “spa model” of respite will include services and programs that aim to proactively promote well-being. Services and programs that provide stress management education and positive lifestyle activities for the carer and person play an important part. A traditional ‘out-of-home’ respite facility tends to simply “house” the person with a life-long disability until the carer returns to take the person home. It would be most appropriate for the person attending the respite facility to be also treated to a positive lifestyle and stress-free experiences such as massage, art therapy, aromatherapy, or other sensory experiences that may make the stay during respite pleasant and healthy. The experiences gained by the person with acquired brain injury will also be viewed positively by carers and potentially
reduce the guilt of accessing respite. This proposal is consistent with the need for continuing rehabilitation for people with acquired brain injury whose needs continue post-injury (Chan, 2007; 2008).

It is also appropriate to offer carers similar experiences when they access respite. It does not necessarily mean that the respite service needs to implement and provide stress-management, or positive lifestyle activities, such as massage. The respite could collaborate with other service providers in referring carers to such a service, establish partnership arrangements for such services to be provided or facilitate the linkages to have some of the activities conducted in the respite service. Many of these activities will mean that respite providers need to plan with carers regarding their needs.

The model of a “Caregiver Resource Center” (Friss-Feinberg & Kelly, 1995) should be considered in the Australian context and be expanded to embrace the notion of a “spa model” approach to practice and service delivery. The “Caregiver Resource Center” provides a range of options including planning, consultancy, education and information giving. Respite providers could consider expanding the model reported by Friss-Feinberg and Kelly (1995) to become a ‘one stop shop’ service. A ‘one stop shop’ service has merits particularly for carers who live in rural and regional areas where often carers are required to travel vast distances and different locations for various services. A ‘one stop shop’ model could provide supplementary support services, such as allied health services and continuing rehabilitation as required. For example, a person with acquired brain injury who accesses respite from a rural or regional area could have the wheelchair being serviced or repaired, undergo health-check screening by a community nurse, review or update the
communication system, or receive consultancy or skills training. The carer and/or the family may also access other relevant service if required such as counseling, case management or support.

The concept of a ‘one stop shop’ respite brings together the service co-ordination and partnership objectives highlighted in the Commonwealth Government’s national policy on services for people with acquired brain injury (Commonwealth Government Department of Human Services & Health, 1994). This is not to suggest that every respite service undertakes such a role but it is prudent investment for certain respite services to consider a “spa model” with a ‘one stop shop’ service. It is not within the scope of this study to examine the implementation of such a proposal but to simply propose the concept based on the evidence as articulated by carers and persons with acquired brain injury.

There are several practice and service delivery implications for respite provision. There was a call to make funding portable and individualized to the needs of carers and persons with acquired brain injury. This section highlights the need for an integrated practice-oriented framework, that is, practice and service delivery must be informed by the evidence as highlighted in this study, and a “spa model” of respite provision was proposed.

The “spa model” views respite as not simply an isolated episode in family’s life and time as a “break from caring”. Respite needs to be responsive to the needs of carers and persons with acquired brain injury and to act as a quality social support system that enhances family well-being and resilience. Therefore the “spa model” starts from the very moment a carer is considering respite. Accessible and readily available information is seen as an important first step as carers who need such a service but are often unaware that
respite exists. Qualified and appropriately trained staff and volunteers play a critical role in enhancing the notion of a “spa model”, where carers and persons with acquired brain injury are seen as customers so that they can feel confident when using respite. Respite staff and volunteers need to be adequately trained to implement programs such as supporting individuals with challenging behaviours.

Another practice implication is for flexible and responsive services. These include for respite funding to be flexible and tailored to the needs of the person. All participant groups in this study call for a wider and more responsive range of services that promote well-being and positive caregiver-care recipient relationships. Some creative ideas are proposed for practice and service delivery. A ‘one stop shop’ model is suggested and its benefits discussed. The notion of a ‘one stop shop’ addresses many of the needs of carers and persons with acquired brain injury as highlighted in the literature review.

Implications for Research

In a review of the benefits of respite, Chan and Sigafoos (2001) suggested that in the short-term respite appears to reduce parental stress in the developmental disability literature. They highlighted that the extent of the benefits of respite may be reliant on the type, extent and quality of respite services as well as child and family variables. Similarly, there is a need to measure the benefits of respite for carers and persons with acquired brain injury over time to assess the effect of different types of respite services, the extent to which respite is being delivered and the quality of the respite service being delivered. More importantly, further research on the quality of life outcomes and benefits that carers and persons with acquired brain injury derive from respite services is warranted in order to
inform policy, resource allocation and practice. Such research should not only be focused on the measurement of stress reduction for the carer but also (a) on the general health and well-being of the carer, the person with acquired brain injury and the family unit; (b) on family resilience as measured by family coping capacity and cohesiveness, (c) on the degree of community integration of the person with acquired brain injury, and (d) the benefits that may be derived from caring (Brown, 2007).

Direct measures of quality of life outcomes (such as direct observations with inter-observer agreement data) will enhance the rigour of the dependent variables that have been studied to date in the developmental disability literature (Chan & Sigafoos, 2001). Furthermore, it is important to have more research studies in respite to allow for meta-analysis which would provide a significant quantitative supplement to the predominantly qualitative and narrative review of research (Chan & Sigafoos, 2001). To better examine the effects of respite, longitudinal research is also required. However, it is acknowledged that in the acquired brain injury area there is a paucity of research in respite. Given the continuing needs of people with acquired brain injury many years post-injury, there is strong argument for both cross-sectional and longitudinal respite research in the relatively uncharted area of acquired brain injury.

Consistent with the integrated practice-oriented framework proposed in this study, it is critical to examine what types and the extent of respite that may benefit particular demographic groups. There needs to be research on whether there are types of respite that may attract, suit or benefit particular demographic groups, such as gender and marital
status. Such information can play an important role in respite practice in terms of strategic planning and allocation of resources for the long-term.

The findings of the study indicated that there are certain person and carer characteristics that predict respite use. For example, it is known that the following characteristics: (a) dependency of the person with acquired brain injury, (b) more than 7 days in coma, (c) single carer status and (d) severity of disability are more likely to predict respite use. While such information is important in terms of planning and resource allocation, determining priority of access, setting eligibility criteria and assisting in management decision-making to determine equity of access to respite, further research is required to examine whether (a) there is potential merit in developing an assessment tool to assist in strategic planning and determining priority of access to respite; (b) there are particular aspects of respite that may benefit these carers and persons with acquired brain injury with such characteristics, and over an extended period of time; and (c) addressing such needs will prevent unplanned and early permanent ‘out-of-home’ accommodation.

