

**Acquired Brain Injury:
Slow to Recover Program
Report of the Therapy Review Project**

FINAL COPY

Sue Sloan

BAppSc(OT), MSc(Clin Neuropsych)

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Prepared by:

Sue Sloan
Osborn Sloan & Associates Pty Ltd
PO Box 2191
KEW VICTORIA 3101
AUSTRALIA
Telephone: +613 9853 2638
Fax: +613 9855 1435
Email: sue@osbornsloan.com.au
Website: www.osbornsloan.com.au

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EXECUTIVE SUMMARY

As a result of improved medical and rehabilitation management, the number of people with acquired brain injury (ABI) has increased dramatically over the past two decades, with 1 in 45 Australians (432,700 people) estimated to have an ABI resulting in activity limitations or participation restrictions due to disability (Papastrat, 1992; Victorian Government Department of Human Services, 2001). People who sustain very catastrophic ABIs, are now surviving with a life expectancy comparable to the general population. (Baguley, Slewa-Younan, Lazarus, & Green, 2000; Brown et al., 2004; Harrison-Felix, Whiteneck, DeVivo, Hammond, & Jha, 2004; Ratcliff, Colantonio, Escobar, Chase, & Vernich, 2005).

This group have specialised and complex needs and report more health conditions than the average person with disability (*Australian Bureau of Statistics*, 2004). The fact that a high percentage of these survivors are young implies that they will require lifetime care (Ponsford, 2003; Strettles, Bush, Simpson, & Gillet, 2005; Tate et al., 2003).

The Acquired Brain Injury: Slow to Recover (ABI:STR) program was established in 1996 for people with catastrophic brain injuries who were not eligible for compensation or not accepted into traditional rehabilitation services. The ABI:STR program is a Victoria-wide program that is managed by Southern Health. This program provides individually targeted slow-stream rehabilitation services to people to maximise their potential to achieve functional gains and thereby to assist them to achieve optimum levels of independent functioning.

The purpose of the current Therapy Review Project was to examine the framework for therapists providing services to ABI:STR Program clients and to make recommendations to enhance program outcomes. The methodology for the review included:

- An extensive review of state, national and international literature
- The development of a Therapy Forum Group, consisting of six service providers with extensive experience in working with ABI:STR clients and expertise in acquired brain injury and life time care needs and involving six, two hour focus groups

- A qualitative study of ABI:STR client satisfaction and experience of therapy services. This study involved telephone interviews with 11 individuals and families receiving services through the ABI:STR Program.
- Analysis of existing program expenditure and client resource allocation data provided to the author by the ABI:STR program
- Phone and face-to-face consultations and checking of developing themes with key stakeholders and the ABI:STR program manager.

This report is divided into three main parts: Part A provides background information including the literature review; Part B documents the outcomes of consultations undertaken with consumers, therapists and other key stakeholders in the ABI sector; and Part C provides recommendations to meet the aims of this therapy review.

Part A of the Therapy Review includes a current literature which demonstrates the following:

- Lifetime slow stream rehabilitation is required following catastrophic brain injury.
- The timing and nature of rehabilitation intervention will be influenced by an understanding of a range of factors including the individual's level of consciousness, insight and readiness to benefit from intervention.
- Minimisation of secondary complications is a key element of rehabilitation intervention.
- The recovery potential for neurological is influenced by the physical and social environment to which the individual is exposed.
- Skill development is encouraged by providing consistent and repeated opportunities for contextualised practise of personally meaningful activities.
- Disability management plans require that skills and routines which are developed in active rehabilitation phases are maintained over time when therapy input is reduced.
- Better health status and functional outcomes are seen following specialist ABI, rather than generic, programs, indicating that expert knowledge and experience in working with catastrophically brain injured individuals is crucial to outcome.
- Progress towards life role participation is an overarching long-term goal following catastrophic brain injury.
- Given high levels of family and carer distress, provision of education and training and support for care-givers is an essential component of ABI rehabilitation.

Part B of the Therapy Review details results of the consumer feedback and therapy forum. These consultations highlighted the following points in regard to the ABI:STR Program:

- The experiences of the individual, their families, and therapists indicate that individuals should be able to access timely and necessary rehabilitation over the course of their lifetime.
- Long waiting periods for Program access was a key concern for both consumers and their families, and therapists identified the significant risks associated with delays in service provision.
- Families and therapists suggested a more flexible model of rehabilitation funding that is tied to measurable outcomes and that is based on the individual's specific needs and readiness for intervention.
- Families highlighted experiences of service fragmentation and uncertainty regarding funding allocations and the detrimental impact this had on long term planning and carer stress.
- The importance of interdisciplinary team work was emphasised as well as the role of the family and individual in setting the direction of the therapy program. Team leaders with sound clinical acumen are required to facilitate this process.
- Less experienced therapists working with catastrophically injured clients benefit from supervision / mentoring from experienced therapists.
- There is a looming workforce crisis due to a diminishing pool of senior therapists working with ABI:STR clients. A review of Program remuneration and mentoring of less experienced providers will be integral to maintaining and expanding a skilled workforce.
- Targeted clinical intervention, including positive behavioural programming and implementation of goal-oriented plans with attendant care and / or allied health assistant input, have the potential to strengthen Program outcomes.
- Initial and subsequent measurable rehabilitation goals should be set by the therapist in conjunction with the individual and family, with team goals developed to guide the overall direction of the therapy program.
- Improved ABI:STR discharge rates or transition to maintenance level Program funding can be achieved by the provision of ongoing attendant care and case management funding by other generic sources or DHS programs.

