

Accommodation in NSW for adults with high care needs after Traumatic Brain Injury



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Executive summary

This report documents a research project conducted at the Brain Injury Rehabilitation Unit (BIRU) at Liverpool Hospital Sydney.

The research project identified that the inappropriate placement of younger people with complex high support needs after Traumatic Brain Injury (TBI) into nursing homes pleases no-one. When the nursing home option is taken it is because there is a lack of any true alternative.

Over a three year period more than one in twenty patients (5.6% 10/178) admitted to the Liverpool Brain Injury Rehabilitation Unit inpatients rehabilitation program were discharged into nursing homes.

During the same period 44 people with similar levels of functional impairment were discharged to the community.

People with TBI can have a combination of motor-sensory, cognitive and behavioural impairments that interferes with function. The interaction between the different types of impairments is a major reason why people with TBI have complex high-level support needs. Case Study 1 illustrates the effects of these impairments for daily living.

This project entailed interviewing 39 people with complex high care needs as a result of TBI. The interviews were done with the person with TBI, an associated family member and/or involved staff member and used a specially designed survey form (Appendix 1).

Of the 39 people with TBI interviewed, nine were discharged to a nursing home (NH group) and 30 were discharged to the community, primarily to the family home (HOME group).

This research project aimed to identify:

- > key factors that resulted in adults with complex high level care needs after TBI being inappropriately admitted to nursing homes
- > unmet needs and the gaps in the current service system that result in this outcome
- > potential improvements to existing service systems and the development of alternative service options

The research includes both quantitative and qualitative data.

Factors that resulted in a nursing home admission for adults with high care needs after TBI

A range of factors influence the discharge destination decision. The opinions of the rehabilitation team and their relative with a TBI are key factors for families when making this decision.

Table 3.1 illustrates the discharge decision process.

- > A nursing home discharge was more likely if the person with TBI was older, had a more severe initial injury and had higher levels of dependence. The median age of the NH group (n=9) was 39 years of age
- > Almost 20% of people in the HOME group had identical profiles in terms of age, initial injury severity and level of dependence at discharge to the people placed in nursing homes
- > There was no significant difference in the length of stay (days in BIRU), between the NH and HOME groups
- > Access to compensation did not have a significant influence on initial discharge destination
- > The core factor that determined an individual's discharge destination was a willingness by family to undertake the role of providing for the individual's care and support

- > Some families were interested in exploring other options, but in the absence of viable alternatives, willingly chose to take their relative home
- > Some families had wanted viable alternatives but given that the only other choice was a nursing home admission, viewed this as unacceptable, and felt forced by this absence of real choices into taking the person home
- > Some families had wanted viable alternatives but given that the only choice was between home or a nursing home admission, felt forced into taking the nursing home option
- > The considerations that shaped the choice to support the person at home included home as the natural place to go, the opinion of the person with TBI, the opinion of the rehabilitation team and resources to meet care needs. Resources included physical and mental health of the family, anticipated support from extended family, optimism about the potential for further improvement and practicalities such as being close to family and the physical environment of the home
- > 33.3% (3/9) of participants initially discharged to nursing homes had upgraded to less restrictive settings after spending between almost 3 months and 18 months in a nursing home. Two participants were at home with their partner. One participant moved into an alternative, residential accommodation service for people under 65 years with a disability
- > The availability of compensation per se was no guarantee that a person will have the option of being supported in a community living arrangement. There was no simple pathway available that would provide a means for the money to be spent to identify and arrange such a transition

Stability of discharge destination and transition from nursing home to community living arrangements (CLAs)

Overall, a remarkable stability was observed in the original discharge placements, with few changes in accommodation status. However, the sample illustrates three transition processes that occurred. Figure 4.1 is a flow chart of post discharge living circumstances.

- > 87.2% (34/39) of participants had no change in accommodation status since discharge from the BIRU inpatient program, over a median period of 31 months (range 4 -54 months)

Current living arrangements

Information was collected on how satisfied families and people with TBI were with their accommodation arrangements. Overall, when the arrangement was working well it was working well for both the family and the person with TBI.

Based on an analysis of interviews, three (3) domains were identified as important in providing quality living arrangements for adults with complex high care needs after TBI. The three (3) domains are environment, social and psychological well-being for the person with TBI and the relatives.

Problems identified in each domain were often similar for the NH group and the HOME group.

Summary of findings

- > Two-thirds of people with TBI living in the community and two-thirds of their family members endorsed one of the two top satisfaction ratings (delighted, pleased) in describing their level of satisfaction with their current living arrangements. No family member with a relative in a nursing home endorsed the top two satisfaction ratings

- People with traumatic brain injury in nursing homes had little if any opportunity to personalise their immediate living environment. These problems were not encountered in the home environment. The two people living in the long-term accommodation service were also able to live in autonomous living spaces that met their privacy needs and could be personalised
- No one in the NH group thought that living with older residents met their social needs. The level of social support with the HOME group provided by the family was positively affirmed however some families identified problems due to lack of peer involvement and an over reliance on key family members for social relationships
- Some families in the NH group felt a sense of security because the nursing home was able to provide care for their relative into the future. This sense of security was also reported by the relatives of the two people with TBI resident in the ACT long-term disability support service
- Families in the HOME group felt secure when they were able to oversee the health and well being of their relative and were able to provide the care and support. However, some families in the HOME group did not share this sense of security as more care was needed than the family could provide and they became reliant on paid carers and different service providers
- Relatives in both groups reported wide ranging ways in which having a family member with a TBI impacted on family life. These included the impact of specific injury sequelae; the loss of privacy; changed roles; impact on health and well-being; financial impact; and the burden of providing support
- Although eligible for a range of services, families in the HOME group often have significant difficulties in being able to access sufficient levels of services, and there are often long waiting times before a service might become available. Furthermore, although eligible for some services, they may not be given priority and may miss out
- Young people in nursing homes have very few service options, as by definition, their status as a nursing home resident disqualifies them from almost all state-funded disability service programs
- In nursing homes, limited social leave is possible under the legislation, based on typical patterns for the elderly. Families and young people in nursing homes would often be interested in greater amounts of home leave
- The psychological consequences for people with TBI were observed in the effect on personal well being. Feelings of distress were associated with not being in control, not living with people they liked or choose to live with and not being able to do the things they liked
- In NSW there were three issues that were prevalent. Namely the need for staff training in the management of people with TBI, the need for transport to reduce isolation and increase community participation, and the need for behavioural support/consultation for staff and families dealing with people with TBI who have significant behaviour changes
- Respondents in both groups
 - Identified as important factors having staff with a positive attitude and approach, who were reliable and liked the person with brain injury
 - Reported difficulties with appropriate design of accommodation as well as being able to access appropriate equipment
 - Reported problems with the amount and quality of care as well as how care was being provided in meeting the needs of the person with TBI and their family

- Indicated there were issues in how to balance family care and paid care
- Identified problems with the type of therapy available and managing the specific issues for people with TBI arising from their disabilities
- Reported that when pre injury social relationships did not survive it was difficult to develop and maintain new relationships
- Identified transport as an issue
- Referred in positive terms when nursing homes or community-based agencies had processes to resolve issues and have their views listened to when the service was considering changes to the provision of care

Current service systems

Throughout this report, accommodation has been defined broadly as encompassing the place where a person lives, the support they need and the things that they do.

Key questions are examined in this chapter utilising information from the perspectives, experiences, concerns and expressed preferences of research participants. This is supplemented by extensive clinical experience of the authors and a range of reports and submissions about the Australian experience.

Summary of findings

Adults with high care needs after TBI living with family (HOME group) are eligible for most community-based services (eg Home and Community Care [HACC] services). However services are not meeting their care and rehabilitation needs. Barriers include:

- > Exclusion criteria for some day care programs
- > Services not providing what is needed eg not receiving long term rehabilitation
- > Barriers to access eg carers too young for Commonwealth programs
- > Support not available at the level required or there are long waiting times

- > Adults with TBI are not an identified special needs group so they may not be given priority and access is delayed
- > TBI specific programs and services are inconsistently available across the community

Adults with high care needs after TBI who want an alternative to HOME have limited access to existing specialist accommodation services and there is inconsistent eligibility and availability for generic disability accommodation support services. This is largely due to:

- > In NSW there is only one accommodation support service specialising in adults with acquired brain injury
- > Admission to the Department of Aging, Disability and Home Care (DADHC) funded services is restricted by eligibility criteria
- > The level of support need is a barrier to boarding house admissions
- > Eligibility criteria for the Attendant Care Program requires that people can direct their own care therefore cognitive impairments are a barrier to accessing the Attendant Care Program
- > There are extremely long waiting times to access the Home Care High Care Needs Pool so this becomes an extremely unlikely option
- > There is a lack of service co-ordination for adults with high care needs after TBI at the regional and State levels
- > Services are often not available at the local or regional level
- > The NSW Brain Injury Rehabilitation Program (BIRP) teams may not have the resources to provide long term case management
- > Private case management services are mainly available for individuals with compensation

Living in a nursing home is a barrier to community participation for adults with high care needs after TBI because the person often:

- > Is not eligible for community based services and programs
- > Has limited eligibility for long term rehabilitation services
- > Has no access to equipment and modification programs, even when visiting with family
- > Has legislation limiting their nights away from the nursing home (social leave)

Compensation makes a difference to how care and needs are met

With Compensation	No Compensation
Reasonable requests for home support approved	Public funding for home support is generally limited to 5-7 hours per week
Additional care can be provided to facilitate program participation	Staffing levels and resources are limited in community programs and can not provide one to one supports for community participation
Reasonable requests for equipment and modifications approved	Long waiting lists exist for equipment and limited options for home modifications in government programs
Rehabilitation can be funded and provide for goal based therapy including psychological services	BIRP teams may only be able to provide time limited therapy and there are long waiting lists for general rehabilitation services
Individualised, flexible respite options can be provided for in home or out of home care	There is limited respite available from public programs. The only residential option is a nursing home to manage high care needs

Ways forward

The central requirement to moving forward is the identification of a state wide organisation with a TBI focus to integrate key planning principals into enhancing and developing viable long term community options for adults with complex high care needs after TBI.

The core business of a Statewide service would be an integrated approach to managing environmental, social and psychological factors for people with complex high care needs after TBI. The key planning principals would provide the framework for services across the State with interagency networking between government departments and non-government service providers.

A Statewide service would facilitate:

- > A reduction in the number of adults with TBI and high complex care needs living in nursing homes and prevent new admissions
- > An increase in resources for families supporting their relative with complex high care needs at home
- > A coordinated and planned approach to enhancing existing community living models and the development of long term care arrangements in rural and metropolitan settings

Essential to the development of a Statewide dedicated service to support people with complex high care needs after TBI are the service elements and service support structures.

- > Community living models (page 52) detail the model, housing stock, service supports, needs and issues that arise with each model and gives working examples
- > People who wanted to move out of nursing homes or live separately from their family needed pathways to the community developed. A number of interstate services provide successful models that can be adapted for this purpose

- > For the community living models to succeed, individualised support packages; transition pathways and infrastructure supports are required. A Statewide service can be effective in responding to common client and service needs; coordinating long term case management; staff and family training /education programs and monitoring key components of infrastructure supports

In conclusion, the placement of adults with complex high support needs after TBI into nursing homes is not appropriate. It pleases no one.

The central requirement to moving forward is the identification of a dedicated Statewide organisation with a TBI focus to integrate key planning principals into the development of viable and long term community living options.

Implementing a Statewide organisation that identifies adults with complex and high care needs after TBI as a special needs group can result in the creation of a viable service system that would make the practice of nursing home admissions redundant.

1. Introduction

1.1 Aims

This research project aims to identify:

- > key factors that resulted in younger people with complex high level care needs after TBI being inappropriately admitted to nursing homes
- > unmet needs and the gaps in the current service system that result in this outcome
- > potential improvements to existing service systems or alternative service options

1.2 Definitions

Key definitions have been included in this chapter to assist readers to better understand the extent, variety and complexity of brain injury impairments. A case study illustrates the interaction of these impairments for daily living (case study 1 page 12).

A TBI can be defined as an “injury to the brain [from external causes] which results in deterioration in cognitive, physical, emotional or independent functioning.... these impairments to cognitive abilities or physical functioning may be either temporary or permanent and cause partial or total disability or psychosocial maladjustment” (Department of Human Services and Health, 1994).

People with TBI may have the following permanent motor-sensory, cognitive and behavioural impairments and consequent disabilities. These include:

Motor-sensory impairments

Includes visual problems, poor balance, incoordination, paralysis or restricted range of movement in the arms or legs, difficulties producing intelligible speech, and changes in taste and smell. Up to 42% of people with TBI may experience one or more of these types of impairments (Olver, Ponsford, & Curran, 1996; Tate, Broe, & Lulham, 1989).

Cognitive impairments

Includes problems with memory, attention, speed of information processing, planning and organising, problem-solving, difficulties understanding what other people say, poor mental flexibility and problems communicating to others in a way they can understand (also called receptive and expressive aphasia). Up to 74% of people after TBI may report one or more of these types of impairments. (McDonald, Togher, & Code, 1999; Ponsford, Olver, & Curran, 1995; Tate, Fenelon, Manning, & Hunter, 1991).

Behavioural impairments

Includes increased impulsivity, reduced levels of control of emotions, being self-centred, lack of insight, irritability and temper control problems, including verbal or physical aggression. Between 60% and 80% of people with TBI may have one or more of these type of impairments. (Thomsen, 1984; Thomsen, 1992).

The motor-sensory, cognitive and behavioural impairments result in people with TBI having a range of support needs. These can include but are not restricted to the following domains.

Physical care

Includes tracheostomy management, continence and toileting, bed mobility (ie: turning), medical care (eg: management of pressure sores), bathing, dressing, feeding (includes nasogastric or abdominal tube [PEG] feeding), transfers on and off the bed, in-house mobility (eg: indoor surfaces, stairs), and mobility in the community (eg: outdoor surfaces, transport).

Cognitive supervision

Includes assistance with orientation (ie: to time, person and place), memory prompts, use of aids to compensate for memory impairments, use of assistive communication devices, assistance in problem-solving and decision-making, and making allowance in interactions for reduced speed of information processing.