A review of the respite literature in acquired brain injury indicated that there are no outcome evaluations; that is, studies evaluating whether there are significant quality of life outcomes for carers and persons with acquired brain injury who use respite and who do not use respite. There are also no respite intervention studies comparing different types of respite and their benefits. Intervention studies in respite in acquired brain injury need to examine what carers actually do for themselves during periods of respite because having more respite does not necessarily translate to a reduction in stress or to achieving the quality of life outcomes for the carer (Chan & Sigafoos, 2001; Ridley et al., 2004).
There are several implications for research in acquired brain injury area. There is a need for future research to investigate the quality of life outcomes and benefits of respite, and what types and extent of respite benefit the different demographic respite user profiles. Longitudinal research and intervention methodology are useful so as to fully understand the benefits that respite ought to deliver to carers and persons with acquired brain injury. Research in understanding the predictors of respite use is important in order to assist in the planning and resource allocation of respite in both practice and policy development.

**Limitations of the Study**

Several limitations of the study were noted in the published papers (Chapters 9, 10 and 11). They are summarized in this section. First, the small sample size limits the generalization of the findings, particularly to carers and people with acquired brain injury population generally (n = 90 respite providers, n = 85 carers, and n = 62 people with acquired brain injury). Second, the findings are limited to New South Wales and are more likely to reflect respite provision in this state. Hence the findings need to be carefully considered before generalizing to other localities because access issues, respite service provision or funding models may differ from state to state, or from country to country.

Third, self-selection of respondents with acquired brain injury meant that the sample could be biased towards (a) people with mild disability who could complete the survey independently, and/or (b) people with live-in carers who could help them complete the survey. Similarly, this study was limited to members of the New South Wales Brain Injury Association and Interchange New South Wales. There are respite providers who may not
be members of the peak association of Interchange New South Wales as there are carers and people with acquired brain injury who may not be members of the Association.

Fifth, there was no objective data on the actual amount of respite use by respondents. Carers and people with acquired brain injury reported their use or non-use of respite. The amount of respite actually used would be important in future research in enabling more rigorous statistical analysis. Furthermore, the study used a cross-sectional snapshot period with limited capacity to evaluate change over time regarding respite use or non-use. Finally, the study was predominantly descriptive and lacked quantitative data to argue more strongly for the implications for policy and practice. Despite its limitations, this study is important because it is the first study that examined respite and acquired brain injury; and investigated the perspectives of people with acquired brain injury, their carers and respite providers together. It was also the first comprehensive study of respite provision in New South Wales. The survey methodology allowed for a wide range of issues to be addressed despite the inevitable research resource constraints that accompany doctoral dissertations.

Conclusion

People with acquired brain injury require continuing care and support many years post-injury. Carers who support and care for persons with acquired brain injury need respite to assist them in continuing the care. Little is known about respite in the area of acquired brain injury. Prior to the current study, there were no studies that examine the perspectives of carers, people with acquired brain injury and respite providers regarding respite. There was also no comprehensive mapping and profile of respite services in New South Wales.
This study has been designed to address these questions regarding respite in acquired brain injury.

This study used a survey methodology with carers, persons with acquired brain injury and respite providers. The responses of participant groups were analysed using logistic regression and frequency counts. Briefly, the findings show that people with acquired brain injury and their carers require on-going assistance. Respite is an on-going unmet need for people with acquired brain injury and their carers. The findings of the study also indicate there are certain person and carer characteristics that predict the use of respite. Some of these findings included (a) severity of disability, (b) dependency of the person on the carer and (c) more than 7 days spent in coma. There are several common factors reported to influence respite use among the three participant groups, and these factors relate to the stress level of the carer and severity of disability. There also appear to be several common expectations of respite among the participant groups.

These findings have several key implications for policy direction and development, practice and service delivery, and research. Practical policy implications are discussed, such as funding portability. In terms of respite practice and service delivery implications, several creative ideas are proposed in the concept of a “spa model” of respite. These ideas include flexible funding that is individualised and tailored to the needs of carers and persons with acquired brain injury. Adequately trained staff and volunteers are important to provide carers with confidence and promote more use of respite. Further research is required in the area of respite in acquired brain injury, such as an investigation of the benefits and quality of life outcomes over a period of time. Research into what types and
what extent of respite are more beneficial for certain demographic profiles would further inform practice and policy development. Respite in acquired brain injury is an uncharted area that deserves urgent attention by government, respite providers and researchers.
REFERENCES


APPENDIX A

Respite Care Services in Acquired Brain Injury (ABI)

Survey Questionnaire to the Individual with ABI

PLEASE HELP ME AND COMPLETE THE SURVEY. I APPRECIATE IF YOU CAN TAKE SOME TIME TO COMPLETE AND MAIL THE SURVEY TO ME BEFORE 11 OCT 2002. THIS IS A SECOND SURVEY SENT TO YOU. THANK YOU IF YOU HAVE ALREADY COMPLETED THE SURVEY. THANK YOU AGAIN FOR YOUR TIME.

Dear Member of the NSW Brain Injury Association,

My name is Jeff Chan and I am doing a survey of respite care services for people with acquired brain injury. This survey is part of my Ph.D. research at The University of Sydney. The NSW Brain Injury Association has sent this questionnaire to you on my behalf in the hope that you might be willing to complete and return the questionnaire.

I am doing this survey because very little is known about respite services in New South Wales. This survey is aimed at gathering information on respite services from your point of view. The information you provide will add to the knowledge on respite services and how service providers can assist carers or families and people with acquired brain injury who need or may need respite services.

What is respite care?

Respite care is simply defined as a short-term break or temporary relief provided to the carer and/or family or the person with acquired brain injury. It can be planned or
unplanned (i.e., during an emergency). Respite care may be provided at home (e.g. home support worker), out-of-home care (e.g. day programs, centre-based care, residential care centre), and other flexible options (e.g. recreational activities, weekend camps, funding packages, or financial assistance for an equipment).

**Who should complete the survey?**

A person who has an acquired brain injury should complete this questionnaire. If you want to participate, feel free to seek for any assistance that you might need to complete the survey. Or a family member or someone may assist to complete this survey with you.

Please note that participation in this survey is voluntary and independent of whether or not you are receiving any respite care services. You do not have to complete or return this survey and your decision will in no way affect the services that you receive.

The survey is confidential and there is no way of identifying you in the survey. Completion and return of the survey will be taken to mean that you consent to participate.

Please note that you have the right to retain this front page for your records.

Any person with concerns or complaints about the conduct of a research study can contact the Manager for Bioethics and Safety Administration at the University of Sydney on (02) 9351- 4811.

If you like more information about the study, please contact Jeff Chan at Ph: 02 9808 6411. If you decide to participate, please return the survey using the attached envelope to JEFF CHAN, Community Integration Program, 59 Charles Street, Ryde 2112 BY 11 October 2002.
Survey Questionnaire

Section A: About Yourself

Please tick one (1) box for each question or follow the instruction carefully.