- The life-time requirements for therapy and support for people with catastrophic brain injuries could be met through the development of a universal insurance scheme.

Part C provides detailed recommendations stemming from a synthesis of the first two sections of the Therapy Review. Key recommendations to be adopted by the ABI:STR program are encompassed in five main areas: referral and eligibility guidelines; best practice therapy services for ABI:STR clients; flexible resource allocation; Program outcome measurement; and therapy reporting. Recommendations include:

- Extension of the referral proforma with clearer documentation of injury severity and eligibility criteria
- Establishment of a Clinical Resource Panel to oversee and promote best practice therapy services, and address workforce issues
- Development of a structured, transparent and flexible funding model with identified funding bands
- Strengthening the interdisciplinary care team approach through the appointment of team leaders
- Clearer definition of case management roles within therapy teams
- Trialling the use of Allied Health Assistants
- Development of a research protocol for Program outcome evaluation
- Development of report proformas to ensure plans focus on achievement of specific, measurable treatment objectives

The ABI:STR program is innovative and unique in Australia. The rehabilitation services aim to make a significant difference to the lives of younger Victorians with catastrophic brain injuries, by decreasing their secondary health complications, maximising their independence, increasing their quality of life and subsequently reducing their life time care needs. The recommendations outlined in this report provide a road map enabling the ABI:STR program to offer an even better service; document an evidence base of program outcomes; and ensure more efficient and effective use of existing resources. This will establish the Program as an international leader in the provision of rehabilitation services to people with catastrophic brain injuries.

PART A: BACKGROUND

1. INTRODUCTION

1.1 Background to the Development of the ABI:STR program

In 1993 the Ministerial Implementation Committee on Head Injury (MICHI) identified the unique and long-term needs of individuals with ABI. This led to the development of services to support people with ABI, including the ABI Case Management Service and the ABI Behaviour Consultancy. Additionally, a study of the rehabilitation and long-term care needs of people with catastrophic brain injury was undertaken.

This study identified long-term high dependency needs of catastrophically brain injured younger adults who, as a result of their inability to access or benefit from mainstream acute and sub-acute rehabilitation, either remained in acute hospitals for inordinate periods or were inappropriately discharged to residential aged care residential facilities. The ramifications included ineffective and inefficient use of already limited hospital resources, excessive costs to the acute health and residential care sector, and inadequate opportunity for brain injured individuals to achieve optimum levels of independent functioning. Given the long-term implications for unrealised recovery potential and thus ongoing disability levels, the pre-existing model gave rise to increased life-time costs and poorer quality of life for these individuals and their family members.

The findings of the study and a pilot program led to the Department of Human Services (DHS) developing the Acquired Brain Injury: Slow to Recover (ABI:STR) Program in 1996.

The aim in establishing the ABI:STR program was to develop a model of service delivery that would redress the difficulties faced by people with severe ABI in accessing the level and type of rehabilitation, equipment and support they required ("Acquired Brain Injury: Slow to Recover Program Report 1996-1998," 1999). After seven years of operation, DHS commissioned an evaluation of the program which was published in November 2004.

The 2004 review assessed the service delivery model from the period 1996 to 2003. The method of review included consultation with key stakeholders (DHS, Southern Health, case managers, therapists, attendant care agencies and families) and analysis of data.

The areas covered in the review included the program's reach and ability to meet need, program costs, client and service outcomes, referral pathways, care planning and review processes, service duration and range, aged care and disability services involved, the program's relationship with other health-care services and with TAC/Workcover. The review did not aim to assess or evaluate the clinical pathways or clinical outcomes achieved by the program.

One of the recommendations of the 2004 Review, and further explored in a DHS Working Group, was a review of therapy practices. Accordingly DHS commissioned the author to undertake the current Therapy Review Project.

1.2 Aims of the ABI:STR Therapy Review Project (2008)

The purpose of the Therapy Review Project was to develop a sound framework for therapists to provide services to ABI:STR Program clients.

The objectives outlined in the Project Brief were to achieve a unified approach which would result in:

- Evidence-based therapy
- Measurable outcomes for clients
- Improved consumer satisfaction through clearer support plans
- Standardisation of processes and service delivery
- Increased staff and client satisfaction.

The recommendations provide in Part C of this report address these objectives.

2. OVERVIEW OF THE CURRENT ABI:STR PROGRAM

2.1 The Client Group Profile

The ABI:STR Program is designed to cater for a small but significant group of younger adults who are not eligible for compensation and who are distinguished by:

- The severity of their ABI
- Their slow recovery and persisting high dependency requiring prolonged rehabilitation and therapy
- The complexity of their care needs
- Their inability to access, through any other means, services that are appropriate to their age, level of disability and limited recovery potential (*Acquired Brain Injury Slow to Recovery Program Review*, 2004, p. 3)

A number of ABI:STR Program clients have participated in previous research examining outcomes following catastrophic brain injury. In particular, a retrospective outcome study of the ABI:STR program was conducted by Dr John Olver and colleagues in 2003. Also, in 2007 the *my future my choice (mfmc)* study of 105 people under the age of 50 years who live in residential aged care facilities involved a subset of 35 individuals who had had a catastrophic brain injury, as defined by a Level 7 or 8 on the Care and Needs Scale (refer to page 88 for further information on the CANS). About half of those 35 individuals were in receipt of ABI:STR rehabilitation programs (Winkler, Sloan, & Callaway, 2007).

The data obtained from these two studies provides detailed information on the disability levels, health issues and support needs of individuals with catastrophic brain injury, and are summarised below. Further detail can be found in Appendix 1.