Behavioural management

Includes care or support to conduct or maintain appropriate social interaction, control impulsive behaviour, improve anger management, set boundaries on inappropriate sexual behaviour, and additional monitoring of safety issues due to an increased level of risk associated with poor insight.

Emotional/social support

Includes care or support to address social isolation and loneliness, monitor and treat psychological reactions to brain injury (eg: anxiety, depression, suicidality, acute and post-traumatic stress disorders), and foster participation in age-appropriate social activities.

1.3 Background to project

Traumatic Brain Injury (TBI) is a common form of acquired disability among 18 to 65 year olds.

The incidence of TBI in Australia is estimated at 100 per 100,000 new cases per year (Tate, McDonald, & Lulham, 1998). TBI's are caused by road traffic accidents (40%) sport and recreation accidents (25.2%), falls (20.6%), assaults (8.2%) and miscellaneous other causes (6.1%).

For the most severe injuries the pattern is different. Road traffic accidents are far more prominent, (64.3%) followed by falls (16.1%), sport and recreation accidents (12.5%), and assaults/miscellaneous other causes (7.1%).

Males sustain TBI more frequently than females, (2.7:1). The most common age group is the 15–24 year age group (incidence rate 245 per 100,000), with the rate for young males being 386 per 100,000.

A small group of people sustain very severe injuries that result in permanent complex high care needs.

Many in this group are discharged from acute hospital medical or rehabilitation wards into institutions defined by the Commonwealth as “high level aged-care residential facilities”. These facilities are commonly known in the community as nursing homes.

A survey of all Commonwealth accredited aged-care facilities in Queensland indicated that 26% (n=97) were providing care for 209 people with a brain injury younger than 65 years (Cameron, Pirozzo, & Tooth, 2001).

As of March 2004, 2,222 people under 65 years were in residential aged care facilities in NSW (National Alliance of Young People in Nursing Homes, 2004).

A survey in South Western Sydney highlighted that 4% (n=78) of residents in 20 nursing homes surveyed were aged between 15 and 65 years, of whom 53 had brain injury (Hooper, Lovett-Iskander, Veerabangsa, & Hodgkinson, 1994).

Increasingly, the inappropriate placement of persons under 65 years, in aged care facilities is being questioned. There are growing calls in the media, at forums and conferences from people with TBI and their families, the peak community disability organisations, and various other agencies involved to develop positive alternative accommodation support options. Currently there are virtually no alternatives to family care or nursing home care within NSW for adults with complex high-level support needs after TBI.

The reason nursing homes are not considered an appropriate service option to provide long term supports to this group are:

- > The placement of younger people with TBI in nursing homes is contrary to the principles of care for people with disabilities, outlined in the national disability standards that are contained in the State disability legislation (NSW Disability Services Act 1993)
- > Generally nursing homes do not have the resources nor staff to meet the specialised needs of this group (Cameron et al., 2001). Providing accommodation support to people under 65 is outside the core business of aged-care service provision

- > Adults in nursing homes are not eligible to services provided under the Commonwealth-State Disability Agreement, and unable to access service supports including equipment aides and community-based avocational programs funded by the State government
- > Nursing homes do not have a rehabilitation orientation critical to the ongoing care and development of people with TBI
- > There is a growing awareness that best practice models of support for people with TBI are flexible, community-based options that allow for continuing improvement and maximum social participation (Pryor et al 2002)

Case study 1

People with catastrophic injuries due to TBI can have a combination of motor-sensory, cognitive and behavioural impairments. The interaction between the different types of impairments is a major reason why they have complex high-level support needs. The following case study illustrates this complexity.

George was a single 28 year-old plumber when he sustained an extremely severe TBI as the result of a motor bike crash and was deemed to be at fault. As a result of this crash, George had permanent brain damage and his sister agreed to be responsible for his money management. After almost eight months of rehabilitation, George was medically stable but still needed high levels of care and support. Home with family was not possible so George was discharged to a nursing home.

At the nursing home, George feeds himself with supervision and set up assistance. He talks to others but isn't able to sustain a topic and gets distracted in groups. He requires a moderate to high level of physical assistance for self care transfers and continence. He uses a wheelchair but needs verbal prompts to navigate doorways and corridors, to not bump into others or yell at them to get out of the way, and to remember where he is going so that he gets there.

George experiences difficulties with his problem solving and memory. These problems cause him to be very anxious and exacerbate his difficulties.

Many times a day he will forget when he went to the toilet so yells for someone to take him there and then gets frustrated at any delays so yells even more. George is distressed when he has accidents and frets that it will happen again and the cycle continues. George gets frustrated over little things but can't work out how to fix what troubles him so he yells, calls out for staff and shouts when people don't answer him.

Cognitive changes for George also mean that he is unable to generate ideas and so needs support to initiate things to keep him occupied. He can play bingo for about 30 minutes. He manages better when things are done the same all the time and he has one to one support to provide consistent feedback, to distract him or talk through what is bothering him so he can settle quickly. His behaviour improves dramatically when he is occupied and supported to do tasks and his anxiety is addressed.

George goes to MacDonald's and other places about once a month with a worker from a community program and manages well with this support.

2. The research study

The MAA project included undertaking a study at the Brain Injury Rehabilitation Unit (BIRU) at Liverpool Health Service and conducted in the South Western Sydney Area Health Service.

2.1 Methodology

The Human Research Ethics Committee of the South Western Sydney Area Health Service granted approval for the study.

A total of 178 first-time admissions to the BIRU inpatient rehabilitation program over a 3-year period (Oct 99 to Sep 02) were reviewed. During this period 10 of the patients were discharged to nursing homes who had scores on the Functional Independence Measure (FIM; Linacre, Heinemann, Wright, Granger, & Hamilton, 1994)¹ between 18–108. Another 44 people with a similar level of disability (ie: FIM scores between 18-108) were also discharged from the BIRU during the same time period. This group of 54 people was approached to participate in the study.

Thirty nine people with TBI and/or a relative agreed to participate². Nine people were discharged to nursing homes and 30 people were discharged to the community (primarily to the family home).

Information is presented using 2 groups. People discharged to a nursing home are identified as the NH group and those discharged to the community are identified as the HOME group.

Quantitative data collected on each client included the Care and Needs Survey (CANS; Tate, R.L. 2004), the FIM as well as demographic, injury and compensation data.

The assessment of current functioning using the CANS is provided in Appendix 2, discharge CANS were not available.

Qualitative data was collected using a semi-structured interview protocol, the Brain Injury High Care Needs Accommodation Survey (see Appendix 1). Using this survey, the person with TBI (if not too impaired), a relative, and relevant staff member/s were interviewed. Interpreters were used to complete three relative surveys. The interview protocol focused on eliciting information about the discharge process and destination, satisfaction with current living arrangements and future preferred living options.

A relevant staff member involved in the discharge process was interviewed for 20 of the participants. Similarly, a relevant staff member was interviewed regarding the participant's current living circumstances for 24 participants.

Groups interviewed included:

- > Patients discharged from the BIRU to a nursing home
- > Patients with a similar level of disability discharged from the BIRU to the community
- > Relatives of the person with TBI
- > Staff members associated with original discharge planning, as well as those involved in current management

¹ The FIM provides a reliable and verifiable approach to measuring support needs. The FIM is a widely used international scale that measures functioning on 18 self-care, motor and cognitive tasks. Scores on the scale range from 18-126. A FIM score of 18 represents someone who needed 24 hour nursing care. Scores between 18 and 108 inclusive indicate that some level of assistance or support is needed. Scores between 109 and 126 represent people who are independent in the 18 self-care, motor and cognitive tasks.

² The reasons the other 15 people did not participate included refusal (n=6), did not respond to letter or phone call (n=4), ill health (n=2), could not contact (n=2) and deceased (n=1).

2.2 The people with traumatic brain injury (TBI)

Thirty nine people with TBI and/or a relative agreed to participate comprising of thirty one (78.4%) males and eight females (21.6%).

Road accidents were the cause of TBI in 64.9% (n=26) of people (including drivers, passengers, pedestrians, motor bike riders, and a push-bike rider). Other causes included falls, struck by an object, and gunshot accounted for the remaining 35.1% (n=13).

A range of different compensation schemes potentially covered 67% (26/39) of study participants:

46%	(n=18)	Road-related compensation
13%	(n=5)	WorkCover (all were road accidents)
3%	(n=1)	Victim's compensation
5%	(n=2)	Other compensation ³

However, at the time of the study only 33% (n=13) were eligible for compensation and liability had been accepted.

2.3 The relatives

In total, 37 relative/carers who were most involved in the care of their relative agreed to participate. The female: male ratio of carers was 2:1 (females 67.6%; n=25). While females are generally assumed to be the primary carers, one-third of the carers in the current sample were male.

The relationship of the relatives interviewed to the person with TBI was as follows:

40.5%	(n=15)	Mother
10.8%	(n=4)	Father
10.8%	(n=4)	Husband
21.6%	(n=8)	Wife
2.7%	(n=1)	Daughter
2.7%	(n=1)	Son
8.1%	(n=3)	Brother
2.7%	(n=1)	Grandmother

The age of the carer was disclosed for 33/37 respondents. The age range was 27 years to 68 years.

- > 28 respondents who were the primary family member involved in providing care were less than 60 years of age
- > 3 respondents were over 65 years and a further 2 respondents were between 60 and 65 years

The mean age of carers in the current sample was 48.36 years.

³ A public liability claim commenced in response to an injury sustained in a boating accident; A civil case commenced against a Council for the condition of a public road

3. Factors influencing discharge destinations

A range of factors have been identified as influencing the decisions made by rehabilitation teams about discharge destination for people with TBI.

Factors mentioned in the literature include personal mobility, ability to manage their own affairs, expressed preference, activity of daily living skills, domestic management and community participation skills, general health status, social situation, and premorbid living arrangements (Unsworth, Thomas, & Greenwood, 1995).

In this study a range of variables was evaluated using quantitative and qualitative data to identify the key factors that influenced the discharge destination.

A number of characteristics of the person with TBI in both the NH and HOME groups were examined by comparing the demographic, injury and compensation profiles.

Characteristics of the relatives were also examined, to determine the role they played.

3.1 Characteristics of the person with TBI

Was age a factor? Specifically, were people with TBI who were older more likely to be discharged into a nursing home?

The median age of the NH group (n=9) was 39 years. The youngest person discharged to a nursing home in the current study was 27 years. The oldest was 57 years.

The median age of the HOME group (n=30) was 24 years. This means that 50% of the people within the HOME group were under 24 years of age. The range of ages in the HOME group was 15 to 59 years.

Participants in the NH group were significantly older than the HOME group.⁴

⁴ Statistical analyses contained in Appendix 2

⁵ Post traumatic amnesia (PTA) is a confusional state that people experience as they emerge from unconsciousness after a TBI. PTA can last for minutes, hours, days, weeks or months. Longer periods of PTA indicate more severe injuries. The maximum length of time that PTA is measured is for 183 days or 6 months from the date of injury. Injuries associated with a PTA greater than 30 days are classified as extremely severe.

Yes, age was a factor.

People with complex high support needs who were older were more likely to be discharged to a nursing home.

However, the median age of people discharged to a nursing home after a TBI (39 years) was still 26 years younger than the normal minimum eligibility criteria of 65 years.

Was initial severity of injury a factor? Were people discharged to nursing homes more severely injured?

The Glasgow Coma Score (Teasdale, G et al 1974) is a measure of the severity of brain damage and is routinely administered when people are first admitted to hospital. There was no difference in the median Glasgow Coma Score between the two groups.⁴

Duration of post traumatic amnesia (PTA) is a strong predictor of the long-term outcome after TBI. PTA could be measured for 4 out of the 9 participants in the NH group. The median duration of PTA for the NH group was 183 days, the maximum length of time over which PTA is assessed. The other 5 patients were either minimally conscious or had such a severe global level of cognitive impairment that it was not even possible to measure a PTA score.

There was a significant difference in initial injury severity as measured by length of PTA.⁴

The median duration of PTA for the HOME group was 105 days. Seven people in the HOME group also had a PTA of 183 days.

Despite these differences, in terms of duration of PTA, all participants in the NH group and the majority of participants in the HOME group (88.5%, 27/30) had a period of PTA greater than 30 days, therefore falling into the most extreme category of injuries, classified as extremely severe.⁵

Factors influencing discharge destinations

Yes, severity of injury was a factor.

People who had the most severe injuries (maximum duration of PTA) were more likely to be discharged to a nursing home.

However, a substantial number of clients in the HOME group (7/30) also recorded the maximum duration of PTA (183 days).

Access to compensation claims did not have a significant influence on initial discharge destination. However, not all claims had been decided at discharge and 15 claims were still pending when contacted for this study.

Were people who stayed in hospital longer more likely to be discharged to a nursing home?

No.

There was no significant difference in the length of stay (LOS) between the NH and HOME groups.⁴

The LOS in hospital for the NH group was 1–11 months (median 5.2 months). The LOS for the HOME group was 1–16 months (median 2.5 months).

Did a high level of dependence of the person with TBI on others to meet their care and support needs increase the likelihood of a nursing home placement at discharge?

FIM scores measure an individual's functional status, one way of identifying the severity of their disability and the level of care/support needs.

The FIM scores for the NH group were significantly lower than the FIM scores for the HOME group.⁴

The median FIM score at discharge for the NH group was 27.0 and the range was 18–108. One participant had a FIM score of 108, with the remaining 8 having FIM scores between 18–65.

The median FIM score for the HOME group was 98.5. The range was also 18–108.

Six of the participants in the HOME group had FIM scores of 65 or less. Therefore, 20% of people in the HOME group were discharged home with FIM scores similar to those admitted to nursing homes.

Did access to compensation decrease the chance of being discharged to a nursing home?

No.

There was no significant difference in the proportions of people in the NH and HOME groups who had compensation claims.⁴

As outlined in chapter 2, a range of compensation schemes potentially covered 67% of study participants. At the time of the study only 33% (n=13) of participants were eligible for compensation with liability accepted.

Within the NH group, 3 participants had compensation claims pending or settled. Within the HOME group, 12 people had compensation claims pending or settled.

However, as will be illustrated in the following chapter, access to compensation played a potentially important role in the accommodation choices available to people with TBI in the longer-term.