1) I completed this survey

☐ independently ☐ with help from someone

2) I am from:

☐ an Aboriginal or Torres Strait Islander background

☐ an English-speaking background, please specify: ______________________

☐ a Non-English speaking background, please specify: _________________

3) I am

☐ married/defacto ☐ single/separated/divorced

relationship

☐ unemployed

4) I am currently

☐ employed full-time ☐ a student

☐ employed part-time or in casual employment

☐ unemployed
5) **Before my injury, I completed:**

- [ ] Less than Year 10
- [ ] School Certificate / completed Year 10
- [ ] HSC / completed Year 12
- [ ] Trade / TAFE certificate / vocational / diploma
- [ ] Tertiary education (university level, other professional)

6) **Where do you live? Please state suburb you live in:**

- [ ] Sydney metropolitan
- [ ] Regional city/town
- [ ] Other, specify: ________________________________
- [ ] country town
- [ ] rural/remote area

7) **How old are you?**

___________ years.

8) **Please tell us about your living arrangements:** (Please tick one only)

- [ ] alone without support
- [ ] with my family who support me
- [ ] with my family who receives help from paid carers sometimes
- [ ] shared accommodation supported by paid carers, e.g. group home
- [ ] alone with support from paid carers
9) I am

☐ male ☐ female

10) What is the type of brain injury that you had?

☐ Traumatic brain injury (e.g., motor-vehicle accidents, other injury to the head)

☐ Non-traumatic brain injury (e.g., stroke, alcohol-related, hypoxia at birth, etc.)

11) How many years ago did you sustain your brain injury?

_______ years

12) Can you tell me how long you were in a coma? If it is too long ago and you cannot remember, please estimate:

☐ less than 1 hour ☐ more than 7 days

☐ 1 – 23 hours ☐ not applicable

☐ 1 – 7 days

13) What is the level of disability that you sustained as told to you by a medical specialist?

☐ mild disability ☐ profound

☐ moderate ☐ not known

☐ severe
14) How would you rate your current overall level of dependency?

- □ totally dependent (e.g. needing 24 hours care)
- □ moderately dependent (e.g. where personal help or supervision is required sometimes)
- □ somewhat dependent (e.g. where no personal help or supervision is required, but has difficulty performing one or more tasks)
- □ mildly dependent (e.g. 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 difficulty or cannot easily pick up an object from the floor)
- □ independent
15) Are you currently receiving services?

☐ Yes  ☐ No

*If YES, please tick many as appropriate:*

☐ Respite support  ☐ Occupational Therapy

☐ Special Education  ☐ Physiotherapy

☐ Recreational support  ☐ Programming support for behaviour management

☐ Case Management/Service Co-ordinator  ☐ Medical support (e.g. regular attendance at clinic, hospital, Dietitian etc.

☐ Return to work support or employment support  ☐ Other, please

☐ Speech Pathology

specify:_________________________
**Section B: Factors Influencing Respite.**

**Instruction:** Tick one box only for each question. Please answer ALL questions.

If you HAVE used respite before, please indicate below how IMPORTANT each of the following reasons had on your decision to use a respite service OR why do you think your family and/or other people think you require respite.

If you have NOT used respite before, please rate which of the following reasons might be IMPORTANT in your decision to use respite in the future OR why respite might be important for people with brain injury.

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<tr>
<th>Reason</th>
<th>Not Important 1</th>
<th>Least Important 2</th>
<th>Important 3</th>
<th>Quite Important 4</th>
<th>Very Important 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 The level of severity of disability</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
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<td>5 ☐</td>
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<td>2 The dependency on the family (level of care required daily – e.g. dressing, eating, etc.)</td>
<td>1 ☐</td>
<td>2 ☐</td>
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<td>5 ☐</td>
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<td>3 The level of challenging behaviours that I might have presented (e.g. difficult behaviours, self-injury, aggression, etc.)</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
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<td>5 ☐</td>
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<tr>
<td>4 My medical problems or health care needs</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
<td>5 ☐</td>
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<td>5 My communication difficulties</td>
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<td>2 ☐</td>
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<td>5 ☐</td>
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<td>6 Level of intellectual or cognitive disability</td>
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<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
<td>5 ☐</td>
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<td>7 Personal day to day stress level of carer</td>
<td>1 ☐</td>
<td>2 ☐</td>
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<td>5 ☐</td>
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<td>8 Stress level of family members/carers</td>
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<td>2 ☐</td>
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<td>9 Poor health of carer, a spouse or family</td>
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<td>Potential family break-up or other family problems</td>
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<td>11</td>
<td>Family needs a break from person with BI</td>
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<td>12</td>
<td>Carers need some time to spend with spouse or family members</td>
<td>1 ☐</td>
<td>2 ☐</td>
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<td>13</td>
<td>Unexpected situations e.g. other family member needing medical attention, etc.</td>
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<td>14</td>
<td>Carer needs own time (e.g. to pursue leisure or other activities, etc.)</td>
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<td>15</td>
<td>Job opportunities of carer, spouse, family member.</td>
<td>1 ☐</td>
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<td>16</td>
<td>Advice from professionals.</td>
<td>1 ☐</td>
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<td>17</td>
<td>Difficulty of carer trying to relate with person with brain injury (BI)</td>
<td>1 ☐</td>
<td>2 ☐</td>
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<td>18</td>
<td>Person with BI may need a break from carer or family.</td>
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<td>19</td>
<td>Person with BI need experience outside carer/family, e.g. outings with peers, day programs.</td>
<td>1 ☐</td>
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20. Are there any other reasons that are not listed above? Please specify:

___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________
### Section C: Your Expectations of Respite Services.

**Instruction:** Please indicate how important each of the factors are to you when using or choosing a respite service. Tick one (1) box only for each question. Please answer ALL questions.

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<td>Have trained and qualified staff and/or volunteers.</td>
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<td>Access to other professionals easily, e.g. OT, doctor, nurse, speech therapist, etc.</td>
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<td>Respite staff who are able to manage or implement challenging behaviours program.</td>
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<td>Have other professionals implement challenging behaviour programs.</td>
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<td>Respite staff to implement other programs, e.g. school work, etc.</td>
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<td>Have other professionals implement other programs (e.g. school work, etc.) with person with BI</td>
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<td></td>
<td>Increase frequency of respite for some families who need it.</td>
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<td>Provide a homely environment in the respite service.</td>
<td>1 □</td>
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<td>A more flexible respite service.</td>
<td>1 □</td>
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<td></td>
<td>A wider range of services for family than currently receiving (e.g. family support groups, counseling, etc.)</td>
<td>1 □</td>
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<td>11</td>
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<td></td>
<td>Have emergency beds or funds readily available all the time.</td>
<td>1 □</td>
<td>2 □</td>
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<tr>
<td></td>
<td>Respite Care Services in Acquired Brain Injury</td>
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</tr>
<tr>
<td>12</td>
<td>A wider range of activities for person with BI</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>13</td>
<td>Have a mixture of male and female staff working in the service.</td>
<td>1 ☐</td>
<td>2 ☐</td>
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<td>4 ☐</td>
</tr>
<tr>
<td>14</td>
<td>Have staff members that are the same culture and/or language group as the person with a BI.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>15</td>
<td>Person with BI is together with own age group.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>16</td>
<td>Person with BI is with own ability group.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>17</td>
<td>Provide a summary report to family after each respite service or stay.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
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<tr>
<td>18</td>
<td>Provide case management or service co-ordinator.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
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</tr>
<tr>
<td>19</td>
<td>Meet the family’s cultural, religious or dietary needs.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
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<td>20</td>
<td>Sufficient funding allocation for respite service or unit.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>21</td>
<td>Support for respite staff from senior management or organisation.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>22</td>
<td>Policies from respite service that are relevant to family needs.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>23</td>
<td>Respite service recruits appropriate staff and/or volunteers.</td>
<td>1 ☐</td>
<td>2 ☐</td>
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<td>4 ☐</td>
</tr>
<tr>
<td>24</td>
<td>Respite service close to home</td>
<td>1 ☐</td>
<td>2 ☐</td>
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</tbody>
</table>