It is evident from the data of the two studies that the ABI:STR group have complex and extremely high needs. A significant proportion of this group requires 24 hour daily support and, for some, this includes support of carers awake overnight. For those with non-compensable injuries, such high levels of support cannot be met by funded carer hours, so there tends to be a high level of family involvement on a daily basis. The following information provides an indication of the nature and scope of the issues faced by people with catastrophic brain injury.

The *mfmc* study revealed that of the 35 people with catastrophic ABI, 63% had compromised awareness. This may be an overestimate of the extent of compromised awareness in the catastrophic ABI group, as all the participants in this study were in an aged care facility whereas only 34% of people were living in aged care in the Olver study.

The *mfmc* study found that the average number of health problems of each individual was 2.6, with a high incidence of balance problems, spasticity, epilepsy and pressure areas. Multiple and complex medical conditions require specialist input. Many people were highly physically dependent and appropriate positioning was seen as critical to reduce the risk of secondary complications such as choking, pressure areas and challenging behaviour.

Extremely high physical support needs were evident in both studies and most individuals were found to require assistance for bed mobility, and for moving within their residence as well as accessing the community. STR clients experience dramatic changes in their ability to manage their daily routines and activities with over 80% requiring help with self-care (J. Olver, 2003). There is a high incidence of swallowing problems in STR clients and many are PEG fed.

This group have significant needs for equipment and consumables. The average number of different types of consumables used by each person in the *mfmc* study subset was 5.2 and the average number of pieces of equipment used by each person was 6.2.

There were also high levels of support needs in the areas of communication and cognitive function, particularly receptive and expressive communication and memory (Winkler et al., 2007).

STR clients in the *mfmc* sample also demonstrated high levels of mental health problems, including clinically significant depression and complex co-morbid conditions such as anxiety. Complex challenging behaviours were also common with a particularly high incidence of irritability and aggression as well as sexually inappropriate behaviours (Winkler et al., 2007).

The nature and complexity of the various issues arising from catastrophic brain injury determine the specific nature and timing of rehabilitation services, which is further explored throughout this report.

2.2 ABI:STR Program Aims

As documented in the 1999 ABI:STR Report, the aims of the program are to:

- Provide individually targeted slow-stream rehabilitation services to people with severe ABI who have the potential to achieve functional gains in their level of independence, and thereby to assist these people to achieve optimum levels of independent functioning.
- Monitor and provide passive rehabilitation for clients not able to benefit from active rehabilitation in the early weeks or months post-ABI, while allowing time to assess realistically the person's potential for recovery and / or to await further neurological recovery that may enable the client to participate in more active rehabilitation.
- Ensure timely and appropriate discharge from acute care and reintegration into community care by providing the necessary level of support and assistance not otherwise provided by mainstream programs for these clients.
- Ensure a maintenance level of rehabilitation and sufficient attendant care services to prevent physical deterioration for those who have sustained major irreversible brain injuries and who may require long-term or life-long support.
- Extend the currently very limited knowledge of the process of recovery following severe ABI, and the place of rehabilitation services in maximising recovery and independence for these clients, to develop evidence-based guidelines for optimum management of ABI:STR clients.

At the time of the 2004 review, further aims had been developed for the ABI:STR Program and are summarised as follows:

- To deliver timely rehabilitation and ensure services are provided in an efficient manner.
- To develop a service delivery model that reduces the number of younger people residing in nursing homes.
- To increase rehabilitation services including expert clinical support and advice, in order to reduce the demand on the mainstream service sector.
- To ensure that people with ABI and complex care needs are discharged to appropriate community care and receive appropriate integration services.

- To provide new clinical rehabilitation services with resources on the techniques for treating severe ABI and information on the recovery processes involved.
- To obtain support from generic services in the form of financial cost-sharing and the provision of expert knowledge on complex community care needs in catastrophic ABI.

2.3 Service Delivery Model

The ABI:STR Program is managed by Southern Health and operates as a Victoria-wide program which contracts case management agencies, as well as attendant care and therapy providers, to deliver rehabilitation programs to people with catastrophic ABI.

The aims of the ABI:STR Program are achieved by:

- Identifying the rehabilitation and clinical care needs of individual clients that cannot be met through other program areas, purchasing services to meet those needs and ensuring clients can remain with extra support within generic and community-based services.
- Contract purchasing of core services, including slow-stream inpatient rehabilitation (within existing rehabilitation hospitals), case management, and the management and provision of aids, equipment and home modifications. This ensures a baseline level of services that can be augmented as needed and supports the development of specific expertise in working with ABI:STR clients
- Coordinating, through case management, services funded by the ABI: STR Program, and advocating for client access to mainstream services.

2.4 ABI:STR Program Eligibility

The ABI:STR Program specifically targets younger adults who:

- Have a diagnosis of severe ABI in relation to an acute health episode within the proceeding two years, and are medically stable
- Have been assessed as requiring long-term, high level nursing care
- Are ineligible for compensation
- Are at least 5 years of age and no older than 65, with priority to those under 50 years of age
- Are unable to access, through other means, age-appropriate services that cater to their level of disability and limited recovery potential ("Acquired Brain Injury: Slow to Recover Program 1996-1998," 1999).

2.5 ABI:STR Program Organisational Structure & Processes

The 2004 Review outlined the organisational structure in some detail. In that it impacts on the delivery of therapy services, it is noted that the Independent Committee and the Service Panel that were original components of the Program structure and model are no longer in existence.

When the ABI:STR Program was established, the role of the Independent Committee was to determine policy and program direction and oversee the development and administration of the program. This Committee has not met since 2002. The role of the Service Panel was to decide individual eligibility, consider applications to the program and allocate services and funds to individuals based on the care plan. This Panel was to be comprised, amongst others, of allied health professionals with expertise in ABI, but it ceased meeting in 1998.