Yes.

People who had the most severe disabilities as the result of a TBI were more likely to be discharged to a nursing home.

However, 20% of clients discharged home had FIM scores similar to those admitted to nursing homes.

⁴ Statistical analyses contained in Appendix 2

Summary of characteristics of the person with TBI associated with discharge to a nursing home

People with TBI were more likely to be discharged to a nursing home if they:

- > were older
- > had a more severe initial injury
- > had higher levels of dependence

However, almost 20% of people in the HOME group had identical profiles in terms of age, initial injury severity and level of dependence at discharge to the people placed in nursing homes.

Therefore, although characteristics of the person with TBI played some role in nursing home placement, the key factor appeared to be whether the person had access to a social or service support network that could provide a viable accommodation alternative.

At the time of the study, family members were the primary support structure available in NSW to adults with TBI and high care needs.

3.2 Family factors

The qualitative data collected in the semi-structured interviews with family members was analysed to identify the key characteristics that shaped the decision about discharge destination and whether to provide accommodation support.

The analysis identified willingness as a main factor that shaped the family's decision-making.

If families wanted to take the person with TBI home, it did not matter how severe the motor-sensory, cognitive or behavioural impairments were, or how complex the physical, cognitive, behavioural or emotional support needs.

This core factor and other related issues are displayed in Figure 3.1 (page 22).

Willingness to have the person with TBI at home

The core factor that determined an individual's discharge destination was whether the family was willing to provide the individual's care and support. In analysing the content of the 37 relative interviews, there was a clear spectrum in the willingness of families to undertake this commitment.

Some families made a decision, often early in the recovery process, that come what may, they were going to take their relative home.

- > Even if alternative viable community living arrangements were available, it would have made no difference. These family members saw that home was the "natural place" for their relative to be

"...my willingness to give up everything, to put him first over myself and the rest of the family..."

(mother of son in mid thirties commenting on what made a home destination achievable for her son)

- > In some situations, this willingness was a dominant factor evident from early in the recovery and rehabilitation process before the extent of recovery was known or the level of care that would be required

"Nursing homes were only mentioned once, by the doctor at the acute hospital and I told them then that I'd be taking him home no matter what"

(mother of son in early twenties)

"They were never going to consider anything else but taking her home"

(staff reflecting on family of teenage girl)

Some families were interested in exploring other options, but in the absence of viable alternatives, were willing to take their relative home.

"We were told that there were no options for him because of his age and behaviour so we brought him home...."

Factors influencing discharge destinations

Some families had wanted viable alternatives but given that the only other choice was a nursing home admission, viewed this as unacceptable, and felt forced by this absence of real choices into taking the person home.

“There was no choice”

(the father of a young man who was considering options and so visited nursing homes. He believed that his son would have died if he went to a nursing home because his behaviour would not be able to be managed without using sedation, he wouldn't progress and his risk of aspiration would increase)

Some families had wanted viable alternatives but given that the only choice was between home or a nursing home admission, felt forced into taking the nursing home option.

When relatives were forced to make the choice of a nursing home, it was usually in the light of the dearth of community services, or because they were unable to make the necessary commitment and sacrifices. They often had to review competing priorities in making this decision.

“...I had to think of my teenage son...”

(wife of a man in a nursing home. Without compensation or extended family support and with only very limited community services on offer she was simply not able to provide for her husband's 24 hour care needs at home without totally neglecting the needs of herself and her son).

What were the other considerations that shaped the choice of whether to support the person with TBI at home?

A number of factors influenced families in their decision-making. These included:

- > an attitudinal factor about the importance of a person living at home
- > the consideration of the opinion of the person with TBI
- > the opinion of the rehabilitation team, and
- > the resources to meet the care and support needs of the person with TBI, and their own needs in carrying out the carer role

Home as the natural place to go versus an unnatural place to go

Home as the natural place to go was a recurring attitudinal factor for families. It was where the person with TBI lived before the trauma, it was their home and they had their family around them. The following comments were typical descriptions used by families when they reflected upon their discharge choice.

“Where else would he go?”

“It's his home.”

“She lived here before the injury.”

In contrast, relatives saw the BIRU inpatient ward and nursing homes as unfamiliar and/or unnatural places to live. They felt nursing homes focused on meeting the needs of elderly people at the end stages of their lives. Families who visited nursing homes as part of the discharge planning process were depressed at this option and reluctant to make this choice.

Factors influencing discharge destinations

Opinion of the person with TBI

Families took into account the view of the person with high care needs after TBI when deciding on a discharge destination.

- > Invariably the view of the person with TBI was that they wanted to go home
- > Some people with a TBI had no memory of their injury circumstances and didn't understand why they needed to remain in hospital at all. Families and staff in this situation often reported that the person with TBI was pushing to go home
- > In circumstances where the person with TBI was unable to give a view their families made assumptions about what the person would have wanted or did what they thought was best

"He (my husband) wouldn't have liked that (going to a nursing home)..."

Opinion of the rehabilitation team

The opinions of the rehabilitation team influenced the family's views about discharge destination.

- > For many families, it was important that the rehabilitation team "thought they could do it" (take the person home and manage)
- > Some families followed the advice given as they saw the doctors and rehabilitation team as the experts, the people with experience

The wife of one man who went to a nursing home explained that "nothing like this had ever happened to anyone in our families, we had no experience at all and the doctors told us this would be the best thing for all of us"

- > Other families were more sceptical of the opinion of the rehabilitation team

A family member who acted as a strong advocate for an alternative to a nursing home said, "... (in hospital) families are usually disempowered so when they don't know what to do they follow the advice given..."

Resources to meet care needs

Garnering the resources necessary to meet the needs of the person with high care needs after TBI influenced a family's decision about discharge destination.

Resources covered a wide range of factors including:

- (i) the physical and mental health of the primary care givers
- (ii) anticipated support from extended family
- (iii) optimism about further improvements in the person with TBI, and
- (iv) the perception that the resources and logistical practicalities of arranging the discharge home were achievable

(i) Physical and mental health of the primary care givers

- > Primary carers considered issues including physical health, age, the relationship to the person with high care needs after TBI, the cohesiveness of the family and their personal ability to reorganise their lives and cope with difficult situations, in their decision-making

"I stopped work, moved so I could be close to the hospitals he was in so I could help my son...be there for him...and now I am his full time carer."

(a father whose son is in his early twenties)

(ii) Anticipated support from extended family

- > The perceived availability of the extended family and their capacity to reorganise their lives to provide support was identified as a factor for families in deciding whether going home was achievable
- > Some families had a supportive network of friends and family to provide emotional and practical support to help make the discharge destination work. They were able to utilise this social network and make the choice of going home achievable

"...We have a big family... and we naturally brought her back home..."

(daughter of an Asian woman who lives in an extended family household)

Factors influencing discharge destinations

“His daughter was finishing university at the same time we (staff) were organising the discharge so she stayed home to help her mother look after her Dad (54 year old man with high physical and behaviour support needs)”

- › Sometimes the help that was expected from extended families was not forthcoming

“...Our families said that they would help out when she came home... they were often at the hospital and I thought they would keep coming... they said they would at the meeting with the doctor... but they didn't...”

(husband who is the primary carer for his young wife plus their 3 pre-school children)

(iii) Optimism

Optimism about the potential for further improvement influenced the decision.

- › Often families were buoyed by the reality that the person with TBI had not died and they continued to hope for further recovery. They saw the person improving and interpreted this as a positive sign. Few families had experience of disability and providing long term care. They often factored longer-term hoped-for improvements into their decision to take the person home. Some of this optimism could also be understood as naivety

“... I (husband) didn't understand what they were trying to tell me... it was really hard... she just sat on the lounge and didn't do the things she use to do...”

“I thought he'd be okay and didn't understand that he'd be different...”

(Mother whose son returned to live with her)

(iv) Practicalities and resources

There was a range of practical issues that affected a family's decision. These included:

- › **Proximity** – the possibility of being close to family, access to support services and community amenities
- › **Physical environment of the home** – modifications or relocation to a more suitable home
- › **Equipment** – purchase or accessing needed equipment
- › **Support services** – securing support services within the home such as paid carer support and access to day programmes to support the person with high care needs after TBI and the family in their care role
- › **Financial resources** – availability of funds and the financial resources to implement these plans

For families who did not take their relative home, resource factors were often identified as the main factor underpinning their decision. These included:

- › a lack of health
 - “We wanted to bring our son home but we are just too sick to look after him all the time”*
(crying mother, both she and her husband are aged pensioners)
- › isolated with few family and friends to provide support
 - “...there was no-one to help at home...”*
(wife of a man in a nursing home)
- › pre-injury financial commitments and/or an inability to stop work for financial reasons
 - “I have to work”*
(wife of a man in a nursing home who had been the family breadwinner and was non-compensable. She now needed to work full time to maintain self and to finish their children's education).

Factors influencing discharge destinations

- > a lack of hope for the future
“When he went to the nursing home he (my son) wasn’t expected to live”
- > a lack of support services
“She (his wife) tried very hard to make a home discharge work but couldn’t get enough support”
(Staff talking about a man discharged to a nursing home)

3.3 Staff influences

The staff interviews provided a picture of the Unit’s philosophy about discharge destination.

Specifically:

- > Staff implicitly and explicitly took a client-centred approach, using their expertise to enable the family/person with TBI to decide the discharge destination
- > The starting point for unit staff in this process was that home or community based accommodation is typically the preferred discharge destination
- > Unit staff did not subscribe to the expert-driven models where clinicians promote a specific destination for discharge planning as described in the literature (eg Unsworth et al., 1995)

This unit philosophy and staff orientation was in sympathy with the factors arising from the family’s own views about discharge destination, in particular, home being the natural place to go and family willingness. Therefore, this approach reduced the likelihood of conflict arising between staff and family members during the complex process of discussion, decision-making and ensuing organisational steps required to effect the decision regarding discharge destination.

Staff worked to ensure that families adequately considered the ongoing needs of the person with TBI and what would be required to address these needs. In considering discharge destination staff assessed the:

- > needs of the person with TBI
- > available alternatives for discharge
- > personal and physical resources of the family to support the person with high care needs after TBI
- > availability of supports and resources within the community to assist with meeting the person’s specific needs

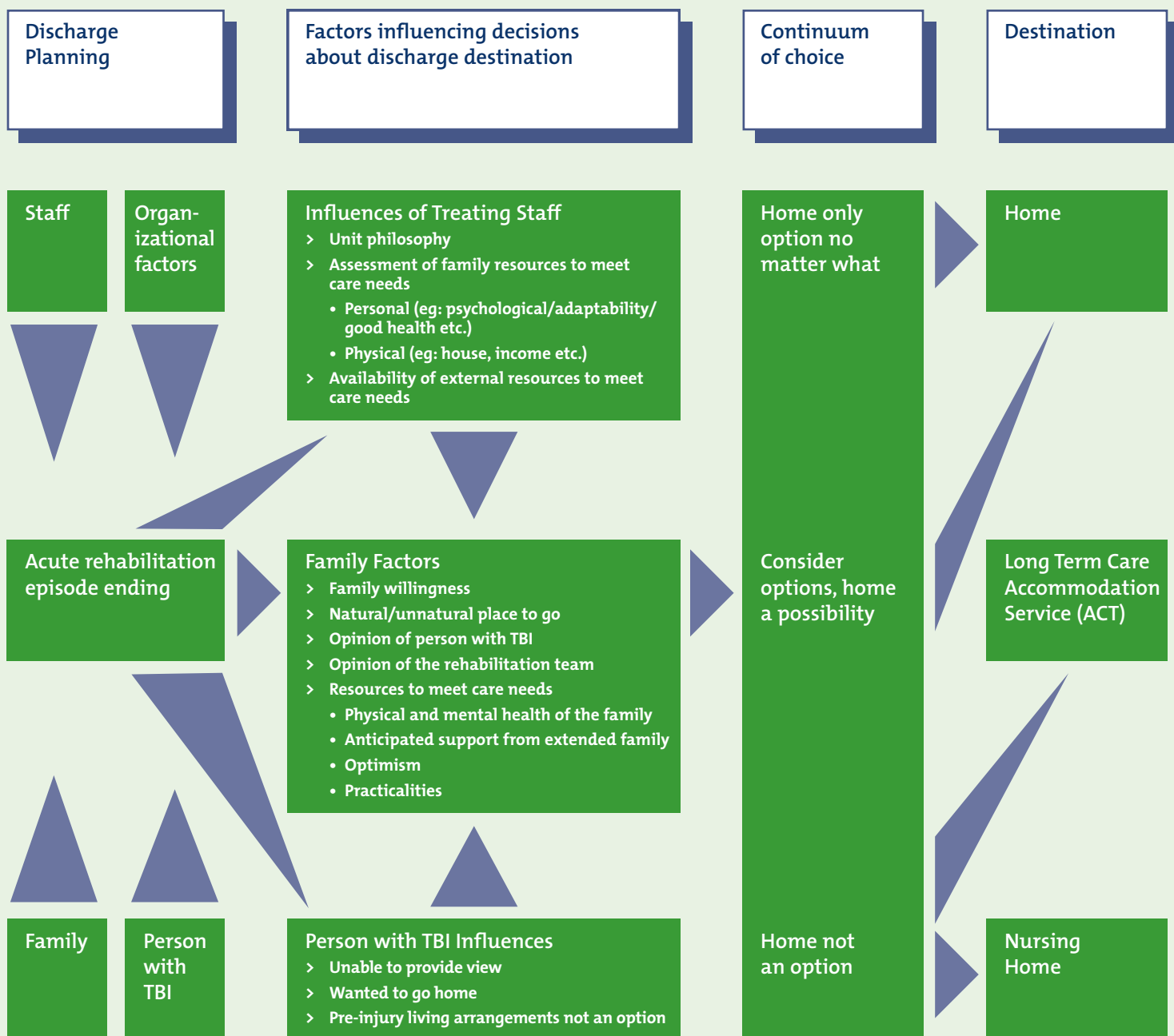
This information was used to identify issues that needed to be worked through with families in identifying the appropriate discharge destination.