25. Are there any other issues or concerns that you wish to elaborate further? Please specify:
**Section D: Other Needs.**

**Instruction:** Please indicate which of the following services are IMPORTANT to you in assisting you to care for yourself. Tick one (1) box only for each question. Please answer ALL questions.

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<tr>
<td></td>
<td>Description</td>
<td>Not Important</td>
<td>Least Important</td>
<td>Important</td>
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</tr>
<tr>
<td>17</td>
<td>Help in planning services for my future.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>18</td>
<td>Medical or health care advice/help for me</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>19</td>
<td>More information and help about other services that I can use.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>20</td>
<td>Case management or service co-ordination (i.e. a professional to assist me in getting services, someone to call for help, etc.)</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>21</td>
<td>For me to mix and socialise with other people with brain injury in groups</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
</tbody>
</table>

22. Are there any other concerns, ideas or advice that you wish to elaborate further?

_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
Section E:

1) If you have used a **Government** respite service, please state how satisfied or dissatisfied you are with the services you received:

   - □ 1. Very dissatisfied
   - □ 2. Dissatisfied
   - □ 3. Satisfied
   - □ 4. Quite satisfied
   - □ 5. Very satisfied

2) If you have used a **Non-Government** respite service, please state how satisfied or dissatisfied you are with the services you received:

   - □ 1. Very dissatisfied
   - □ 2. Dissatisfied
   - □ 3. Satisfied
   - □ 4. Quite satisfied
   - □ 5. Very satisfied

3) Are you able to access sufficient respite?

   - □ Yes
   - □ No

4) Do you have any other comments?

   _____________________________________________________________
   _____________________________________________________________
   _____________________________________________________________
   _____________________________________________________________
Thank you for completing this survey.

Please put it in the stamped self-addressed envelope and returned by 11 OCTOBER 2002.

*If you have missed the due date please return the survey anyhow.*
Dear Carer,

My name is Jeff Chan and I am doing a survey of respite care services for people with acquired brain injury. This survey is part of my Ph.D. research at The University of Sydney. The NSW Brain Injury Association has sent this questionnaire to you on my behalf in the hope that you might be willing to complete and return the questionnaire.

I am doing this survey because very little is known about respite services in New South Wales. This survey is aimed at gathering information on respite services from your point of view. The information you provide will add to the knowledge on respite services and how service providers can assist carers or families and people with acquired brain injury who need or may need respite services.

*What is respite care?*

Respite care is simply defined as a short-term break or temporary relief provided to the carer and/or family or the person with acquired brain injury. It can be planned or
unplanned (i.e., during an emergency). Respite care may be provided at home (e.g. home support worker), out-of-home care (e.g. day programs, centre-based care, residential care centre), and other flexible options (e.g. recreational activities, weekend camps, funding packages, or financial assistance for an equipment).

**Who should complete the survey?**

The person who is mainly responsible for the day to day care of the person with acquired brain injury (it may be the parent, grandparent, etc.) should complete this survey. This person is described in this survey as the “primary carer” or “carer”.

Please note that participation in this survey is voluntary and independent of whether or not you are receiving any respite care services. You do not have to complete or return this survey and your decision will in no way affect the services that you receive.

The survey is confidential and there is no way of identifying you in the survey. Completion and return of the survey will be taken to mean that you consent to participate.

Please note that you have the right to retain this front page for your records.

Any person with concerns or complaints about the conduct of a research study can contact the Manager for Bioethics and Safety Administration at the University of Sydney on (02) 9351-4811

If you like more information about the study, please contact Jeff Chan at Ph: 02 9808 6411. If you decide to participate, please return the survey using the envelope provided to JEFF CHAN, Community Integration Program, 59 Charles Street, Ryde 2112 by **11 OCTOBER 2002**
Survey Questionnaire

Section A: About Yourself and Family.

Please tick one (1) box for each question or follow the instruction carefully.

1) This survey is completed by:

___________________(e.g. father, mother, spouse, etc.).

2) Who is the primary carer or main person who cares for the person with brain injury (BI)?

☐ mother       ☐ sibling

☐ father       ☐ relative

☐ grandparent  ☐ others: specify:_________

3) I am from:

☐ an Aboriginal or Torres Strait Islander background

☐ an English-speaking background, please specify:__________________

☐ a Non-English speaking background, please specify: _______________

4) Marital status of primary carer:

☐ married/defacto       ☐ single/separated/divorced relationship
5) **Employment status of primary carer:**

- paid employment full time
- not working in paid employment
- paid employment part-time
- retired

6) **If currently employed, please state Occupation ________________ and hours of work:**

- 1 – 16 hrs per week
- more than 35 hrs per week
- 17 – 35 hrs per week

7) **Combined family income per week after tax:**

- $0 - $200
- $201 - $400
- above $800
- $401 - $600

8) **Please tick highest education level of primary carer:**

- Less than Year 10
- Tertiary education (university level, other professional)
- School Certificate / completed
- currently studying for ________________
- Year 10
- HSC / completed Year 12
- vocational / diploma
- Trade / TAFE certificate /
9) How many children are living at home NOT including person with BI?

- None
- 1 other
- 2 – 3
- 4 – 5
- more than 5


- Sydney metropolitan
- Regional city/town
- country town
- rural/remote area
- Other, specify: _______________________

11) How old are you? (primary carer’s age):

___________ years.

12) Are there any other person/s involved in caring for the person with BI?

- Yes
- No

*If Yes, please tick as many as appropriate.*

- spouse/partner
- friends
- sibling/s
- nanny/carer employed by you (you pay from your private expense)
- grandparent/s
- relative/s
other – please specify: ________________

13) Has looking after the person with BI prevented you from working outside the home?