The current ABI:STR model of service provision is depicted in Figure 1 and summarised below:

1. The Program Manager receives referrals and determines eligibility and priority
2. The Program Manager contracts case management from one of five metropolitan based Case Management Agencies (Melbourne City Mission, ARBIAS, Care Connect, or Brain Foundation). For those clients that are rural, metropolitan based case management agencies further sub contract other case management agencies.
3. The case management agencies are responsible for assigning a case manager who:
 - Develops the individual care plans
 - Facilitates the purchase of therapy and other services
 - Co-ordinates services and reviews the client's progress.
4. The Program Manager reviews the submitted care plans and decides on service provision and funding allocation, initially and on an ongoing basis.

The case management agencies sub-contract external clinical therapists and attendant care agencies who deliver the pre-specified services either in the family home, residential aged care facilities, inpatient rehabilitation centres, private hospitals, or community supported accommodation. Clinical therapists employ their knowledge and

expertise to design therapy programs, which are then implemented by attendant carers under the direction of therapists.

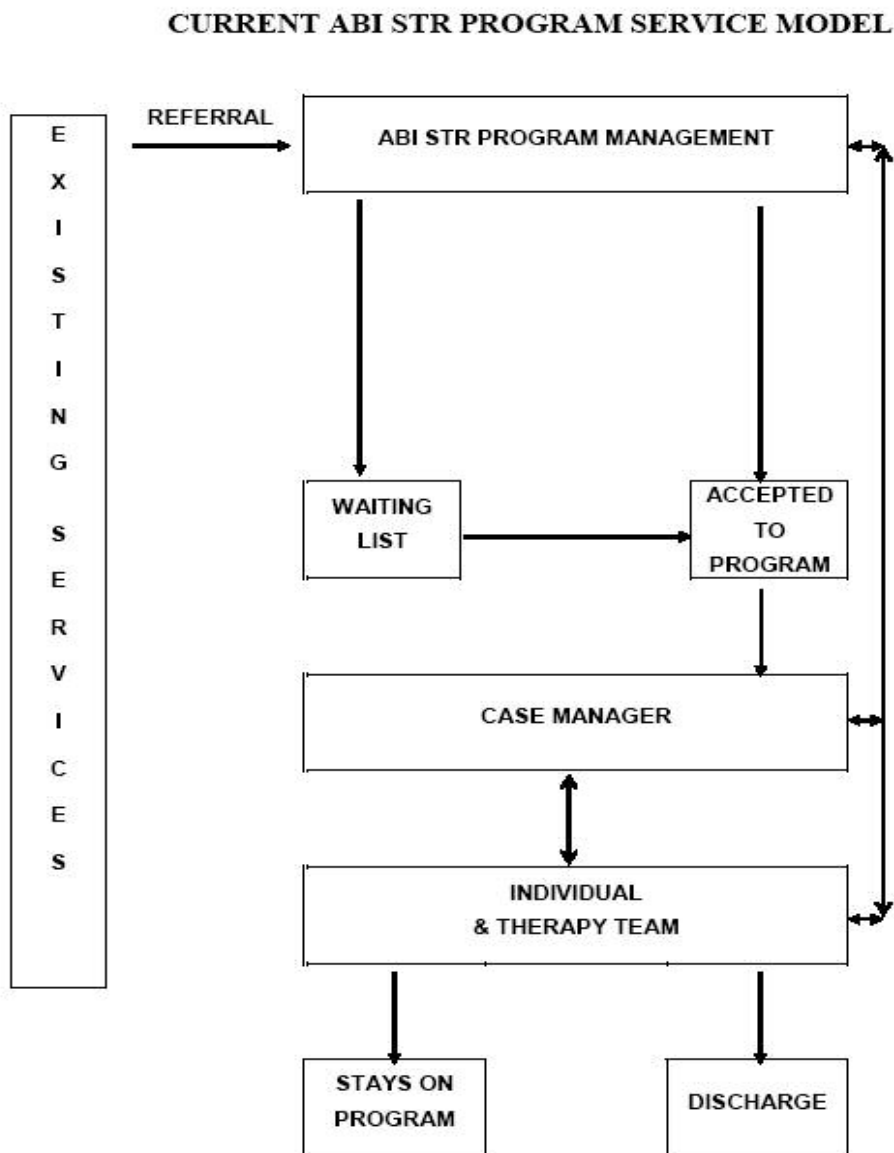


Figure 1: Current Pathways for Accessing and Monitoring ABI:STR

2.6 Rehabilitation Service Model & Funding

The current ABI:STR model of service provides two levels of rehabilitation support: intensive and maintenance rehabilitation support.

‘Intensive’ level of service is based on:

- Up to three hours each week of physiotherapy, occupational therapy and speech therapy.
- 10 – 15 hours per week of attendant care to support the rehabilitation program, depending on whether they reside in their home (10 hours) or residential aged care (15 hours).

‘Maintenance’ level of service commences at 18-24 months after entry to the program and is based on:

- Up to 8 hours per annum each of physiotherapy, speech therapy and occupational therapy.
- 10 – 15 hours per week of attendant care to support the rehabilitation program, depending on whether they reside in their home (10 hours) or residential aged care (15 hours) (*Acquired Brain Injury Slow to Recovery Program Review*, 2004).

Over the lifetime of the ABI-STR Program there have been 234 admissions. Of these admissions, 62 people have been discharged from the program and 39 people have died. 133 people currently remain on the program. Approximately 70-75% of these individuals are on “maintenance” funding.