3.4 Conclusions

- > Severity of disability of the person with TBI was not the central factor in determining placement in a nursing home. People with similar disability profiles were in nursing homes or in the community. Choices could be made about being cared for/supported in the family home or in their own homes. Only two people were able to choose living in an accommodation service with support from disability agencies when home was not an option
- > In undertaking discharge planning for people with complex high support needs, the BIRU adopted a family-centred approach rather than a discharge option promoted by the clinicians (expert-driven approach)
- > A proportion of families will want to take their relative with TBI home, no matter what alternative service options were available or will be available in the future
- > A proportion of families felt forced to take their relative with TBI home, or felt forced to agree to a nursing home discharge, due to the absence of viable alternative service options in NSW

Factors influencing discharge destinations

Figure 3.1 Factors influencing decisions about discharge destination



4. Stability of discharge destination and transition from nursing home to community living arrangements

This chapter looks at the stability of discharge and highlights three case studies that involve movement from a nursing home to the community.

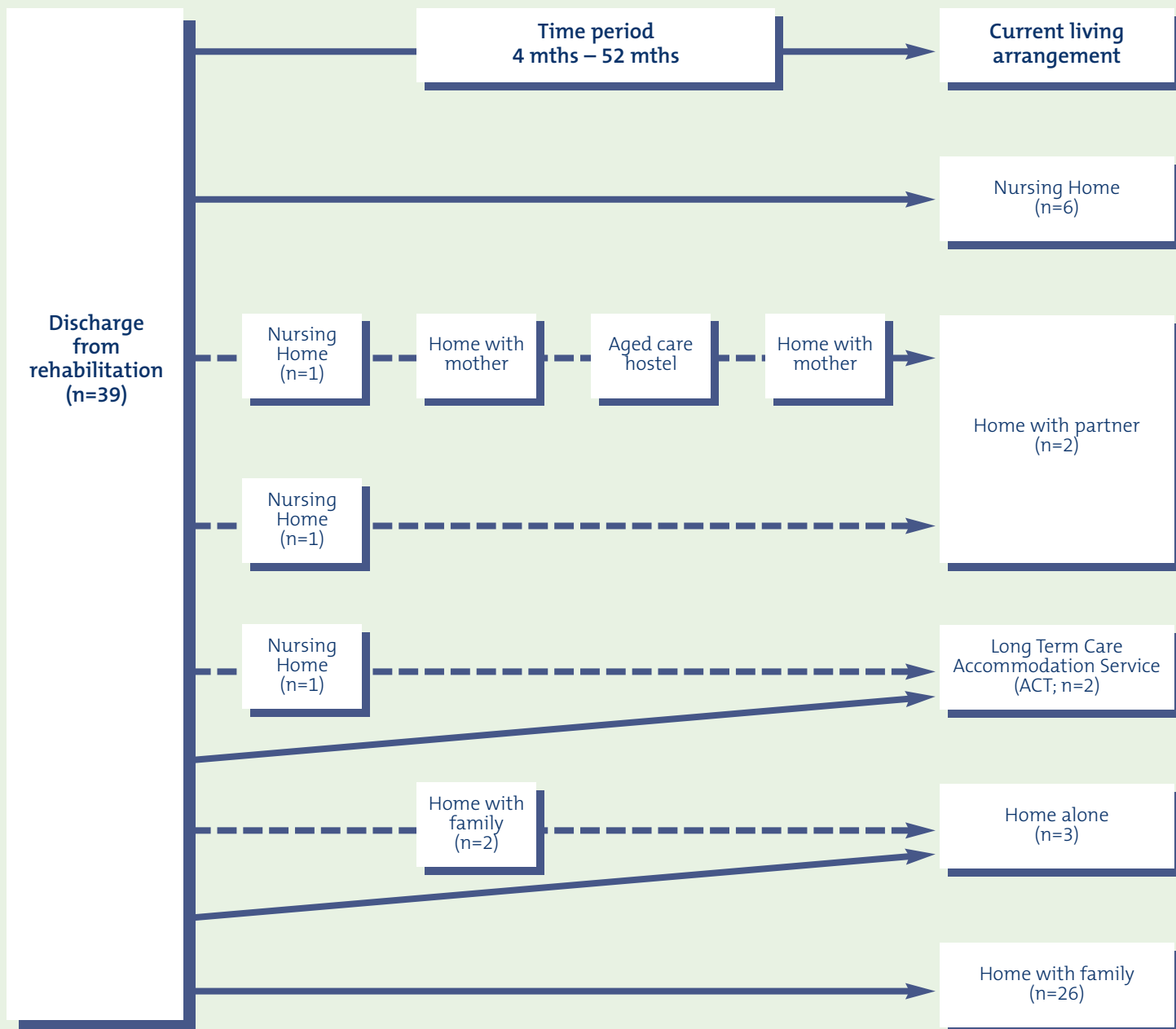
This chapter also considers:

- > Is the family home a viable long-term accommodation option for young people with TBI who have complex high-support needs, or do such placements quickly break down, resulting simply in a deferred nursing home placement?
- > Can a transition process be organised so that the person with TBI in a nursing home can be placed into alternative community housing?
- > Can alternative placements to a nursing home or the family home be arranged at the point of discharge from the inpatient rehabilitation setting?

Figure 4.1 (page 24) outlines the initial discharge destinations and transition processes that occurred prior to the current study.

Stability of discharge destination

Figure 4.1 Flow chart of post-discharge living circumstances



Note.
 Solid arrows = no change.
 Broken arrows = change in accommodation status.
 Overall, a remarkable stability was observed in the original discharge placements, with few changes observed in accommodation status.

87.2% (34/39) of participants had no change in accommodation status since discharge from the BIRU inpatient program, over a median period of 31 months (range 4–54 months). However, the sample included cases that illustrate the three transition processes outlined above.

4.1 The transition from a nursing home into alternative Community Living Arrangement (CLA's)

One way of reducing the number of adults with TBI and high care needs from being admitted to a nursing home is to facilitate their transition into alternative CLA's. This occurred for three participants in the NH group in the current study.

Three of the nine participants initially discharged to nursing homes had upgraded to less restrictive settings after spending between almost 3 months and 18 months in a nursing home

- Two participants were at home with their partner at follow-up
- One participant moved into a community based accommodation service for people under the age of 65 and received additional support to meet his high care needs in a home environment

For two people, the transition would not have been possible without external supports.

- > The availability of compensation funding (Case study 2) enabled Gary to move from a nursing home bed into a community based accommodation service
- > In Case study 3, Stella received further rehabilitation organised by the NH and BIRU community team when her medical condition improved. Changes were achieved and she was then able to move into more independent accommodation with family assistance

Case study 2

Moving from a nursing home to a CLA with the assistance of compensation

Gary was 39 years old when involved in a motor vehicle accident that was not his fault. He had multiple fractures and a severe closed head injury. He was transferred from acute care to the BIRU, Liverpool for rehabilitation where he made gains in his level of awareness, became medically stable, and continued to make very slow, incremental gains.

The family was keen to have Gary closer to home due to the problems of travel and distance. He was still dependent in all his care needs and had only yes/no communication response. Neither his brother Bill nor his wife was able to manage the level of care needed at home. Gary returned interstate to where his family lived with Aged Care Assessment Team (ACAT)

approval for a nursing home bed. Gary spent the next 18 months waiting for an alternative accommodation arrangement. During this time Bill advocated for and negotiated with a number of government and non-government agencies to seek an acceptable solution to his brother's care and support needs.

Gary was finally discharged to a non-government charity organisation that provides supported accommodation for people with intellectual disabilities. Gary is the only person in the accommodation service who has had a TBI and staff needed additional training and education to work with an adult with TBI.

Case study 2 continued over >>>

Case study 2 – continued

Gary moved into a one-bedroom house that was part of a cluster of houses. He required 36 hours of care per day (his personal care required 2 people) paid by his insurer. Gary was able to access private therapy services and purchase the special equipment he needed. He was able to utilise the agency wheelchair bus for outings.

Gary was happy to have left the nursing home for the CLA. He felt he had gotten better since arriving, that it was his place, he had a say in what he did and got on well with his staff. Staff and family saw

improvements. He was more alert and involved. Also, when Gary arrived he was assessed for a communication board but at interview he was able to answer all the survey questions verbally – less than 3 months after discharge from the nursing home environment.

Bill was happy with the service and the changes Gary had made since moving in. He felt secure with the community living arrangement so was able to reduce his involvement to spend more time with his own family.

Key issues

- › Gary had complex physical, cognitive (including communication) and emotional support needs
- › Given the inability of his family to provide full time care, Gary would not have been able to move into an alternative community living arrangement without access to compensation
- › The availability of compensation was no guarantee that a person will have the option of being supported in a CLA
- › The transition process was complex and took almost 18 months to organise
- › Gary was placed in a generic disability service that specialised in supporting people with intellectual disabilities. He was the first person who acquired a brain injury as an adult serviced by the agency. The willingness of the agency to work with Gary was a key factor in achieving the move to community living
- › With adequate funding and a service infrastructure a CLA was possible for a man with complex high support needs, in this case involving 36 hours of care per day

A lack of access to compensation funds meant that some people were placed in a nursing home until compensation claims were settled and funds became available to facilitate an appropriate community living arrangement.

The lack of service pathways from hospital to the community meant that discharge from hospital was delayed when home was not an option, even if compensation funds were available.

Case study 3

Moving from a nursing home to CLA without compensation

Stella was 43 years old when she had a fall and suffered a very severe brain injury. She had significant medical problems due to pre injury alcohol use and her prognosis was poor. Her mother discussed the options with the rehabilitation team and agreed to an admission to an aged care facility for high level care. At the time of discharge Stella was dependent for all aspects of care including gastrostomy feeding, was medically unwell and had reduced awareness of her environment.

At the nursing home she improved and received outpatient therapy and the assistance of the nursing home staff for mobility and self care. She was able to make sufficient gains to return for more inpatient therapy in the BIRU but continued to require additional support so that returning to the nursing home was her only option. Stella became aware of her circumstances and worked very hard to improve as she wanted to get out of the nursing home. Her room-mate kept her awake and she was distressed at having to be there.

This resulted in her mother agreeing to cancel the nursing home bed booking and have Stella live with her. This arrangement was stressful for both due to a poor pre-injury relationship, the limitations of the retirement unit for 2 people and her mother's increasing ill health and inability to meet her daughter's support needs.

Generic services were introduced to assist Stella and her mother to manage this living arrangement. Stella was involved in a number of aged care respite services, residential breaks, hospital and boarding house admissions at times when living with her mother was not working. All of these arrangements were short term and Stella continued to return to her mother's when things did not work out. This unstable accommodation arrangement continued until Stella became involved in a relationship and was able to move into her boyfriend's place, where she was still living at follow up.

Key issues

- › Stella initially had complex physical (ie: medical), cognitive and behavioural support needs arising from her disabilities
 - › Slow stream rehabilitation beds are unavailable in NSW but could have provided a better environment for continuing improvements and prevented this nursing home admission. This type of service can provide people with the opportunity to continue to make gains that can have a significant impact on their level of independence and reduce their level of care needs
 - › When she had recovered there were no available service pathways to effect a transition from the nursing home into supported accommodation with the level and type of supports needed. As a result there was a period of turmoil and turbulence in which she accessed a series of inappropriate aged care services
- Her mother was therefore forced by Stella to take her in and this arrangement continued until Stella moved in with a new boyfriend.

4.2 Viability and stability of placing people with complex high care needs into the family home

A concern has been expressed in the literature that family placements for adults with brain injury who have complex high support needs may not last more than 6 months (Unsworth et al., 1995). The current study has found that families can provide a viable medium – long term accommodation option for people with TBI who have such needs, albeit at some personal cost.

Case study 4

Family-based care with compensation support

Wendy was involved in a motor vehicle accident (MVA) on the way home from work and received very severe injuries from a TBI. Her parents both ceased work and provided constant assistance for her at the hospital and in the inpatient ward. They used their family savings to manage the cost of unemployment until they qualified for benefits. The parent's decision to bring their daughter home was an early commitment regardless of what it involved and their belief that "...families are not just for the good times..."

Wendy was an inpatient for 376 days. During this time she was involved in a multi-disciplinary therapy program including botox injections and splinting programs, identifying equipment to meet her care needs and purchase of appropriate items and discussions about home modifications to manage care at home with paid workers.

Wendy was discharged home with high levels of carer and family support and a rehabilitation therapy program. The home modifications were not completed before discharge and required a further 5-6 months to finish.

Her father tried to return to work but now has health issues that his wife relates to the stress of the accident and what has happened since. Wendy's mother is at home full time to monitor and supervise her daughter's care as she has difficulties trusting the carers and being confident in their abilities to manage care. Wendy has a paid carer for 13 hours a day and a sleepover shift once a week. Her mother provides the sleepover support 6 nights a week. Wendy continues to have an activity and therapy program involving private services and is reported to still be improving.

Key issues

- > Wendy had complex physical, cognitive, behavioural and emotional support needs arising from her disabilities
- > Wendy's family has provided a successful accommodation option that has effectively met her care and support needs to date
- > The family can identify her individual needs and then access funding through her compensation claim to purchase services to meet these needs (eg: purchase of vehicle, home modifications, attendant care, rehabilitation therapy)

Key issues – Case study 4 continued

- › Despite access to these resources, the process of providing care and support has still had an appreciable impact on the family carers, with both parents choosing to give up paid employment and her father now experiencing health problems so is unable to return to work
- › Although Wendy's family can provide a long-term accommodation option for her (potentially 10-15 years), it is unlikely that they will be able to provide lifelong accommodation support, as Wendy could expect to live a normal life span. The only option currently available is for a member of the next generation of her family to take over from their parents the demanding role of meeting her care and support needs

Case Study 5

Home-based care as a forced choice without compensation support

Tony was 22 years old when he suffered anoxic brain damage and he was non-compensable. He has severe physical, cognitive, communication and behavioural changes. He has minimal use of one hand and requires the assistance of two people for transfers and to carry out his personal care routines. Tony's family considered options but was forced to choose home when the only other option was a nursing home. Tony's parents visited nursing homes and understood that they were not appropriate for their son. This was both due to age and due to the combination of his physical needs and behavioural impairments which would not be able to be managed appropriately within that setting.