☐ Yes ☐ No

☐ There are reasons other than person’s disability.

14) Have you used respite care service/s before?

☐ Yes – If Yes, please complete Section B now. ☐ No – If No, please go to Section C now.
Section B: For Those Who Have Used Respite Services.

Instruction: Please tick as many as appropriate.

1) For the period 1 July 2000 to 31 July 2001, what were your reason(s) for using respite.

☐ for emergency (e.g. crises, unexpected family incident/event – medical, etc.)

☐ planned respite (e.g. organised respite care planned ahead, day programs, etc.)

2) For the period 1 July 2000 to 31 July 2001, what types of respite have you used?

☐ funding packages (e.g. financial assistance to purchase an equipment, etc.)

☐ Non-government respite service (but may be funded from the government)

☐ Dept of Community Services respite service or unit

☐ private agency (for profit agency)

☐ Other Government service, e.g. HomeCare NSW

☐ nanny employed by me

☐ help from relatives/friends outside the home

3) For the period 1 July 2000 to 31 July 2001, how many times have you used respite per month on average?

____________ times a month.
4) **Is the person with BI currently using respite?**

- Yes  
- No

*Section C: About Your Child, Spouse, Partner or Person with Brain Injury.*

1) **How old is the person with BI?**

Age: _____________

2) **Gender of person with BI:**

- Male  
- Female

3) **What is the type of brain injury that your child or the person has?**

- Traumatic brain injury (e.g., motor-vehicle accidents, other injury to the head)
- Non-traumatic brain injury (e.g., stroke, alcohol-related, hypoxia at birth, etc.)

4) **How long was the person with BI in a coma?**

- less than 1 hour  
- more than 7 days
- 1 – 23 hours  
- not applicable
- 1 – 7 days

5) **What is the level of the person’s overall disability as told to you by a medical specialist or other health/medical professionals?**

- mild disability  
- profound
- moderate  
- not known
- severe
6) How would you rate the person’s overall level of dependency?

- **totally dependent** (e.g. needing 24 hours care, dependent on you)
- **moderately dependent** (e.g. where personal help or supervision is required sometimes)
- **somewhat dependent** (e.g. where no personal help or supervision is required, but has difficulty performing one or more tasks)
- **mildly dependent** (e.g. 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 difficulty or cannot easily pick up an object from the floor)
- **independent**

7) Is the person with BI currently receiving services other than respite?

- **Yes**
- **No**

*If YES, please tick many as appropriate:*

- Case Management/Service Co-Ordinator
- Return to work support or employment support
- Speech Pathology
- Occupational Therapy
- Physiotherapy
- Programming support for behaviour management
- Special Education
- Recreational support
- Medical support (e.g. regular attendance at clinic, hospital, Dietitian etc.)
- Other, please specify:__________
Section D: Factors Influencing Respite.

Instruction: Tick one box only for each question. Please answer ALL questions.

If you HAVE used respite before, please indicate below how IMPORTANT each of the following reasons had on your decision to use a respite service or place the person with BI in respite.

If you have NOT used respite before, please rate which of the following reasons might be IMPORTANT in your decision to use respite in the future for the person with BI.

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<th>Very Important</th>
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<tbody>
<tr>
<td>1</td>
<td>Level of severity of person’s disability</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>2</td>
<td>Dependency of person on me and/or family (level of care required daily – e.g. dressing, eating, etc.)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>3</td>
<td>Level of challenging behaviours (e.g. difficult behaviours, self-injury, aggression, etc.)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4</td>
<td>Medical problems or health care needs of person with disability</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5</td>
<td>Communication difficulties of person</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
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<td>6</td>
<td>Level of intellectual or cognitive disability</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>7</td>
<td>Personal day to day stress level of carer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8</td>
<td>Stress level of family members/carers</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>9</td>
<td>Poor health of carer, a spouse or family</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>10</td>
<td>Potential family break-up or other family problems</td>
<td>1</td>
<td>2</td>
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<td>11</td>
<td>Family needs a break from person with BI</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12</td>
<td>Need some time to spend with spouse/family.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13</td>
<td>Unexpected situations e.g. other family member needing medical attention, etc.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14</td>
<td>Need some time for self/carer (e.g. to pursue leisure or other activities, etc.).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>15</td>
<td>Job opportunities of carer, spouse, family member.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>16</td>
<td>Advice from professionals.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>17</td>
<td>Difficulty of self, carer or family member relating to person with BI</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18</td>
<td>Person with BI may need a break from carer or family.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>19</td>
<td>Person with BI need experience outside carer/family, e.g. outings with peers, day programs.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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</table>

20) Are there any other reasons that are not listed above? Please specify:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
21) If you have listed “Level of challenging behaviours” in No. 3 above, please tick one or more those behaviours that the person with BI demonstrates:

- Physical Aggression (e.g. throws things, assaults, threats)
- Verbal aggression
- Self-injury
- Property damage (e.g. breaks things)
- Absconding (e.g. runs away)
- Sexual assault
- Inappropriate sexual behaviour
- Alcohol and other drug abuse
- Behaviours have involved Police or criminal justice system
- Others: please specify:
  ______________________________
**Section E: Your Expectations Of Respite Services.**

**Instruction:** Please indicate how important each of the factors are to you when using or choosing a respite service. Tick one (1) box only for each question. Please answer ALL questions. If you have not used respite before please complete it as what you be important