Each month 3-4 referrals are received and they are placed on the waiting list which currently stands at over 70 people. People on the waiting list have been waiting up to 3 years before acceptance onto the program. However there is to be an injection of funding in the 2008/2009 financial year which will result in approximately 60 individuals being accepted onto the program.

The number of individuals in each year of the program as well as the average cost per person for services are provided in Table 1. Also shown below is the average cost per person in each year of the program for occupational therapy, physiotherapy, speech pathology and case management (see Figure 2), attendant care (see Figure 3) and total cost for all services (see Figure 4). While this information is useful in getting an overview of costs of the program by type of therapy, it is limited by absence of information on individual client variability (e.g., ranges of cost). In addition, there are very few individuals in some years of the program (e.g., only two clients in year two), resulting in data for these years potentially being a poor representation of costs during this period for

the overall client group. This appears to be the case in year 2, where the average cost across the 2 clients for attendant care is \$69,898, which appears to be an anomaly and does not represent the amount of attendant care that is typically received.

Despite these limitations, the data reflects that there is significantly greater cost in the first five years of the program, with a mean total cost per person of \$62,509 per year over this period. In contrast, the average total cost of the program per person from year 6 is \$37,729 per year.

The cost for occupational therapy, speech pathology and physiotherapy is highest over years 2, 3 and 4 (reflecting the period during which clients are receiving the greatest intensity of therapy), with an average cost per therapy of \$7,100 per year over this period. The cost of case management remains stable at \$6,367 for the duration of the program, and does not reflect change in intensity of input required at different stages of the client's recovery. With the exception of years 2 and 3, the average case management costs are greater than other therapies.

The attendant care cost for the program were greater than anticipated, potentially reflecting difficulty in accessing funding for attendant care support from other sources. Consistent with costs of therapy, attendant care costs show a decrease from year 5.

This information is again referred to in the Recommendations section as it provides a guide to the current level of program expenditure on therapy services.

Table 1

Average expenditure on each category of ABI:STR services by length of time on Program

Length of time on the program	No of clients	Average cost of therapy services per person					
		OT	PT	SP	CM	AC	Total
0-12 months	20	\$4,368	\$4,545	\$4,219	\$6,367	\$20,958	\$40,457
1-2 yrs	2	\$9,011	\$8,844	\$8,757	\$6,367	\$69,898	\$102,877
2-3 yrs	11	\$7,766	\$5,967	\$6,373	\$6,367	\$27,832	\$54,305
3-4 yrs	8	\$6,211	\$5,382	\$5,592	\$6,367	\$35,737	\$59,289
4-5 yrs	14	\$4,398	\$3,221	\$2,861	\$6,367	\$38,771	\$55,618
5-6 yrs	20	\$2,151	\$1,871	\$2,262	\$6,367	\$33,522	\$46,173
6-7yrs	12	\$1,255	\$1,560	\$1,150	\$6,367	\$28,867	\$39,199
7-8yrs	5	\$1,588	\$2,214	\$898	\$6,367	\$24,782	\$35,849
8-9yrs	19	\$1,434	\$1,596	\$1,776	\$6,367	\$24,496	\$35,669
10+yrs	29	\$1,353	\$1,736	\$1,019	\$6,367	\$21,282	\$31,757
		\$39,535	\$36,936	\$34,907	\$63,670	\$326,145	\$501,193

Note: OT = occupational therapy; PT= physiotherapy; SP = speech pathology; CM = case management; AC = attendant care

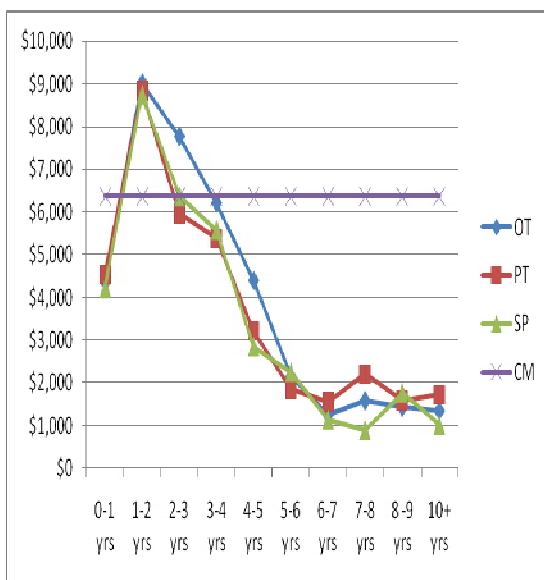


Figure 2: Average annual expenditure per person for occupational therapy (OT), physiotherapy (PT), speech pathology (SP) and case management (CM) services for each year on the program

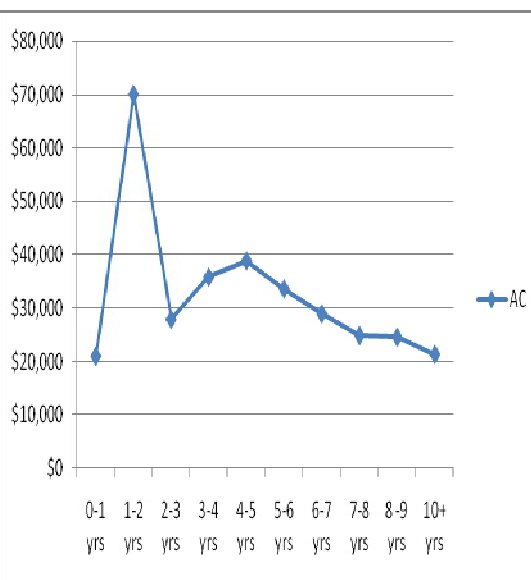


Figure 3: Average annual expenditure per person for attendant care (AC) services for each year on the program