Key issues

- › Tony's father gave up his job to be involved in his care. His mother has continued to work. The level of community support available was inadequate in providing enough support to sustain their care for him at home so an application to DADHC for additional funding was made. This was granted only after the family made representations to their local Member of Parliament and only on an interim short-term basis
- › Two and a half years later Tony has no funding security. Service and family advocacy at a political level is required to support the 3 monthly applications for funds. He has not been able to access a long term funding option
- › He is not eligible for the Attendant Care Program (due to the eligibility criteria that requires that he is able to direct his own care and his level of cognitive impairment) and has been on the waiting list for the Home Care High Needs Pool since discharged home in 2002
- › Tony has only been able to achieve a patchwork of services. Currently in home carer support hours are provided through three different service programs and then brokered to a 4th service which actually provides the carers. This convoluted arrangement achieves continuity of carers within the home. Brokerage fees mean that 4 hours of paid service is reduced to three hours of direct care
- › Tony receives a total of 35 hours paid care per week. This is insufficient to reduce the psychological impact experienced by his parents. His father therefore cannot resume work even on a part-time basis. An admission to a nursing home appears inevitable if funding submissions are rejected or if one of his primary carers becomes ill

There is no foreseeable resolution to these issues for Tony and his family.

4.3 Transition from rehabilitation directly to a CLA

Discharge directly from inpatient rehabilitation to an appropriate community living arrangement is an important alternative to nursing home admission for people with complex high support needs when discharge to the family home is not an option.

Case study 6

Discharge from rehabilitation to a CLA

Marilyn was 49 years old when she was involved in a single car accident on the way home from work. She was living on a rural property in the Southern Highlands with Fred, her husband. Her 2 daughters lived in Canberra.

As a result of an extremely severe TBI Marilyn was severely cognitively impaired with poor memory and minimal ability to learn and remember. She was reliant on environmental cues. She was able to respond to simple conversation but inconsistently communicated her basic needs. Physically, she required a wheelchair, prompts and assistance with transfers and was dependent in most activities of daily living (ADL).

Her incontinence was a major care issue for her husband that he could not manage alone.

Marilyn was able to go home on weekend leave during her rehabilitation. The insurer paid for 24/7 carer support. Fred found this intrusive as he didn't feel comfortable continuing the business of the property while they were in his home. There were difficulties with recruitment, supervision and support with a Sydney based agency until care was arranged locally.

Fred rejected the nursing home option and a proposal was submitted to the insurer for Marilyn to live in a home of her own in Canberra, with carer support. This would provide access to family support, ongoing rehabilitation and options for community participation not available on a rural property. On a cost basis the insurer was reluctant to make this decision so Marilyn's solicitor was involved. Marilyn continued to stay in hospital.

Fortunately, the occupational therapist identified and referred Marilyn to a group home for adults with neurological disorders in the ACT. When a vacancy occurred a trial was organised and existing therapy staff provided training and education for new staff to understand Marilyn and her care needs. Marilyn was accepted as a permanent resident. The group home structure provided a familiar environment for daily living routines and social contact. Supplementary staff were recruited for individual community activities and involvement in craft groups. Her husband was happy with this option as she is visited by her daughters, has things to do, people to live with and can still come home for weekends with paid carer support. The insurer supported this community living arrangement as a viable long term community living arrangement.

Key Issues

- > Incontinence was a primary reason why Marilyn was unable to go home full time. Fred was unable to adjust to providing personal care so full time carers were required
- > Having paid carers in the home felt intrusive. Families consider it necessary to monitor staff
- > Accessing staff to provide the type of support and the level of care required can be problematic, particularly in rural areas
- > Discharge from hospital can be delayed when home is not an option and the only alternative model is to live alone with full time paid staff support. This is an expensive option that can only be implemented with insurer support
- > Marilyn had family in the ACT so was eligible for a group home model of support that was able to meet her high care needs after TBI. Additional staffing was for one to one community participation activities and home leave with her husband. This option required individual advocacy, as there was no clear pathway to community living
- > Fred was pleased his wife was living with other young people. He felt a sense of security with this CLA instead of having his wife live alone with paid carers

4.4 Conclusions

The case studies illustrate that:

- › Successful transition processes can be arranged to upgrade people currently resident in nursing homes to achieve alternative CLAs. Not surprisingly, the transition is a complex and time-consuming process that required expert guidance
 - › Home-based family support is a viable alternative to nursing home placement and has proved stable over time. However, it is important to address how support is provided and what support is available to families choosing this option. Without compensation, this can often be a stressful and difficult process, as there is an inadequate level of available service support. However, some families and people with TBI have felt conscripted into the HOME option by the lack of viable accommodation alternatives
 - › With adequate resources, it is possible to discharge people directly from hospital rehabilitation services to an alternative supported accommodation arrangement without the person needing to have an interim nursing home placement
 - › Living in a nursing home can reduce the skills of the person with TBI. There are different models of community living that can be adapted to meet the high care needs of adults after TBI. A house in the community combined with the resources needed to meet individual care and support needs provides a better living environment
 - › The CLAs in the ACT provide viable service options for adults with complex high-support needs as a direct discharge destination from a hospital rehabilitation service, and also as a destination for people involved in a transition process when already resident in a nursing home
- › Discharge from hospital can be delayed when home is not an option and admission to a nursing home is refused or inappropriate. Having a range of community living models can provide options and choices both financially and for meeting care and support needs when planning discharge
 - › Three other factors that may also reduce the number of people being discharged from acute hospital settings to a nursing home are:
 - The availability of slow stream rehabilitation beds and brokerage within NSW as a stepping stone from hospital rehabilitation to placement in a CLA for people with complex high support needs. This can reduce the time delay in accessing CLAs and is a model provided interstate
 - A review of the time period taken to determine eligibility for some types of compensation as these resources were not always available at discharge to fund an alternative CLA, resulting in the person with TBI being discharged to a nursing home
 - Having available a number of disability agencies with vacancies and the resources to manage adults with complex high care needs after TBI to provide accommodation support for community resettlement

5. Current living arrangements

This chapter reports on how satisfied families and people with TBI were with their current living arrangements and what factors constitute good quality accommodation.

5.1 What was the level of satisfaction with the current living arrangements?

Satisfaction is reported separately for people in community living arrangements and people in nursing homes.

The global satisfaction rating comprised a single item with 7 points (Delighted, pleased, mostly satisfied, mixed feelings, mostly dissatisfied, unhappy, distressed). Some people with TBI were too impaired to respond to the question.

33 people were living in the community at interview and 6 people remained in nursing homes.

Table 5.1 Satisfaction ratings with current living arrangements

	Community living (n=33)				Nursing Home (n=6)			
	Person with TBI		Relatives		Person with TBI		Relatives	
	N	%	N	%	N	%	N	%
Delighted, pleased	21	63.7%	21	63.7%	1	16.7%	–	–
Mostly satisfied	3	9.1%	3	9.1%	1	16.7%	3	50.0%
Mixed feelings,	3	9.1%	3	9.1%	1	16.7%	2	33.3%
Mostly dissatisfied, unhappy, distressed	1	3.0%	2	6.1%	–	–	1	16.7%
Too impaired to answer	3	9.1%	–	–	3	50.0%	–	–
No response given	2	6.1%	1	3.0%	–	–	–	–

> Currently living in the community (n=33)

Two-thirds of people with TBI and two-thirds of the family members endorsed one of the two top satisfaction ratings (delighted, pleased) in describing their level of satisfaction with their current living arrangements (see Table 5.1). However a smaller proportion of people with TBI and their relatives were unhappy with this arrangement. This comprised people with TBI who did not want to live at home but had no choice due to the lack of alternative options. Similarly, relatives who were not satisfied with these arrangements had limited choices and had felt forced to take the home option at discharge as there had been no other acceptable options.

> Currently living in nursing home (n=6)

One person with TBI responded that he was pleased with the nursing home environment. However he indicated that he was pleased because staff looked after all the people there no matter what their problems were and with the food being good. He also said:

"I don't like living here... Sometimes I think I should have died as I shouldn't have to be here..."

No family member with a relative in a nursing home endorsed the top two satisfaction ratings.

Fifty percent of families indicated that they were mostly satisfied with their relative living in the nursing home. However all family members qualified their answers to account for the context of living in a nursing home, getting used to being there, feeling secure and in acknowledgment of the efforts of staff in trying to tailor the care to meet the needs of the individual and family.

Some family members had mixed feelings about the nursing home arrangement or were unhappy. They identified the environment and living with the elderly, a lack of involvement in decision making, being disempowered and reliant on the good will of staff.

6 Spearman's correlation coefficient, $r_s = 0.574^{**}$, $p < 0.002$

7 Spearman's correlation coefficient, $r_s = -0.155$, nonsignificant

What was the level of agreement between the person with TBI and their family members about satisfaction with current living arrangements?

There was a **significant level of agreement** for people with TBI and their relatives about their satisfaction with their current living arrangement.

In the HOME group when the arrangement was working, it was working for both the person with TBI and the family member.

Similarly, when the arrangement wasn't working, both parties were dissatisfied.⁶

Was satisfaction linked to severity of disability and care needs?

No.

There was no evidence of an association between the level of relative satisfaction and the severity of disability or level of care/support needs as measured by the FIM.⁷

Family members were not more likely to be satisfied with the current living arrangement if the person with TBI was more independent. Similarly, family members were not more likely to be dissatisfied with the current living arrangement if the person with TBI was more disabled.

5.2 Domains important in providing quality living arrangements

Based on the analysis of interviews, three (3) domains were identified as important in providing quality living arrangements for adults with complex high support care needs

Environment domain

Importance of a personalised environment, physical access within the environment, staffing, quality of basic care/supervision and access to appropriate and long term rehabilitation

Social domain

Social relationships and access to community activities and broader community participation

Psychological domain of individual well being

- > Mental well being of the person with TBI including adjustment, choice, and happiness
- > Mental well being of the relatives which encompassed attitudes, functioning, adjustment, and coping

5.2.1 The environment domain

The environmental domain included 5 factors:

(i) Opportunity to create a personalised living environment

In the NH group:

The people in nursing homes had little if any opportunity to personalise their immediate living environment, for example their bedroom. This resulted in:

- > lack of privacy
- > impoverished living environments with few personal mementoes

These issues are especially important for people with TBI as:

- > having a private space is critical if the person needs “time out” as part of temper control strategies or when feeling cognitively overloaded
- > personalising the environment with familiar things, adds structure and visual cues that assists with orientation and memory

In the HOME group:

These problems were not encountered in the home environment, as the people with TBI were living in a familiar (“information-rich”) environment.

Importantly, the two people living in the long-term accommodation service were also able to live in autonomous living spaces that met their privacy needs and could be personalised.

(ii) Physical access within the immediate living environment

There were difficulties with an appropriate physical layout as well as accessing appropriate equipment needed to meet care needs for people in both groups.

In the NH group:

- > people with TBI who used a wheelchair for mobility were sometimes unable to go outside because of the lack of physical access
- > specialised equipment needed was not always able to be accessed because it was shared with other residents or not purchased as it wasn't needed by the majority
 - > no access to the Program of Appliances for Disabled People (PADP) for equipment or modifications to the environment and no alternative program to acquire their own specialised equipment

In the HOME group:

Many family homes had physical access problems and lacked suitable equipment

- > Modifications and equipment purchases for people living in the community were often accessible but time delayed – either due to the insurer approval process for major modifications, or waiting lists for community services for families who did not have access to compensation

(iii) Staffing issues

Having staff with a positive attitude and approach, who were reliable and liked the person with TBI, were identified as important factors for both nursing home and HOME groups.

There were some issues identified by respondents that applied to both nursing home staff as well as attendant care staff providing support in the home environment, namely:

- > staff often didn't know how to work with people with TBI due to a limited understanding of the physical, cognitive and psychological sequelae
- > poor staff levels and high staff turnover effected quality of care for everyone
- > staff did not consistently provide an environment that facilitated the person doing things for themselves
- > staff generally had education and training pertaining to elderly people

There were also some specific issues in relation to the staffing in nursing homes, namely:

In the NH group:

- > staff philosophy was about “doing things for the person when they can't do things for themselves due to increasing ill health”

In addition, staff often had:

- > limited time for each person, and so would do things for the person rather than promoting the independence of the person
- > difficulty dealing with cognitive problems or challenging behaviours

In contrast, in the HOME group

- > family members or Attendant Care staff could be more responsive in attending immediately to an individual's care needs compared to nursing home staff
- > staff had a companionship role not evident among nursing home residents

(iv) Quality and quantity of nursing care/supervision

The provision of good quality physical care was important for people with complex high support needs. Both groups (NH and HOME) reported problems with the amount and quality of care as well as how care was being provided.

In terms of quality of care:

- > “family care” was commonly viewed as the best level of care, because of the intimate knowledge family members had of the individual's preferences and needs, as well as the love associated with the provision of care

In the NH group:

- > problems arose with a lack of stimulation in their environment and not enough staff to provide 1 to 1 support for encouraging independence and accessing community activities

In the HOME group:

- > the person with TBI was not always happy about relying on relatives for care
- > attendant care service providers had difficulties meeting individual's needs and needs identified by the family as important

- > families reported a need to supervise the involvement of paid carers in the home environment
- > staff and families themselves identified issues with some family carers being over-protective so limiting individual independence

In terms of the amount of care:

In the NH group:

- > Relatives provided extra care required to provide some degree of quality of life
- > Supplementing care in the institutional environment by utilising volunteers was problematic

“...I tried to get volunteers involved as he needs more stimulation and therapy as there aren't enough staff to do these extra things but it isn't easy to start something like this at the nursing home...”

In the HOME group:

- > Families reported that it was stressful providing continual care without sufficient support

For both groups, there were issues in how to balance family care and paid care to address the needs of the person with TBI:

- > Families in the HOME group had to supplement paid carer hours
- > Families in the NH group needed to supplement the care provided to achieve an acceptable quality of life
- > Developing share care arrangements for people in nursing homes (eg: people spending a greater amount of time at home) was difficult because of limited social leave entitlements and poor access to equipment and modifications at home

(v) Rehabilitation

Both groups reported good access to general rehabilitation, physiotherapy and speech therapy programs. This finding however may be localised as BIRU staff provides active follow-up to clients in nursing homes.

If other NSW Brain Injury Rehabilitation Units do not provide these services or there exist regional recruitment problems then significant problems accessing rehabilitation may exist.