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<th>Important 3</th>
<th>Quite Important 4</th>
<th>Very Important 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Have trained and qualified staff and/or volunteers.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2</td>
<td>Access to other professionals easily, e.g. OT, doctor, nurse, speech therapist, etc.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3</td>
<td>Respite staff who are able to manage or implement challenging behaviours program.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4</td>
<td>Have other professionals implement challenging behaviour programs.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5</td>
<td>Respite staff to implement other programs, e.g. school work, etc.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6</td>
<td>Have other professionals implement other programs (e.g. school work, etc.) with person with BI</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7</td>
<td>Increase frequency of respite for some families who need it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8</td>
<td>Provide a homely environment in the respite service.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9</td>
<td>A more flexible respite service.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10</td>
<td>A wider range of services for family than currently receiving (e.g. family support groups, counseling, etc.)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11</td>
<td>Have emergency beds or funds readily available all the time.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Description</td>
<td>Not Important 1</td>
<td>Least Important 2</td>
<td>Important 3</td>
<td>Quite Important 4</td>
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</tr>
<tr>
<td>12</td>
<td>A wider range of activities for person with BI</td>
<td>1⃝</td>
<td>2⃝</td>
<td>3⃝</td>
<td>4⃝</td>
</tr>
<tr>
<td>13</td>
<td>Have a mixture of male and female staff working in the service.</td>
<td>1⃝</td>
<td>2⃝</td>
<td>3⃝</td>
<td>4⃝</td>
</tr>
<tr>
<td>14</td>
<td>Have staff members that are the same culture and/or language group as the person with a BI.</td>
<td>1⃝</td>
<td>2⃝</td>
<td>3⃝</td>
<td>4⃝</td>
</tr>
<tr>
<td>15</td>
<td>Person with BI is together with own age group.</td>
<td>1⃝</td>
<td>2⃝</td>
<td>3⃝</td>
<td>4⃝</td>
</tr>
<tr>
<td>16</td>
<td>Person with BI is with own ability group.</td>
<td>1⃝</td>
<td>2⃝</td>
<td>3⃝</td>
<td>4⃝</td>
</tr>
<tr>
<td>17</td>
<td>Provide a summary report to family after each respite service or stay.</td>
<td>1⃝</td>
<td>2⃝</td>
<td>3⃝</td>
<td>4⃝</td>
</tr>
<tr>
<td>18</td>
<td>Provide case management or service co-ordinator.</td>
<td>1⃝</td>
<td>2⃝</td>
<td>3⃝</td>
<td>4⃝</td>
</tr>
<tr>
<td>19</td>
<td>Meet the family’s cultural, religious or dietary needs.</td>
<td>1⃝</td>
<td>2⃝</td>
<td>3⃝</td>
<td>4⃝</td>
</tr>
<tr>
<td>20</td>
<td>Sufficient funding allocation for respite service or unit.</td>
<td>1⃝</td>
<td>2⃝</td>
<td>3⃝</td>
<td>4⃝</td>
</tr>
<tr>
<td>21</td>
<td>Support for respite staff from senior management or organisation.</td>
<td>1⃝</td>
<td>2⃝</td>
<td>3⃝</td>
<td>4⃝</td>
</tr>
<tr>
<td>22</td>
<td>Policies from respite service that are relevant to family needs.</td>
<td>1⃝</td>
<td>2⃝</td>
<td>3⃝</td>
<td>4⃝</td>
</tr>
<tr>
<td>23</td>
<td>Respite service recruits appropriate staff and/or volunteers.</td>
<td>1⃝</td>
<td>2⃝</td>
<td>3⃝</td>
<td>4⃝</td>
</tr>
<tr>
<td>24</td>
<td>Respite service close to home</td>
<td>1⃝</td>
<td>2⃝</td>
<td>3⃝</td>
<td>4⃝</td>
</tr>
</tbody>
</table>

25) Are there any other issues or concerns that you wish to elaborate further? Please specify:
Section F: Family Needs.

Instruction: Please indicate which of the following services are IMPORTANT to you in assisting you to care for the person with BI. Tick one (1) box only for each question.

Please answer ALL questions.

<table>
<thead>
<tr>
<th></th>
<th>Not Important 1</th>
<th>Least Important 2</th>
<th>Important 3</th>
<th>Quite Important 4</th>
<th>Very Important 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Some outside help at home to care for disabled person’s daily needs e.g. bathing, dressing, feeding etc.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>2</td>
<td>Some financial help.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>3</td>
<td>Occasional at-home respite or overnight respite.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>4</td>
<td>Occasional out-of-home respite help.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>5</td>
<td>Transportation.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>6</td>
<td>Holiday schemes for person with BI.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>7</td>
<td>Support for siblings.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>8</td>
<td>Parent support group.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>9</td>
<td>Training and/or advice on how to manage challenging behaviours.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>10</td>
<td>Someone else to manage challenging behaviours at home.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>11</td>
<td>Therapy services, e.g. speech, physiotherapy, OT, etc.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>12</td>
<td>Help in school work, leisure or employment services.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>13</td>
<td>Club or other activities for disabled person outside school or work hours.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>14</td>
<td>Respite services at home.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>15</td>
<td>Respite services outside home.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td></td>
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</tr>
<tr>
<td>17</td>
<td>Help in planning services for future.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18</td>
<td>Medical or health care advice/help for person with BI.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>19</td>
<td>More information and help about other services.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>20</td>
<td>Case management or service co-ordination (i.e. a professional to assist me in getting services, someone to call for help, etc.)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

21) Are there any other concerns, ideas or advice that you wish to elaborate further?

__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
Section G:

1) If you have used respite before, please estimate what types of respite you will need and how often will you need the respite for during the period 1 Aug 2002 – 31 July 2003?

If you have not used respite, do you think you will use respite? If yes, please estimate the types of respite and how often you will need respite?

- ☐ No, I do not think I will use respite for next year.
- ☐ No, I do not think I will use respite for next year but may need it in the future.
- ☐ Yes, I will/may use respite. If Yes, please answer the following questions:

<table>
<thead>
<tr>
<th>Type of Respite</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dept of Community Services respite</td>
<td></td>
</tr>
<tr>
<td>Other Government respite (e.g. HomeCare)</td>
<td></td>
</tr>
<tr>
<td>Non-Government respite</td>
<td></td>
</tr>
<tr>
<td>Other flexible options (e.g. holiday schemes)</td>
<td></td>
</tr>
<tr>
<td>Funding packages</td>
<td></td>
</tr>
<tr>
<td>Private respite (e.g. paid nanny, etc.)</td>
<td></td>
</tr>
<tr>
<td>Help from relatives, friends, etc.</td>
<td></td>
</tr>
</tbody>
</table>
Questions 2, 3 and 4 apply to those who have used respite services.

2) If you have used a Government respite service, please state how satisfied or dissatisfied you are with the services you received:

☐ 1. Very dissatisfied
☐ 2. Dissatisfied
☐ 3. Satisfied
☐ 4. Quite satisfied
☐ 5. Very satisfied

3) If you have used a Non-Government respite service, please state how satisfied or dissatisfied you are with the services you received:

☐ 1. Very dissatisfied
☐ 2. Dissatisfied
☐ 3. Satisfied
☐ 4. Quite satisfied
☐ 5. Very satisfied

4) Are you able to access sufficient respite?

☐ Yes
☐ No

Do you have any other comments?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Thank you for completing this survey.

Please put it in the stamped self-addressed envelope and returned by 11 October 2002.

If you missed the due date please mail it anyway.
Dear Respite Service Provider,

I forwarded this survey earlier this year and the response has not been good. I would deeply appreciate if you can take the time to complete the survey and help me to make progress on the urgent issue of respite care services.

My name is Jeff Chan and I am doing a survey of respite care services for people with acquired brain injury. This survey is part of my Ph.D. research at The University of Sydney. It does not matter if your service does not provide a service to people with acquired brain injury. Please complete the survey. The Interchange Association has sent this questionnaire to you on my behalf in the hope that you might be willing to complete and return the questionnaire.

I am doing this survey because very little is known about respite services and of the views of respite service providers in New South Wales. This survey is aimed at gathering information on respite services from your perspective. The information you provide will contribute to the knowledge on respite services and assist people with disability and their families.
**Who should complete the survey?**

The manager of the respite service or another senior staff person should complete this survey.