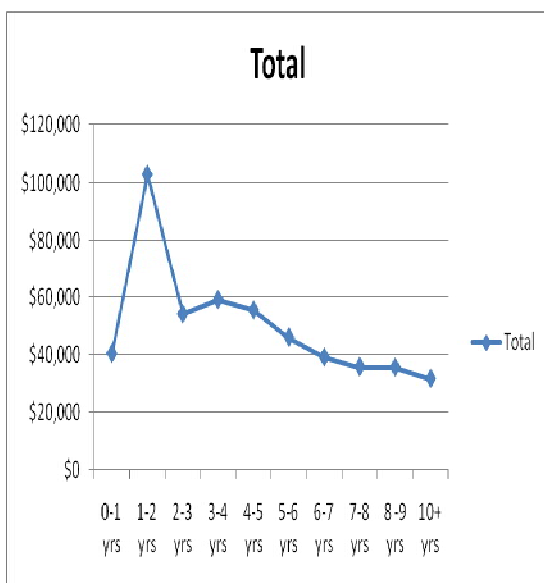


Figure 4: Average total annual expenditure per person for each year on the program

2.7 2004 Review: Key Issues & Findings

The following is a selection of the key issues and findings of the 2004 review that are felt to specifically relate to the focus of the current therapy review. These issues/findings, taken from pages 41-47 of the 2004 Review Report, are listed below and will be addressed later in the Recommendations section of this report.

The 2004 Review recommended:

a. Improvements to transparency, accountability, flexibility and responsiveness of the service delivery model including:

- Further development of the program philosophy and vision of the program as well as information across the stages of care pathways
- Flexibility to cater to individual client needs, including the timing and type of service provision within the boundaries of allocated resources and the inclusion of cognitive as well as physical therapies
- The development of client pathways to map and predict the level of planning and support required by categories of individuals
- Documentation of detailed program standards and proformas to streamline data gathering and report writing and processes for applying for one-off funding
- Development of clear policies and procedures which are transparent and unambiguous, especially in relation to eligibility, allocation of resources, independent appeals and exit from the program

b. Strengthening roles and responsibilities and grievance procedures, including:

- Reconsideration of the service panel structure and/or allocation of clinical resources to undertake program development, interpret clinical recommendations in care plans, assess quality of service provision and undertake program research and analysis.
- Development of key performance indicators
- Access to clinical expertise and case review for independent grievance and appeals processes.
- Development of program information for practitioners

c. Developing a skilled workforce and monitoring quality of service provision to maximise outcomes to consumers, including:

- Strengthening the interdisciplinary 'care team' approach and communication.
- Philosophy of inclusion of family members

- Person-focused care plans and allocation of resources (rather than 'intensive' and 'maintenance' service levels)
- Use of common assessment tools, as well as evidenced based care plans and specific measurable treatment objectives
- Defining case management parameters and standardised position descriptions to ensure consistency
- Streamlining access to therapy providers and attendant care workers
- Accreditation of practitioners and use of preferred provider interdisciplinary teams
- Program induction to ABI:STR and attendance at biannual program updates
- A senior therapist in each discipline to provide secondary consultation and share information with other therapists
- Considering the use of Allied Health Assistants
- Controlling and monitoring the quality of purchased services
- Review pay rate of therapists on an annual basis
- Improving access to case management and therapy services in rural areas.

d. Carer involvement and empowerment

- A partnership approach to empower and include family members
- Incorporation of a carer assessment tool
- Provision of formal assistance to carers (eg training, counselling, respite)
- Provision of information during the rehabilitation stages

e. Continued Research

- Developing a research and evaluation program and protocols to commence a prospective study

3. LITERATURE REVIEW

This literature review focuses on severe to catastrophic brain injury caused by any form of acquired brain injury including traumatic brain injury, hypoxia and stroke. The international and locally published literature was searched through multiple databases that spanned the disciplines of neurology, occupational therapy, physiotherapy, speech pathology and psychology. Papers relating to recovery, outcome and rehabilitation practises following catastrophic brain injury were identified. Prospective, retrospective, experimental and qualitative studies were considered for the review. Unpublished works (e.g. conference proceedings and reports) relevant to the scope of the review were also included.

3.1 Slow Stream Rehabilitation

Brain injured individuals who show severe dependency on care supports and require longer stays in rehabilitation are comprised of a mixed group of aetiologies including stroke, traumatic brain injury, and hypoxia. As the disability needs of this mixed group are comparable, they are discussed together in the literature review.

The factors that are considered important in admitting patients to acute or post-acute rehabilitation include cognitive awareness, communication ability, and capacity to participate in intensive rehabilitation. On this basis, in Victoria, catastrophically brain injured individuals who exhibit a slow recovery rate and demonstrate extreme levels of disability are usually deemed inappropriate for mainstream rehabilitation. In this case, they may either be discharged to long-term aged care residential or hospital facilities where treatment and facilitation of recovery by staff is minimal; otherwise they may receive 'slow stream rehabilitation' programs in community settings (e.g., family home, group home) or in one of a very limited number of residential settings (e.g., Gardenview).

A comprehensive system of slow stream rehabilitation support is now conceptualised as one that includes therapy and living skills training within the natural environment for extended periods or across the entire lifetime (Jacobs, Blatnick, & Sandhorst, 1990). A supported living environment that compensates for residual physical and cognitive disabilities is seen as part of that comprehensive continuum of care.