Problems were identified in the type of therapy available and managing the specific issues for people with TBI arising from their disabilities.

Relatives in both the NH and HOME groups identified issues such as:

- > individual therapy services of sufficient intensity and duration were difficult to obtain without compensation funds
- > difficulties in providing an environment that was conducive to making further gains and improvements

In the NH group:

- > rehabilitation is not a primary focus, the focus is on maintaining rather than improving skills of aged residents
- > the intensity of therapy required to make further gains was generally not available for individuals with TBI, unless they could purchase them
- > specific equipment for example, tilt table cannot be purchased unless useful for the majority of residents
- > in cases where some therapy was provided, there was no carry over of programs into the daily nursing home routines

In the HOME group:

- > families had difficulties managing the cognitive/behavioural sequelae such as inertia, lack of motivation and lack of insight, which were barriers to involvement in rehabilitation and limited gains that can be achieved
- > having family members playing a role in therapy, was also a barrier in some cases, because of the overlay of characteristic conflicts in parental-child role once the child is of adult age

“I (mother) have difficulty getting him (son in mid twenties) involved in things, he can be resistant and doesn't like being told what to do”

- > families also struggled with having to change roles to meet the rehabilitation needs

“His parents are inconsistent in setting boundaries, they have difficulties in changing from a parental role to a carer role and the result is increased poor behaviour of their son”

(staff talking about the not so good things for a teenager)

5.2.2 The social domain

The social domain is comprised of **(i) Social relationships** and **(ii) Community-based activities and participation**

(i) Social relationships

People in the NH and HOME groups both reported that:

- > When pre injury social relationships did not survive it was difficult to develop and maintain new relationships
- > Living with peers was identified as a way of improving social relationships
- > There was a lack of support and training available to enable adults with high care needs after TBI to interact appropriately with others, foster and develop relationships, resulting in social isolation and loneliness

“He really only has me and my friends for company...his friends have moved on and he isn't part of their lives anymore...”(mother explaining about her son's social networks)

In the NH group:

No one thought living in a nursing home with older residents met their social needs:

- > The environment was a disincentive for visitors and pre- injury relationships were difficult to maintain

- > People with TBI were younger and had little in common with the other residents and identified staff as their primary social contact
- > Some people with TBI developed a rapport with a fellow resident that subsequently died and this had a negative effect on future relationships with other residents

In the HOME group:

The level of social support provided by the family was positively affirmed:

- > For some families everything was good and there was nothing further needed to meet social needs
- > Families did identify positively when social networks and pre-injury relationships continued with the extended family, friends and neighbours
- > Some identified that their paid carers had the additional role of providing companionship

However, despite this some families identified that:

- > That it was often difficult to extend social networks when pre-injury networks and relationships end
- > A lack of peer involvement could lead to over reliance on key family members for social relationships

(ii) Community-based activities and participation

An important complement to maintaining and developing social relationships was the opportunity to participate in activities that promote peer involvement as well as having the resources (financial and personal) to achieve this involvement.

For both groups:

- > Transport and location was an issue – the availability and cost of using the taxi subsidy scheme, poor access to and not being able to use public transport, and dependence on family for private transport increased isolation and limited opportunities to participate

In the NH group:

- > A few people were only able to access community day programs on a group basis and if the nursing home was able to provide transport. The frequency of this was extremely limited so that residents were only able to spend a few hours a week or even a month interacting with peers in the community
- > Nursing home programs were aimed at the needs of the majority of residents and had little to interest the younger population. The nursing home was also not funded to provide access to community programs more suitable for the individual
- > Residing in a nursing home was often a barrier or exclusion criterion for attending community-based peer programs. When participation was achieved, it was frequently only as a consequence of individual advocacy

In the HOME group:

Some people did have access to community programs and were able to pursue their own interests at home and elsewhere, however this was a minority. For those who experienced difficulties, there were a number of issues:

- > A limited range of options for people to occupy their time if they were unable to return to employment, including the available activities not being suitable, and suitable activities not being accessible
- > Families found many service options were unsuitable, were tried without success or worked for a while, problems developed or funding was not recurrent
- > Services did not always have the level of staffing support available to enable the person to participate in community activities (eg: to manage cognitive problems, behavioural challenges)

5.2.3 The psychological domain

The psychological domain included elements relevant to the (i) mental well being of the person with TBI, as well as (ii) the mental well being of the family members

(i) The psychological domain for the person with TBI

The psychological consequences were observed in the effect on personal well being.

In both groups:

- > Feelings of distress were associated with not being in control, not living with people they liked or choose to live with and not doing what they want
- > Some people realised they needed their family for support and that was why they lived with them and accepted this
- > Others realised that their disabilities had changed them and this was why things were different
- > Significant numbers of participants required mood stabilising medication due to their personal distress in response to their life situation

In the NH group:

No one reported feeling happy. People reported that they:

- > had “...got used to it...” and were able to think of it as where they lived
 - > typically experienced a strong negative reaction to the experience of living with elderly people who were sick and dying
 - > experienced boredom and loneliness
- “I get bored and lonely and there isn’t anyone to talk to...”*

In the HOME group:

Some reported feeling happy with where they are living, identifying feelings of independence, adjustment to their disability and enjoying their living arrangement.

However, others still reported feelings of boredom, depression and loneliness, due to:

- > increased awareness about how they can't do things like before
- > a loss of confidence in their abilities
- > being confined with limited choices
- > dependent on family and frustrated by their disabilities and limited social relationships and activities

"The neighbour has a bad attitude to me as I look disabled because of my walking and this makes me depressed and I needed medication..."

(young man living with his mother in a Dept of Housing townhouse)

"I'm useless and all I can do is watch TV...before...I used to share what needed to be done (in the business) with my brother and now he has to do everything..."

(husband and father with physical and cognitive problems preventing him from involvement in wheat farming)

(ii) The psychological domain for family members

The three key issues for families were (a) Security that the long-term care needs of the person with TBI are being met (b) Family involvement in decision-making about management of care and support (c) Impact of a relative sustaining TBI on the family.

(a) Security that the long-term care needs of the person with TBI are being met

Family members had a strong understanding of the impairments and disabilities of the person with TBI and how this can make them vulnerable in society. Security was an important issue:

In the NH group:

Some families felt secure because:

- > the person was located in a defined service and the service will be there for their family member as long as it is needed

- > families were reassured that the service support will continue when they are not around

"We (his elderly parents) don't have to worry (about the future)... because he is being looked after (by the nursing home)..."

Importantly, this sense of security was also reported by the relatives of the two people with TBI resident in the ACT long-term disability support service

In the HOME group:

Families felt secure when they were able to oversee the health and well being of their relative and provide the care and support (including emotional support) for the person because he/she was living with the family.

For some families, the security was associated with the view that they provided better care than paid carers. This attitude sometimes arises out of previous negative experiences with carers or caring agencies or lack of trust of anyone outside the family circle.

However, some families did not always share this sense of security, as more care was needed than the family could provide so they were reliant on paid carers and different service providers. Within this context, funding programs lacked continuity and families often struggled to achieve recurrent funding from service providers and therefore felt insecure.

(b) Family involvement in decision-making about management of care and support

Families often wanted to feel in control by either being involved in the decision-making processes, or at least being consulted about decisions, particularly when families' involvement was encouraged by agencies to bridge staffing shortages and service gaps.

For both groups:

Families felt positive when nursing homes or community-based agencies had processes to resolve issues and listened to their views when considering changes to the provision of care

Families felt disempowered because of the lack of recognition of their role. In many situations the service provider was the primary decision-maker about care arrangements not the family. This included decisions about:

- > implementing specific programs
- > hours of support
- > involvement with the person and how they work with the family unit

However, some families recognised they could be over protective and limit the independence of their relative.

(c) Impact of a relative sustaining a TBI on the family

Relatives reported wide ranging ways in which having a family member sustain a TBI impacted on family life. These included the impact of specific injury sequelae; the loss of privacy; changed roles; impact on health and well-being; financial impact; and the burden of providing support.

Impact of specific injury sequelae

Relatives experienced difficulty or distress:

- > dealing with challenging behaviours observed after TBI (eg: temper control problems)
- > inappropriate social behaviours which caused social embarrassment to families

Families face the challenge of making adjustments and developing strategies to deal with the physical, cognitive and behaviour changes.

Loss of privacy

Involvement of services meant a loss of privacy. Some families accepted less paid carer hours to reduce the disruption caused by having paid carers in the home. In circumstances where a number of agencies were involved private and personal information often needed to be repeated. For families in both groups the involvement of services intruded on family life.

Changed interpersonal relationships and roles

Families reported changed interpersonal relationships and roles. This included:

- > losing their life partner, the person who shared their dreams and future goals
- > changing how they related to the person, so that the former mother/husband/wife/son became carers and case managers with a care and rehabilitation role
- > family members needed to change their priorities so they could manage the person with TBI and were often unable to maintain their own social networks
- > relatives centrally involved in the caring and support role were spending time away from other family members. This changed family dynamics and altered responsibilities of different family members
- > the burden of care for parents impacted upon their own relationship

Impact on health and well being of family

The behaviour of the person with TBI placed some family members at risk of harm. More commonly, families were concerned about their ability to continue the role of carer and the effect of stress over time on their health.

Financial Impact

A number of adverse financial consequences were reported including decreased levels of income and increased costs to meet care needs associated with the disability.

Burden of care

In some situations there were barely sufficient resources to sustain a support arrangement for the relative with TBI. Consequently, this support did not extend to assist the families sufficiently in alleviating their stress or reducing their burden when providing constant care and support.

5.3 Conclusions

5.3.1 The NH group

Nursing homes did not provide an acceptable accommodation option for people with TBI with complex high support needs. In brief:

Environment

- > Lack of privacy and personal space
- > Problems with physical access to move around within the immediate vicinity
- > Difficulties accessing needed equipment
- > Staff orientation did not maintain or improve the skills of the person with TBI, it was to assist people at the end stages of life
- > Lack of resources to provide sufficient and appropriate care and support – therefore lack of stimulation and responsive care
- > Limited access to rehabilitation

Social

- > Loss of pre-injury relationships, partly due to disincentive of nursing home ambience
- > Lack of opportunities for peer interaction
- > Co-located with people who were elderly, ill or dying
- > Social and community programs provided targeted needs and interests of aged
- > Difficulties in accessing community-based peer-related activities

Psychological

- > Personal distress at their own disabilities and living in a nursing home environment
- > Family often distressed at the nursing home placement

Nursing Homes however did:

- > provide some sense of security for families unable to provide the care/support themselves

- > typically (but not universally) meet the physical care needs of the person with TBI
- > in some cases, go to some lengths to make the situation bearable for the person with TBI and their families

5.3.2 The Home group

These options provided important and viable alternative for a proportion of people with TBI and their families. They had a number of advantages:

Environment

- > Personalised living space
- > Family able to provide part or the majority of care
- > Family and attendant carers able to be immediately responsive to an individual's needs, and carers also able to play more of a companionship role
- > Opportunity for the person with TBI to maximise independence

Social

- > Maintain family relationships and some social networks (eg: friends, neighbours)
- > Families assist in accessing community-based programs

Psychological

- > These options were often the expressed choice of the person with TBI
- > Families felt more empowered as they were able to coordinate the care

However, there were still a number of difficulties including:

- > Modifications of the living environment to enable easy access
- > Disruption caused by intrusion of paid staff into family life
- > Problems with accessing continuous and appropriate carer support services

- › The conflict that arose between the person with TBI and family members when they were playing roles as carer and rehabilitation aide in addition to their normal family roles
- › The person with TBI not wanting to rely on relatives for support needs
- › Difficult to find appropriate community-based programs
- › Families sometimes acknowledged they were over protective and limited the person's independence
- › The stress of providing care, often with insufficient support, with particular difficulty in managing challenging behaviours

5.3.3 Options for alternative community living arrangements

Alternative options for living in the community are needed in situations where the person with TBI, or the family, does not want to choose to live with family, alone or in a nursing home. Elements needed in such alternatives include:

Environment

- › Availability of single rooms
- › Physically accessible living arrangements within and immediately outside the residence
- › Access or availability of needed equipment
- › Service philosophy that promotes independence and skill development
- › Sufficient staff to provide care
- › Staff with appropriate training in the management and support of people with TBI
- › Rehabilitation services available and therapy programs reinforced within the service

Social

- › Co-location with other peers
- › Staff support clients in maintaining relationships with family and promote peer interaction
- › Staff provide age-appropriate activities and participation within the residence and support access and participation to appropriate community-based activities

Psychological

- › Services available to provide support to adults with TBI experiencing distress and also assist staff to devise ways to manage challenging behaviours
- › Families welcomed as an important part of the management of support arrangements, assuming that the person with TBI wants this

The ACT services provides two examples of how an alternative community living arrangement can successfully meet the needs of an adult with complex high support needs as the result of a TBI and provide a good quality of life long term.

In part, chapter 6 will outline why the current service system cannot consistently deliver these alternative support options to the majority of people who need them.

6. Current service system

Throughout this report, accommodation has been defined broadly as encompassing the place where a person lives, the support they need and the things that they do.

In this chapter, the following questions will be examined:

- (i) what services are currently available to provide quality support to adults with TBI and their families who are in the HOME group?
- (ii) what services are available to provide alternative accommodation options for people not wanting to choose to live alone, with family or in a nursing home?
- (iii) what services are immediately available to assist adults with TBI who will have to go on living in nursing homes over the short-medium term?

The previous 3 chapters were based on the perspectives, experiences, concerns and expressed preferences of the people with TBI and their relatives.

This chapter supplements these experiences with data based on the extensive clinical experience of the authors as well as various reports and submissions of a range of organisations from across Australia.

The following aspects of the service systems will be reviewed. Eligibility for existing services; availability of services and degree of coordination of service delivery.

Finally, the experience of people in the sample who were reliant on publicly funded services will be compared with the service options available to people with access to compensation.