Please note that participation in this survey is voluntary. You do not have to complete or return this survey and your decision will in no way affect the services that you provide.

The survey is confidential and there is no way of identifying you in the survey. Completion and return of the survey will be taken to mean that you consent to participate.

Please note that you have the right to retain this front page for your records.

Any person with concerns or complaints about the conduct of a research study can contact the Manager for Bioethics and Safety Administration at the University of Sydney on (02) 9351-4811

If you like more information about the study, please contact Jeff Chan at Ph: 02 9808 6411. If you decide to participate, please return the survey using the envelope provided by 31 July 2002. Thank you very much for your time.

JEFF CHAN,

Community Integration Program,

59 Charles Street, Ryde 2112

*PLEASE ANSWER ALL QUESTIONS. THANK YOU.*
Section A: About your respite service.

Kindly tick one (1) box only.

Please answer ALL questions.

1) This respite service is a:

☐ government service (DoCS)  ☐ private/for profit service

☐ non-government service  ☐ other, please specify: ____________

2) Funding for this service is provided by:

☐ government only (state &/or Commonwealth)  ☐ mixed (government and other)

☐ charity/non-government funding only  ☐ private enterprise or business

☐ Other, specify please: ___________________________ 

3) This service has been going for:

☐ 0 – 1 year  ☐ 7 – 10 years

☐ 2 – 3 years  ☐ more than 10 years

☐ 4 – 6 years
4) **Approximate percentage of services provided to the following groups (or an estimate):**

Aboriginal & Torres Straits Islander background: %

Non-English speaking background: %

English speaking background: %

5) **This respite service, centre or unit is located in:**

- [ ] Sydney metropolitan area
- [ ] Rural or remote area
- [ ] Regional city or town
- [ ] Other, please specify: ______________________
- [ ] Country town

*To whom do you provide a service to? Tick the appropriate box OR all that apply.*

6) **Service is provided to the following age groups:**

- [ ] infants/toddlers
- [ ] children
- [ ] adults
- [ ] mixed age groups
- [ ] adolescents
7) **Please specify which type/s of disability do you provide a service to:**

- [ ] intellectual disability
- [ ] physical disability
- [ ] deafness/hearing impairment
- [ ] visual impairment/blindness
- [ ] autism
- [ ] cerebral palsy
- [ ] Down syndrome
- [ ] Fragile X syndrome
- [ ] brain injury
- [ ] other developmental disability
- [ ] chronic health condition
- [ ] multiple disability (more than one disability)
- [ ] Other disabilities/syndromes
- [ ] diagnosed mental illness/psychiatric disability
- [ ] Specific disability only, please specify: _______________________
- [ ] Other disabilities/syndromes
- [ ] Chronic health condition
- [ ] Multiple disability (more than one disability)
- [ ] Other disabilities/syndromes
- [ ] Diagnosed mental illness/psychiatric disability
- [ ] Specific disability only, please specify: _______________________

8) **What is the estimated percentage of respite provided to people with brain injury in a year?**

____________ %

9) **Is there a particular type of disability that your service excludes?**

- [ ] Yes
- [ ] No

If Yes, please specify: ________________________________
About your model of service delivery. Tick the appropriate box OR all that apply.

10) This service provides the following:

- Home-based respite (e.g. home support)
- Out-of-home (e.g. residential care)
- Foster-care
- Holiday camps, day excursions, etc.
- Use of volunteers
- Regular Day programs
- Financial assistance
- Equipment loan/production etc.
- Service co-ordination/case management
- Counseling by trained professionals
- Family support (e.g. support groups)
- Information-giving/resource sharing
- Training or teaching of families
- Training of volunteers
- Emergency respite services (includes home-based or out-of-home care)
- Other service/s, please specify: ______________________

Note: “Counseling by trained professionals” are professionals who have received formal training in counseling (e.g. university or accredited courses). “Family support” includes parent groups, groups for siblings, etc.
11) Percentage of staff and/or volunteers that have recognised training in disability studies:

Staff: ________%
Volunteers ________%

Note: “Disability studies” are formal training provided by your organisation (e.g. in-house training, DoCS Competency Level) and/or accredited courses in disability (e.g. nursing, TAFE, university, VETAB).

12) Do you provide 24 hour care (either home-based or out-of-home care)?

☐ Yes ☐ No

13) Do you provide unplanned respite care? (For example, a family emergency or crises such as a family member requiring medical attention, etc. is considered an “unplanned respite”)

☐ Yes ☐ No

If YES, please elaborate your service’s ability to attend to unplanned respite care (e.g., if your provide residential service, how many beds are reserved for emergency, etc.):
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

14) Is there a criteria for entry into your service or unit?

☐ Yes ☐ No

If YES, please specify briefly:
15) Do you charge for the respite service provided?

☐ Yes  ☐ No

If Yes, what is the minimum and maximum fee that is charged to a family or carer?

Minimum fee $__________

Maximum fee $__________
Section B: About clients and families. Please tick only one (1) box for each question.

Factors Influencing Respite Use

This section examines the reason/s individuals or families might use your respite service. Based on your perception as a service provider, how important the following reasons may have on carer’s decision to request for respite services. Answer ALL questions please.

<table>
<thead>
<tr>
<th></th>
<th>Not Important 1</th>
<th>Least Important 2</th>
<th>Important 3</th>
<th>Quite Important 4</th>
<th>Very Important 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Level of severity of person’s disability.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>2</td>
<td>Dependency of person with disability on the family (level of care required daily – e.g. dressing, eating, etc.).</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>3</td>
<td>Level of challenging behaviours of the person (e.g. difficult behaviours, self-injury, aggression, etc.).</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>4</td>
<td>Medical problems or health care needs of the person with disability.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>5</td>
<td>Communication difficulties.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>6</td>
<td>Level of intellectual or cognitive disability.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>7</td>
<td>Personal day to day stress level of carer.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>8</td>
<td>Stress level of family members/carers.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>9</td>
<td>Poor health of carer, a spouse or family.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>10</td>
<td>Potential family break-up or other family problems.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>11</td>
<td>Family needed a break from the person with a disability.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td></td>
<td>Respite Care Services in Acquired Brain Injury</td>
<td>308</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td>Not Important 1</td>
<td>Least Important 2</td>
<td>Important 3</td>
<td>Quite Important 4</td>
<td>Very Important 5</td>
</tr>
<tr>
<td>12</td>
<td>Carer needs time to spend with family members.</td>
<td>1 □</td>
<td>2 □</td>
<td>3 □</td>
<td>4 □</td>
</tr>
<tr>
<td>13</td>
<td>Unexpected situations e.g. other family member needing medical attention.</td>
<td>1 □</td>
<td>2 □</td>
<td>3 □</td>
<td>4 □</td>
</tr>
<tr>
<td>14</td>
<td>Carer needs some time for self e.g. to pursue leisure or other activities.</td>
<td>1 □</td>
<td>2 □</td>
<td>3 □</td>
<td>4 □</td>
</tr>
<tr>
<td>15</td>
<td>Job opportunities for carer, a spouse or family member.</td>
<td>1 □</td>
<td>2 □</td>
<td>3 □</td>
<td>4 □</td>
</tr>
<tr>
<td>16</td>
<td>Advice from professionals.</td>
<td>1 □</td>
<td>2 □</td>
<td>3 □</td>
<td>4 □</td>
</tr>
<tr>
<td>17</td>
<td>Difficulty of carer or family relating to the child with a disability.</td>
<td>1 □</td>
<td>2 □</td>
<td>3 □</td>
<td>4 □</td>
</tr>
<tr>
<td>18</td>
<td>Person with disability may need a break from their care/family.</td>
<td>1 □</td>
<td>2 □</td>
<td>3 □</td>
<td>4 □</td>
</tr>
<tr>
<td>19</td>
<td>Person with disability needs experience outside carer/family e.g. outings with peers, day programs.</td>
<td>1 □</td>
<td>2 □</td>
<td>3 □</td>
<td>4 □</td>
</tr>
</tbody>
</table>