In considering the international literature on catastrophic brain injury it is clearly very important to match the timing and type of intervention to the conscious level of the individual. Catastrophic injury is characterised by a lengthy period of coma from which the individual emerges over an extended time frame. Stages / levels of consciousness are identified and include:

- Vegetative state
- Minimally conscious state
- Post traumatic amnesia

In the transition to full consciousness (i.e., alert, aware and oriented), the individual may move through these stages over variable time periods. Some individuals remain in one of these states on a more permanent basis, as shown in Figure 5.

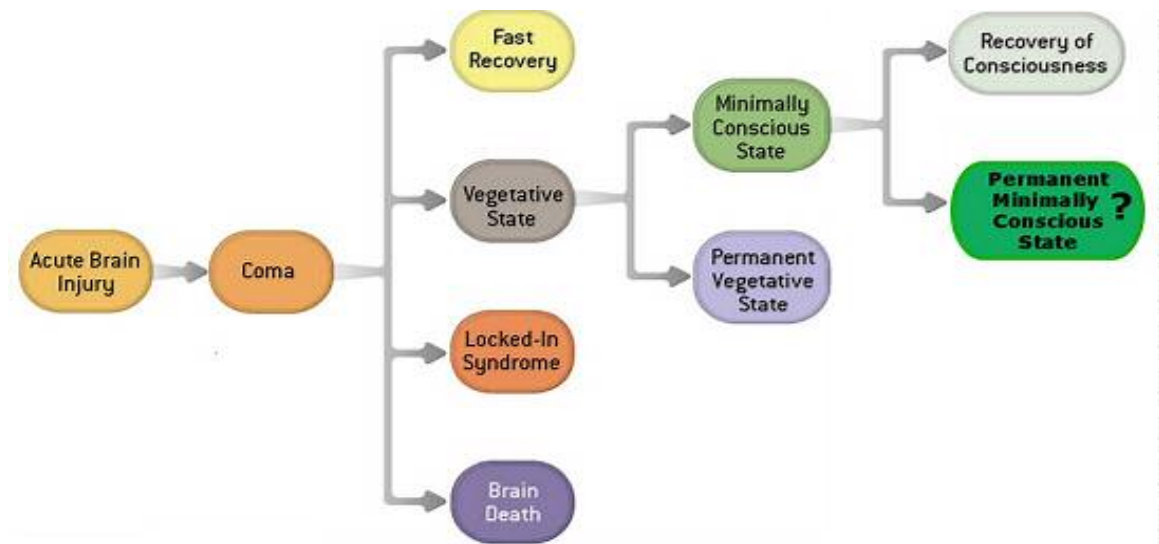


Figure 5: Transition phases of reduced consciousness following coma

3.2 Vegetative State

Once a person with catastrophic brain injury emerges from coma they may pass through, or remain in, a vegetative state.

The vegetative state (VS) has been defined as a state of arousal without behavioural evidence of awareness of self or capacity to interact with the environment ("The Multi-Society Task Force on PVS: Medical aspects of the persistent vegetative state," 1994).

Patients in the VS show:

- no evidence of sustained reproducible, purposeful or voluntary behavioural responses to visual, auditory, tactile or noxious stimuli,
- no evidence of language comprehension or expression,
- intermittent wakefulness manifested by preserved sleep-wake cycles,
- sufficiently preserved autonomic functions to permit survival with medical and nursing care,
- bowel and bladder incontinence
- variably preserved cranial nerve and spinal reflexes.

Until more recently, a lack of research into prognosis and functional outcomes in VS lead to a nihilistic perception of this group. Denial of treatments led to confirmation of poor prognosis, contributing to the myth that all meaningful recovery occurs within the first 6 months following injury. There is now an increasing body of literature that counters this earlier belief and is discussed below.

3.3 Minimally Conscious State

The minimally conscious state (MCS) is a phase between coma and full conscious awareness that the individual may pass through, or remain in. Like the patient in VS, the minimally conscious patient is able to sustain their basic functions (breathing, blood pressure regulation and digestion) and demonstrate eye-opening, sleep-wake cycles, and visual object tracking. Crucially, in minimally conscious patients there is intermittent evidence of awareness (e.g., response to pain, stimuli in the environment, people) and, under optimal conditions, the ability to comprehend and follow basic commands (Giacino et al., 2002).

The Aspen Workgroup defined the minimally conscious state as a condition of severely altered consciousness in which minimal but definite behavioural evidence of self or environmental awareness is demonstrated (Giacino et al., 2002). According to the Aspen workgroup, MCS should be diagnosed when there is clearly discernible evidence of one or more of the following behaviours:

1. Simple command-following.
2. Gestural or verbal yes/no responses.
3. Intelligible verbalisation.

4. Movements or affective behaviours that occur in contingent relation to relevant environmental stimuli and are not attributable to reflexive activity. Any of the following examples provide sufficient evidence for contingent behavioural responses:

- Episodes of crying, smiling, or laughter in response to linguistic or visual content of emotional but not neutral topics or stimuli.
- Vocalisation or gestures that occur in direct response to the linguistic content of comments or questions.
- Reaching for objects that demonstrate a clear relationship between object location and direction of reach.
- Touching or holding objects in a manner that accommodates the size and shape of the object.
- Pursuit eye movement or sustained fixation that occurs in direct response to moving or salient stimuli.

3.4 Research on prognosis following VS and MCS

The prognosis is usually uncertain for individuals who have suffered a catastrophic brain injury. Lengthy periods of time spent in reduced states of consciousness are generally associated with ongoing, severely impaired function. There are cases, however of emergence of function, including the development of consistent communication many years after injury.