6.1 What services are currently available to support the adults with TBI and their families who are in the HOME group?

Eligibility for existing services

People in the HOME group are eligible for most community-based disability services. These include:

- > home support services (eg HACC, Home Care)
- > equipment/home modifications
- > community social support programs (eg: HACC respite programs)
- > community transport services (eg: HACC transport, state funded taxi subsidy)
- > home-based rehabilitation

However, there are a number of eligibility issues:

- > adults with TBI may not be eligible for long-term rehabilitation services (eg: some services give priority to adults with TBI who are within a certain time limit of the injury)
- > some generic disability services including day activity programs and respite programs exclude adults with TBI
- > family members are generally not eligible for a new respite program provided by the Commonwealth Carer Respite Centres that target the elderly carer, as the age entry criteria is higher than that of most relatives participating in this survey (only 5/33 over 60 years of age)

Availability of services

Although eligible for a range of services, families in the HOME group often have significant difficulties accessing sufficient levels of services, and there are often long waiting times. Although eligible for some services, they may not be given priority and may therefore miss out.

Home support programs

- > People with TBI without compensation can only access a limited range of home support hours through programmes such as Home Care and then only if a vacancy is available at the level of care the person requires. If someone is needing a higher level of care than the maximum available through Home Care then they are referred to the High Needs Pool to await a vacancy on that program. The diagnosis of TBI is generally a barrier to access other programs with high care funding.

Equipment/Home modifications

- > There are often long waiting times to get approval for equipment or home modifications. This can delay discharge from hospital. Also, there are limits on the type of equipment that can be accessed. Despite playing a central role in providing transport to the person with TBI, modified cars for families are not funded under existing programs

Respite services

The benefits of providing a break for the carer/family are well known.

- > The request for respite services in this survey ranged from 2–3 nights per week to regular bookings of 2–4 weeks per occasion to give the carer/family a break. However, the Commonwealth Carer Respite Centres can provide flexible and responsive respite solutions but it does not provide regular respite as a component of lifestyle planning. Funding is primarily targeted at crisis or short-term solutions. Families are often only able to get minimum levels of respite at these times
- > People with TBI living at home with family did not want to have respite at a NH. Families who had rejected NH as an option for discharge did not accept this as an option for residential respite

Respite can also be achieved for families by the person with TBI attending day activities.

- > Out of home respite that is a positive experience for the person with TBI was an identified need not available in the community at the level of support required
- > Adults with TBI may end up attending day programs principally organised for the elderly or for other disability groups
- > Existing community access programs provided by organisations such as Headway are limited in number and resources
- > Community-based programs that provide support by enhancing community participation activities and social relationships are not readily available or sufficiently funded to provide 1 to 1 personal care or the cognitive/ behavioural supervision needed

Psychological services

These services are needed to deal with behaviour changes after TBI and counselling for emotional distress.

- > Community Health Centres only provide set numbers of sessions, there are often long waiting lists and knowledge about specific TBI issues may not be well known. Purchasing private counselling is associated with high costs – a single session at \$100 is the equivalent of half the weekly pension
- > Clinical Psychology services are inconsistently available through the BIRP

Coordination of service delivery

The current HACC service model is based on a purchasing process, and in the case of adults with complex high care needs, may involve purchasing the same service types from different providers. Families found it confusing and frustrating when required to deal with several different agencies and staff for the same services.

6.2 What services are available to provide alternative living arrangements for people not wanting to choose to live alone, with family or in a nursing home?

Eligibility for existing services

Wareemba Community Living (WCL) Inc is the only specialist ABI accommodation support service available in NSW. They have supported adults with complex high support needs as a result of TBI with up to 24 hours support per day. The funding arrangements are specific to the individual and their circumstances.

There is **inconsistent eligibility** for people with TBI seeking access to generic disability accommodation services:

- > Adults with a TBI are eligible to be considered for admission to DADHC funded accommodation services. However, the reality of admission is restricted by specific eligibility criteria set by some non-government funded services, the issues of compatibility with other residents and the shortfall of disability accommodation services generally
- > Aged Care Assessment Teams screen admissions to boarding houses. Adults classed as needing a level of care available in a high or low-level aged care facility (ie: aged care hostel or nursing home) are ineligible for admission to a boarding house due to their higher support needs

Adults with TBI are unable to access two programs that provide higher levels of support than the standard HACC-funded home support services for people with disabilities living independently in the community:

- > The Attendant Care Program. This provides up to 5 hours per day 7 days per week of personal/domestic care services. However the target group is people with physical care needs who can manage their own carers. People with a TBI and significant cognitive impairments are therefore ineligible for the program

- > The Home Care High Needs Pool. Adults needing a high level of Home Care services (more than 20 hours per month) can be placed on this list. However waiting times are extensive so the reality of admission into the program is that it is an extremely unlikely option

Availability of services

Wareemba Community Living (WCL) has only a small number of government funded clients who are usually tenants of the Dept of Housing. The majority of WCL clients have compensation. It is not a statewide service. Gary (case study 2 in Chapter 4) needed 36 hours per day of funding to meet his care and support needs. WCL has the infrastructure to meet this level of care and needs in the community providing housing and support funding is available.

Existing home support services would not be able to meet this level of support needs.

In NSW there is no generic disability accommodation service that targets people with TBI. This combination has been achieved in other states for adults with ABI (eg: Brightwater in WA has an ABI program within their aged care services).

Coordination service delivery

Coordination between a range of services is critical to manage the successful transition from the nursing home to the community, to support people living in the community, alone or with family or to develop alternative community living arrangements. There are few services that have this role or expertise. There is limited networking possible to achieve coordination across services or to develop a range of different living arrangements.

No specialised long term community-based coordination or case-management services are available. The level of long-term case management provided by the BIRP teams vary from service to service depending on the level of demand and resources.

Private case management services are available for people with compensation. Generally these services are provided on an individual basis.

6.3 Can services address some of the immediate needs identified for the people currently living in nursing homes?

Adults with TBI in nursing homes have very few service options, because, by definition, their residential status disqualifies them from almost all state-funded disability service programs.

Eligibility for existing services

Adults living in nursing homes cannot access the broad array of state-funded disability support services, by virtue of their residence in a nursing home even though they are younger than the target population.

The National Alliance of Young People in Nursing Homes (2004) has highlighted this anomaly.

Participants in the NH group are not eligible for most services including home support services (eg HACC, Home Care); equipment; community social support programs (eg: HACC respite programs); and community transport services (eg: HACC transport).

There is limited eligibility for:

- > long-term rehab services (some BIRPs do not service clients in nursing homes)
- > generic disability services including day activity programs, respite programs, etc. (some of which exclude adults with TBI living either at home or in nursing homes)

Adults living in nursing homes have no access to funding for equipment and modifications through schemes such as PADP. There is limited funding to enable families to purchase equipment for home or to undertake home modifications to facilitate increased time at home.

Special issue

In nursing homes, limited social leave is possible under the legislation, based on typical patterns for the elderly. Families and their relatives with TBI living in nursing homes are interested in greater amounts of home leave being possible.

6.4 Compensation vs. publicly funded services

Table 6.4 (page 48) provides a brief comparison between the options available for adults with TBI who are compensable and people with TBI dependent on publicly funded programs.

Table 6.4 Comparison between public services and compensation funded services

	Public	Compensation
Home support	HACC or Home Care is generally limited to 5 – 7 hours per week.	No upper limit- based on reasonable and necessary test.
Equipment / Home modifications	Long waiting list through PADP or Home Modifications Programs and limited options available.	Any reasonable proposal funded including home modifications, computer aides, electric wheelchairs, special mattresses etc.
Rehabilitation	Local brain injury rehabilitation service may provide only time-limited services. Public clinic in rehabilitation services have long waiting lists. Private rehabilitation can be extremely expensive.	Any reasonable request for treatment can be funded and provided through private rehabilitation providers.
Respite	Limited respite through HACC & CRC. Only residential option is a nursing home to manage high care needs.	Purchase individualised flexible respite services and residential services needing payment/supplementary care.
Transport	Taxi subsidy but long wait or difficulties booking modified taxis. Can be costly.	Payment for modifications to vehicles family/carers drive.
Community activities	Few programs available and limits on attendance due to lack of resources to provide needed levels of staff support.	Staff available to provide 1 on 1 support for community access and participation in groups when available and appropriate.
Psychological services	BIRP services may not provide. Long waiting list and limited sessions available through community health centres.	Any reasonable proposal for counselling or behaviour management services can be approved.

6.5 Common themes

There were three service delivery issues that were common across all situations.

6.5.1. Staff with limited training and expertise

The lack of education and training that affects quality of care can be improved. A state wide approach is needed to coordinate education and training of staff to increase knowledge and skills to manage issues arising from TBI. The Brain Injury Association of Queensland is a nationally accredited training organisation (ATO) providing ABI specific courses. This option is not available in NSW. However, generic aged care and disability training is available via NSW TAFE and privately accredited training organisations (eg Nursing Group NSW). Training can be provided by RTOs to individuals and organisations with a disability focus but this is not ABI specific. Training can be costly for professional development of existing workers and to entice new workers into the sector.

6.5.2. Generic disability services

Despite the current emphasis on generic disability service provision, there is still widespread inconsistency about whether generic services are willing, able and sufficiently resourced to accept adults with TBI and meet their care and rehabilitation needs. This was noted across a number of service types including accommodation, community access, and respite.

Families and their relative with TBI who need a high level of support identified the difficulties obtaining disability services. The programs are often not suitable or well liked by the person with TBI for many reasons such as the activities not being suitable for their age and type of interest.

6.5.3. Behaviour support

There was a need for specialised behaviour support for families and agencies providing support to adults with TBI (eg: staff in generic residential services, community access and respite programs, home support services) to deal with some of the behavioural change that occurred post-injury.

6.6 Conclusions

The current service system is producing poor outcomes for adults with TBI who have complex high support needs:

- > some people are being placed in nursing homes
- > families in the HOME group incur substantial personal and financial costs in providing this level of care due to the limited availability of service supports
- > in this study two interstate community living options have been identified, and the viability of these options has depended on the person with TBI having access to compensation to supplement care (Gary, *Case study 2* and Marilyn, *Case study 6*)

There are a number of issues with the current service system that have resulted in these poor outcomes.

Critically, there is no overall coordinating agency or strategic planning to address the complexity of ensuring that adults with high care needs after TBI have access to appropriate community living options. Many agencies work on a local level whereas, given the relatively small numbers and complex needs shared by this group, a supra-regional approach may produce better long- term outcomes.

In addition, neither DADHC nor Home Care currently has a long-term plan to address this issue for people with high care needs after TBI separate to people with other disabilities.

Other issues include:

- > inconsistent eligibility for needed services
- > insufficient resources within the services that can be accessed to provide the needed level of support
- > lack of appropriately trained staff
- > lack of access in NSW to community living options, services and appropriate housing models for adults with TBI and high care needs
- > lack of equity between compensable and non compensable adults for planning, organising and implementing community living arrangements

7. Ways forward

The inappropriate placement of younger people with complex high support needs after TBI into nursing homes pleases no one. This is not one of the options of choice. When the nursing home option is taken it is not a real choice but a forced choice because of the lack of any true alternatives.

A Statewide service is required whose core business is an intergrated approach to managing the environmental, social and psychological factors for people with complex high care needs after TBI.

A Statewide service would facilitate:

- > a reduction in the number of adults with TBI and high care needs living in nursing homes and prevent new admissions
- > an increase in support for families supporting their relative with high care needs after TBI at home
- > a co-ordinated and planned approach to enhancing existing community living models and the development of long term care arrangements in metropolitan and rural settings

This chapter will outline some of the planning principals that could address the diverse community living arrangements for adults requiring complex high level care after TBI, and recommend ways to implement change.

7.1 Key planning principles

- > Many adults with TBI resident in nursing homes are medically stable and could have their care needs met within a community model of support
- > Community living arrangements need to be creative, flexible, supported by legislation and funded appropriately
- > Adopting a person /family-centred approach can assist in identifying the issues, developing strategies and providing local solutions to meet individual needs

- > Individual circumstances will influence decisions about how care and support needs are organised and resourced.
- > A number of existing models of community living arrangements can be utilised to enable individual solutions to be developed in local communities where pre-injury relationships and social networks could be maintained
- > A mix of service approaches that incorporates improving the skills of existing generic disability service staff, increasing the level of support to home-based models of care and the introduction of dedicated, specialised community living options

7.2 Service elements

Community living models

Four community living models were reflected in the study. All these models provide a starting point in developing a range of viable, community living options. These are outlined in Table 7.2. (pages 52-53). Detail is provided on the housing stock and service supports as well as some of the needs and issues of the different models.

Individualised support packages

A variety of accommodation options is required to meet the needs of adults with TBI.

It is therefore critical to explore tailoring individualised support packages that provide for improvements to environment (physical, staff and care and rehabilitation needs) as well as social and psychological factors.

- > a set of criteria needs to be developed to identify people with high and complex needs after TBI as a target group so that they can access individualised accommodation support funding packages
- > the packages would promote service coordination, provide secured levels of support long term and manage environmental factors

These support packages are of particular relevance in

- (i) arranging a community living option for people about to be discharged from inpatient rehabilitation to the community;
- (ii) supplementing support services for people in the family home to reduce the burden of care and maintain family relationships;
- (iii) increasing the activity of people currently resident in a nursing home as a short term solution to social isolation; and
- (iv) assisting the transition of people out of a NH or family home into an individualised community living arrangements.

Transition arrangements

People who want to move out of NHs or live separately from their family need pathways to the community.

- > Sometimes there is a need to be involved in a transitional rehabilitation service to manage upgrade from a nursing home or home to more independent accommodation
- > Needs include skill development for the person, provision of equipment and home modifications as well as discharge planning with liaison and coordination of community based services to achieve community living

The ABI: Slow to Recover Program in Victoria provides an example of an innovative rehabilitation and support program for young people who have suffered a catastrophic brain injury. This model can be adapted for use in NSW to assist adults with high care needs after TBI to move to a community living arrangement. It is flexible and responsive to individual and family needs. The service utilises brokerage funding for the care and rehabilitation resources required. This program has a number of locations for the service including nursing homes and family homes.

However, it does not provide solutions to meeting care needs when the family home is not an option. There is no service development program for supported accommodation.

Sometimes the cognitive impairments of the individual mean that they are unable to transfer skills learnt in one environment to another environment. In this situation the transition program would be directly into their new accommodation with high staffing levels to facilitate learning and then reduce the level of support to maintenance levels once the situation had stabilised.