20) Are there any other reasons not listed above? Please specify:
**Section C: Please tick one (1) box for each question.**

Based on your experience in respite services, please indicate accordingly the factors that are most difficult OR easy as a service provider in providing respite services to the person with a disability and their carers. Answer ALL questions.

<table>
<thead>
<tr>
<th></th>
<th>Not Important 1 □</th>
<th>Least Important 2 □</th>
<th>Important 3 □</th>
<th>Quite Important 4 □</th>
<th>Very Important 5 □</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Level of severity of person with disability.</td>
<td>1 □</td>
<td>2 □</td>
<td>3 □</td>
<td>4 □</td>
</tr>
<tr>
<td>2</td>
<td>Level of daily care required of person on staff (e.g. dependency level in dressing, eating, etc.).</td>
<td>1 □</td>
<td>2 □</td>
<td>3 □</td>
<td>4 □</td>
</tr>
<tr>
<td>3</td>
<td>Level of person’s challenging behaviours e.g. difficult behaviours, self-injury, aggression, etc.</td>
<td>1 □</td>
<td>2 □</td>
<td>3 □</td>
<td>4 □</td>
</tr>
<tr>
<td>4</td>
<td>Medical needs or high health care required by person with disability.</td>
<td>1 □</td>
<td>2 □</td>
<td>3 □</td>
<td>4 □</td>
</tr>
<tr>
<td>5</td>
<td>Lack of communication skills of person with disability.</td>
<td>1 □</td>
<td>2 □</td>
<td>3 □</td>
<td>4 □</td>
</tr>
<tr>
<td>6</td>
<td>Level of intellectual disability of person with disability.</td>
<td>1 □</td>
<td>2 □</td>
<td>3 □</td>
<td>4 □</td>
</tr>
<tr>
<td>7</td>
<td>Day to day stress of service providers, e.g. staff stress levels.</td>
<td>1 □</td>
<td>2 □</td>
<td>3 □</td>
<td>4 □</td>
</tr>
<tr>
<td>8</td>
<td>Expectations of families on your service.</td>
<td>1 □</td>
<td>2 □</td>
<td>3 □</td>
<td>4 □</td>
</tr>
<tr>
<td>9</td>
<td>Working with families (e.g. getting adequate information, etc.).</td>
<td>1 □</td>
<td>2 □</td>
<td>3 □</td>
<td>4 □</td>
</tr>
<tr>
<td>10</td>
<td>Working with other professionals outside your service.</td>
<td>1 □</td>
<td>2 □</td>
<td>3 □</td>
<td>4 □</td>
</tr>
<tr>
<td>11</td>
<td>Funding issues for your service (e.g. difficulty getting funding, access to funds, etc.)</td>
<td>1 □</td>
<td>2 □</td>
<td>3 □</td>
<td>4 □</td>
</tr>
</tbody>
</table>
12. Are there other reasons not listed above? Please specify briefly:

_________________________________________________________________________

_________________________________________________________________________
**Section D: Please tick one (1) box for each question.**

Based on your current experience in providing a respite service, please indicate which of the following factors are important OR not important to your service in achieving outcomes for the person with a disability and their families. Answer ALL questions.

<table>
<thead>
<tr>
<th></th>
<th>Not Important 1</th>
<th>Least Important 2</th>
<th>Important 3</th>
<th>Quite Important 4</th>
<th>Very Important 5</th>
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<td>Description</td>
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<td>Important</td>
<td>Quite Important</td>
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</tr>
<tr>
<td>12</td>
<td>Offer a wider range of activities for person with disability.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>13</td>
<td>Have a mixture of male and female staff working in the service.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>14</td>
<td>Have staff members that are the same culture and/or language group as the person with disability.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>15</td>
<td>Person with disability is together with own age group.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>16</td>
<td>Person with disability is together with own ability group.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>17</td>
<td>Provide a summary report to family after respite service or stay.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>18</td>
<td>Provide case management or service co-ordinator.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>19</td>
<td>Meet the family’s cultural, religious or dietary needs.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>20</td>
<td>Sufficient funding allocation for respite service or unit.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>21</td>
<td>Support from senior management or organisation.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>22</td>
<td>Policies from your service that are relevant to your work.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>23</td>
<td>Recruiting appropriate staff and/or volunteers.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
<tr>
<td>24</td>
<td>Provide respite service close to client/family home.</td>
<td>1 ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
<td>4 ☐</td>
</tr>
</tbody>
</table>

25) Are there any other issues that you wish to elaborate further? Please specify:
Section E – Answer ALL questions.

1) In general are you satisfied or dissatisfied with the respite service that you provide in terms of meeting the required legislative standards and achieving outcomes for people with disability and their carers?

☐ 1. very dissatisfied  ☐ 4. Quite satisfied

☐ 2. dissatisfied  ☐ 5. very satisfied

☐ 3. satisfied

2) In general how satisfied or dissatisfied do you perceive families feel about your service in meeting their needs and that of the person with disability?

☐ 1. very dissatisfied  ☐ 4. Quite satisfied

☐ 2. dissatisfied  ☐ 5. very satisfied

☐ 3. satisfied

3) How does your service achieve advisory feedback from stakeholders? (For example, is there a regular parent/client/stakeholder advisory group, client satisfaction measurement, etc.?). Please provide brief description.

_________________________________________________________________________
_________________________________________________________________________
4) What is your ideal respite service? Please describe in terms of services, models of services, etc.?

_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________

5) Please make any other comments that you think are not covered by this survey.

_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________

Thank you for your time and co-operation in completing this survey.

Kindly mail your response by 31 July 02 or sooner to:

Jeff Chan
Community Integration Program
59 Charles St, Ryde 2112