

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

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Author's contribution

Respite Services and Acquired Brain Injury in New South Wales:

The perspectives of persons with acquired brain injury, their carers and service providers

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

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

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Date:

Declaration

Respite Services and Acquired Brain Injury in New South Wales:

The perspectives of persons with acquired brain injury, their carers and service providers

I certify that this thesis and the research reported in it are original. It contains no material which has been submitted for the award of any degree in any other university, and that to the best of my knowledge and belief, this thesis contains no copy or paraphrase of material previously published or written by another person, except where due reference is made in the text of this thesis.

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### **Abstract**

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

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

The survey questionnaires were developed and designed after an extensive review of the literature, and were reviewed by experts in the fields of respite, disability and acquired

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

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

There were common perspectives regarding the expectations of respite among all three participant groups, such as the need for trained and qualified respite staff; a wider range of respite services and more flexibility of respite service provision. The study also indicated a reported lack of sufficient respite for persons with acquired brain injury and their carers. Some of the findings of the study appeared to be consistent with the research literature on acquired brain injury; such as the majority of carers being mainly female; there is a reliance

on informal networks for the care and support of the person with acquired brain injury; and the majority of the persons with acquired brain injury being male. The study also found that many respite providers in New South Wales had extensive experience in running a respite service.

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

The study highlights the perspectives of persons with acquired brain injury, their carers and respite providers. Respite is an important support system to enable persons with acquired brain injury to receive the continuing care and support from their carers. Respite in acquired brain injury is a new field that merits further research as it holds the potential for addressing the needs of people with acquired brain injury and their carers.

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

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Publications and Presentations

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Chan, J., Hudson, C., & Parmenter, T. (2004). An exploratory study of crime and brain injury: Implications for mental health management. *Australian e-Journal for the Advancement of Mental Health* 3(1), [www.ausienet.com/journal/vol3iss1/chanhudsonparmenter.pdf](http://www.ausienet.com/journal/vol3iss1/chanhudsonparmenter.pdf)

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Chan, J., & Parmenter, T. (2002). *What do families, individuals with brain injury and service providers think are predictors of respite?* Paper presented at the 37<sup>th</sup> National Conference of the Australian Society for the Study of Intellectual Disability, 13-16<sup>th</sup> November, Hobart, Tasmania.

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Ridley, G., Chan, J., & Roberts, J.M.A. (2004). *Appropriate and effective models of respite care for children under 7 years with disability and for children with disability and challenging behaviour or high medical support needs*. Sydney: Centre for Developmental Disability Studies.

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