In NSW the BIRP Transitional Living Programs provide skill development as a transition to community living options. However, the current limitations of staffing and resources (eg physical environment and equipment) are a significant barrier to utilising this option for people with complex high support needs after TBI.

Table 7.2 Community Living (CL) Models

CL model	Stock	Support services	Needs
1. Family home-based support	Owner occupied, private rental, Department of Housing	Primarily provided by family and supplemented by offsite staff	<ul style="list-style-type: none"> > Family members manage necessary changes to their lives and adjust to the impact of disability. They are meeting the care/rehabilitation needs of their relative with TBI > Balance between family care and paid care > Effective social relationships and activities that had a positive influence on the lifestyle of the relative with TBI > Difficulty for family members playing multiple roles
2. Living on own with individual support organised	Owner occupied, public housing, stock or part of the housing stock of an existing agency	Offsite staff services are organised to support the person in their home	<ul style="list-style-type: none"> > Option for people who are unable to live with family or share with others because of significant behaviour and cognitive changes after a TBI > Flexible in addressing individual needs, allowing for close proximity to family > Suitable for people who can be left alone as well as for people who cannot be left alone > Expensive option where there are high levels of care and support needs > Potential to increase social isolation if adequate resources for community participation and social skills are not included

Table 7.2 Community Living (CL) Models continued

CL model	Stock	Support services	Needs
3. Living on own within a small cluster of units/ town houses	Purchased or purpose-built funded through compensation moneys or acquired through negotiation with Department of Housing by direct tenancy with client or organisational agreement	Onsite staff services support the person in their individual environment	<ul style="list-style-type: none"> > People can live alone while sharing staff within the same management framework. Provides support and there can be access to staff up to 24/7 > Generic or specific service infrastructure > It may not be suitable for people with medical vulnerability (unstable epilepsy) > Staff working with people in a cluster develop knowledge and understanding of issues
4. Sharing with others with a disability in a group home model of care	Purpose built, funded through compensation moneys, acquired through negotiation with Department of Housing or tenancy with a disability service	On-site staff services support the person in their individual environment, as well as managing group dynamics	<ul style="list-style-type: none"> > This model has the potential to improve social contact, reduce boredom and unhappiness while providing a cost-effective option for people with high care and support needs > Specific or generic service > Compatibility and limiting numbers to enable care and rehabilitation needs to be met are critical issues > Creative design in building may assist in increasing numbers while continuing to manage interpersonal interactions > Staff working in the organisation develop knowledge and understanding of the residents

7.3 Service support structures

People with high care needs after TBI require a statewide coordination service to:

- > implement the support structures that are necessary for the success of the community living models, individualised support packages, and transition arrangements
- > identify those people inappropriately living in nursing homes across the state
- > develop solutions in partnership with local service providers on an individual case basis
- > facilitate the establishment of new community living models
- > provide direct services introducing individualised packages and arranging transition programs if a local service provider is not available to do so

Existing service systems are not providing the focus, resources and expertise required to address the issues to improve outcomes for people with TBI and their families. DADHC do not have a separate funding program specifically for adults with TBI and complex and high care needs as this group is not identified as “special needs” under the HACC National Guidelines.

A state wide coordination service would address the following service system issues in order to:

- > improve the support to families living with and providing care to an adult with high support needs after TBI
- > facilitate the transition of adults currently in nursing homes into appropriate community living accommodation options
- > facilitate the transition of adults with TBI and high support needs directly from rehabilitation services into appropriate accommodation options

A state wide program would need to liaise with the following types of services at a regional level, to purchase services when they exist and be involved in

creating services where there are gaps. A Statewide perspective and inter-departmental liaison would enhance opportunities in metropolitan and rural areas.

a) Long term case management

Case management provides a structure for long-term monitoring and support for the person with TBI, as well as assists in the reorganisation of services when changes occur. Long-term case management can work on goals over time and have a fluctuating level of intensity of support and involvement. The case manager can facilitate integration of people with TBI into existing generic disability service structures, as well as developing new living arrangements if required.

The statewide service could coordinate with local BIRP units to play this role, or where such a service was not available identify and purchase private case management services.

Some BIRP community rehabilitation teams provide case management/case monitoring services for adults with TBI in nursing homes within their region. There is no coordinated approach to creating community living solutions when gaps are identified at local, regional and state service levels.

(b) Training/Staff education

The development and coordination of staff education and training at a state wide level is a current service gap and a strategy to improve this issue needs to be developed. This would target generic and TBI specific staff.

Victoria and Queensland have identified training pathways at TAFE appropriate to staff working with adults with TBI. In NSW a mapping exercise of current training structures may be useful in conjunction with an audit to identify existing training resources and programs that provide skill development opportunities, teaching and learning styles.

Introducing a system that can be integrated with mandatory training or a similar structure that already exists within services may be possible to facilitate staff access to education and training.

Examples:

- > The BIRU, Liverpool provides an Introduction to TBI Training Day for generic staff. This option could be provided more broadly across NSW when the current MAA project is completed and the information is available in a CD format for presenters and a self learning format for workers. This training could become a minimum standard of education for staff working with adults with TBI
- > In 2005 the Attendant Care Industry Association (ACIA) was established in NSW with support from the MAA. Over the next 3 years this group may assist in identifying and responding to education and training needs in the sector
- > Current accredited courses in aged care and disability for workers in the community provided by TAFE and private agencies could be identified. Training pathways and workplace practice could be modified so that the information is appropriate for staff working with adults with TBI

(c) Transport

Improving transport is a key to accessing social supports and maintaining community participation. Providing transport is not often a component of community programs. Transport could be addressed as a component of an individualised support package.

There are no current examples of this service option.

(d) Development of residential respite options to reduce the impact of prolonged caring by families

A number of different service models exist to provide respite. This includes individual and group holidays/activities with staff support, increased hours of support in the home when the family is away, residential respite services that are usually a shared living arrangement in a house in the community. Gaps in services can be addressed by negotiating solutions with local service providers /the person /the family to develop creative options and a process to apply and achieve new funding.

Examples

Hunter Brain Injury Respite Options; the Community Living Unit of the Liverpool BIRP at Chipping Norton and The North West Disability Service residential respite program at Gemhill Cottage in Castle Hill. Wareemba Community Living Inc organise small group holidays with their clients. There are a small number of private holiday destinations that are physically altered for adults in wheelchairs but staff support is not included. There are a small number of escorted holiday programs for people with disability.

(e) Increasing community participation

Integrating into community participation programs or events to provide meaningful activities is an essential component of long term care for people with complex high support needs. There are a range of community-based options available but people with high support needs are often resource intensive. Consequently, agencies are reluctant to provide services or will limit the amount of services they provide to manage within resources so supplementary funding may be required to achieve the support needed.

Examples

Families and their relative with TBI who are compensable often organise the support they need by recruiting attendant care staff to work with them on a 1 to 1 basis to enable them to attend and participate in community-based programs and activities.

(f) Psychological services

There is a need to provide services to manage the psychological effects of living with a brain injury. These include:

- > counselling for people with long term disability after TBI
- > addressing problems people with TBI have in participating in their community and social life because of cognitive problems including poor motivation, lack of insight into support needs, poor judgement and vulnerability to others

- > addressing challenging behaviours including verbal and physical aggression

Examples

Psychological services are inconsistently available through the NSW BIRP teams. In addition, BIRP teams often purchase private psychological services for their clients who have compensation.

In Victoria the ABI Behavioural Consultancy unit provides a statewide behavioural consultancy service to agencies and families facing challenging behaviours as a consequence of ABI.

7.4 Recommendations

In NSW there is an urgent need to change how services are provided to adults with complex high care needs after TBI. Support and rehabilitation needs are often not being met within the current services and support structures.

A nursing home admission can be avoided if community living arrangements could be accessed as a continuum of rehabilitation and discharge planning.

- > Adults with TBI are not an identified special needs group with either Commonwealth or State governments. This is a barrier to accessing existing services and in the development and long term funding of appropriate service models at the state level
- > The MAA has a key role within the NSW CTP scheme to support improved management of claimant's injuries. The MAA has experience with a variety of programs and initiatives for adults with TBI on a project basis and in the development of policy

The central requirement to moving forward is the identification of a statewide organisation with a TBI focus to integrate key planning principals into the development of viable long term community living options for adults with complex high care needs after TBI.

A Statewide organisation could integrate and develop the essential elements⁸ of a service system to make the practice of nursing home admissions obsolete and facilitate transition to community living arrangements.

A Statewide organisation whose core business is people with complex high care needs after TBI could facilitate service access with Generic Community Services and Generic Specialist Services.

A Statewide organisation could identify common client and service needs; resolve sector wide issues; be involved with systemic planning and commitment of resources. Additionally, a statewide organisation can review legislation, evaluate and monitor service quality, outcomes and effectiveness.

A planned and coordinated statewide approach could involve formal and informal collaboration with community and government agencies. Inter-agency representation would facilitate the development of options for accommodation support; flexible approaches to meeting the environmental, social and psychological needs of the person with a TBI; education and training.

The placement of adults with high care needs after TBI into nursing homes is not appropriate. It pleases no one. The outcome of implementing a state wide organisation with a TBI focus would be the creation of a viable service system that would make this a redundant forced choice for adults with high care needs after TBI.

⁸ NSW Department of Aging Disability and Home Care, Innovative Models of Community Support for People with High and Complex Support Needs, Fig 2.2 page 37, CDDS, Sydney

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Appendix 1 Brain Injury High Care Needs Accommodation Survey

1. Participant No:

2. Currently Living:

3. Living circumstances: (please tick)

- | | |
|---|---|
| <input type="checkbox"/> Own home | <input type="checkbox"/> Parents home |
| <input type="checkbox"/> Boarding house | <input type="checkbox"/> Rent |
| <input type="checkbox"/> Nursing home | <input type="checkbox"/> Acute/rehab hospital |
| <input type="checkbox"/> Transitional living unit | <input type="checkbox"/> Other |

If other:

Questions for the most appropriate person possibly non paid carer or family member

4. When did the person with BI leave hospital?

5. What was the discharge destination?

6. At the time was this decision: (please tick)

- | | |
|--|------------------------------------|
| <input type="checkbox"/> Very easy | <input type="checkbox"/> Easy |
| <input type="checkbox"/> Not easy or difficult | <input type="checkbox"/> Difficult |
| <input type="checkbox"/> Very difficult | |

7. Why was this decision made?

I am now going to ask you four questions concerning your understanding of the thoughts/attitudes of the person with the brain injury. Remember, the person with a brain injury may have a different opinion to yours about the following issues.

8. Does the person with the brain injury like their current living situation? (please tick)

- Yes No

9. How satisfied do you think the person with the BI is with where they live? (please tick)

- Delighted Pleased Mostly satisfied
 Mixed Mostly dissatisfied Unhappy
 Highly distressed

10. Where would the person like to live?

11. What understanding does the person with the BI have about why they are living at their current address?

I would now like you to answer the following questions from what YOU feel/believe from your knowledge of your relative and all the factors that impact on his/her life.

12. Do you like the person with BI living in their current accommodation setting? (please tick)

- Yes No

13. How satisfied are you with the current accommodation setting. (please tick)

- Delighted Pleased
 Mostly satisfied Mixed
 Mostly dissatisfied Unhappy
 Highly distressed

14. What do you consider the good things about the current living situation?

15. What do you consider the not so good things about the current living situation?

16. Is there anything else the person with BI currently needs? (may need to prompt – equipment, activities, therapy, etc).

17. If so, what resources would be needed to meet these needs? (try and get details not just more money but what it would purchase).

18. If it was possible to provide alternative accommodation for the person with the BI, what would be better, if anything, to their current living situation?

19. What do you perceive the barriers are to providing alternative accommodation?

20. What do you think are the resources (not just money but what it would purchase) needed to achieve alternative accommodation?

Question 21. Only when the person is NOT living in a nursing home.

21. Some people with high support needs live in nursing homes and others with similar high support needs are able to live in a range of other accommodation.

From your experience what do you think made the difference, even little things that allowed the person with the brain injury to live at home and NOT have to live in a nursing home. (Interviewer may need to prompt without being directive eg. was there a special person that helped organise things, frequent respite, day facility, willing family, etc)

Person conducting interview

Name

Signature

Appendix 2 Statistical analysis

Table 3.1: NH versus HOME group

Variable	NH group (n=9)		HOME group (n=30)		
	N/Med	%/IQR	N/Med	%/IQR	x ² /z
Sex					
Male	7	17.9	24	61.5	–
Female	2	5.1	6	15.3	0.021
Compensation status					
Compensable	3	7.7	12	30.8	–
Not compensable	6	15.4	18	46.2	0.130
Injury related variables					
GCS	3	9	4.5	4	-0.231
Length of PTA (days) ¹	183	–	105	144	-2.377*
Age at injury (years)	38.9	18	24.8	20	-2.133*
Rehabilitation episode					
Occurrence (days) ²	49	35	39	33	-1.158
Length of stay (mths)	5.2	7	2.5	9	-0.267
Discharge FIM (total)	27	42	98.5	34	-2.890*
Current FIM (total)	47	46	99	31	-2.185
Current Function CANS					
CANS levels 6-8	7	17.9	17	43.6	–
CANS levels 2-5	2	5.1	13	33.3	1.304

* Significant with Bonferroni correction (0.05/7; p<.004)

1 Data available for 4/9 NH group and 26/30 HOME group

2 Time frame from injury to rehabilitation episode

Glossary

Acquired Brain Injury (ABI)

Brain Injury Rehabilitation Unit, Liverpool (BIRU)

Care and Needs Survey (CANS)

Community Living Arrangement (CLA)

Commonwealth Respite Centre (CRC)

Department of Ageing Disability and Home Care (DADHC)

Functional Independence Measure (FIM)

Glasgow Coma Score (GCS)

Home and Community Care (HACC) program

HOME group (study group mostly discharged to family home)

Length of Stay (LOS)

NH group (study group discharged to nursing homes)

NSW Brain Injury Rehabilitation Program (BIRP)

Post Traumatic Amnesia (PTA)

Program of Aids for Disabled Persons (PADP)

The Motor Accident Authority (MAA)

Traumatic Brain Injury (TBI)

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