The literature on VS and MCS is currently evolving through publication of neuroanatomical studies, functional imaging research and electrophysiological investigations. Based on a coma data bank, Levin et al. (1991) reported that of 650 severely injured individuals with TBI, 14% were vegetative at 1 month. However when followed up at 6 months, 1 year and 3 years post-injury, a significant proportion had regained consciousness (41%, 52% and 58% respectively; Levin et al., 1991).

Studies using diffusion tensor and PET imaging have shown axonal regrowth in patients who have been in MCS for extended periods (Voss et al., 2006). For example, a MCS patient demonstrated his first reliable communication 19 years post injury, uttering the words “mum” and “pepsi”. Over several days, his speech became increasingly fluent, although continued to be dysarthric. Subsequent continued improvement was observed and correlated with radiological evidence of axonal regrowth (Voss et al., 2006).

Such evidence highlights that both early and late recovery from VS and MCS is a potential phenomenon and underlines the importance of providing intervention to this group so that when consciousness level improves, progress is not impeded by secondary complications that are likely to develop when treatment for fractures and tone management (for example) is withheld.

3.5 Research on brain function in VS and MCS patients

A large body of research has been conducted over the past 10 years on brain function in VS and MCS, including the first report of evidence of cortical processing in persistent vegetative state (Menon et al., 1998). Functional brain imaging of a 26 year old female, who had been in VS for 4 months, showed that she was able to process images of familiar faces.

In terms of processing auditory information, studies on patients in VS and MCS have found evidence for activation of brain areas connected to the primary auditory cortex (Boly et al., 2004; Laureys et al., 2000). Furthermore, electrophysiological studies and PET scanning of patients in MCS has revealed evidence of cortical processing in response to hearing their own name (Laureys et al., 2004; Perrin et al., 2006).

Research examining touch sensation in VS patients showed that all 15 individuals studied showed electrophysiological activation in response to highly unpleasant to painful stimulation (Laureys et al., 2002).

There is also a growing body of evidence to support the possibility of retained speech perception (Di et al., 2007), language comprehension (Bekinschtein et al., 2005), response to tactile stimulation (Schiff et al., 2005) and emotional processing in VS and MCS patients (Bekinschtein et al., 2004). Covert awareness has also been observed in VS, whereby functional MRI detected a patient's ability to mentally represent a game of tennis and a spatial navigation task (Owen et al., 2007).

Another striking finding is the evidence of widespread cortical networks in patients in MCS, which resemble the networks activated in healthy controls (Schiff et al., 2005). Cortical learning has been shown through electrophysiological studies in some VS and all MCS patients such that there is evidence that the cortex is able to learn to selectively ignore repeated irrelevant stimuli (Kotchoubey et al., 2006).

As stated by Schiff et al. (2005), MCS patients may retain widely distributed cortical networks with potential for cognitive and sensory function despite inability to follow instructions or communicate reliably". The remarkable findings have been suggested to indicate the possibility that MCS patients may indeed "have the capacity to experience subjective states and to benefit from therapeutic interventions" (p522). In other words, the non-responsiveness of patients in VS and (at times) MCS is not necessarily indicative of unawareness.

3.6 Understanding Recovery following Brain Injury

The early assumption that recovery of cognitive, sensory and physical functions plateaus one to two years after brain injury has now been discounted. Patients sustaining severe TBI have been shown to achieve ongoing functional improvements over many years (Khan et al., 2003; J. Olver, Ponsford, & Curran, 1996; Sbordone, Liter, & Pettler-Jennings, 1995; Whitlock & Hamilton, 1995). Empirical findings have revealed that even after extremely severe brain injury, some individuals have been able to return to education or employment 10-15 years after injury (Thomsen, 1984).

3.7 Plasticity and Reorganisation

The phenomenon of neural plasticity has important implications for rehabilitation following brain injury in humans. Over the past forty years, neuroscience literature in animals and humans has consistently shown that neural repair, regeneration, and reorganisation are possible following brain injury (Elbert et al., 1994; Gross, 2000; Kolb, 1999; Rosenzweig & Bennett, 1996).

According to Dobkin, self repair may take place through the replacement of cells, neurotrophins and neurochemicals. Axons, dendrites, and synaptic connections may re-develop and uninjured circuits may undergo reorganisation, enabling the re-wiring of functional networks and eventually behaviours (Dobkin, 2000; Voss et al., 2006). The capacity for brain reorganisation interacts with the environment in a bi-directional and dynamic manner such that new experiences in the environment cause the brain to reorganise, which subsequently affects the way the brain processes further information from the environment, and so on (Kempermann, 2002).

The extent of self-repair that takes place is, however, heavily dependent on the range of experiences and types of environments to which a brain injured person is exposed

(Gould et al., 2002). A number of factors have been identified that create optimal conditions for recovery following nervous system damage (Elbert et al., 2004; Liepert et al., 2000; Liepert et al., 1998).

Research has shown that complex, stimulating environments and enriching experiences result in an increased rate of neurogenesis (i.e. the process by which neurons are created) through the altered genetic expression of plasticity compounds and growth factors (Cao et al., 2004; Johansson, 2000, 2003; Rampon et al., 2000). The effects of higher levels of neurogenesis in turn improve therapeutic effectiveness (Johansson, 1996; Will et al., 2004).

Given that behavioural change is highly correlated with plastic reorganisation of brain structure, effective therapies are those that stimulate morphological changes in the brain. Therefore, it is necessary to incorporate the following environmental enrichment factors into a rehabilitation management approach:

- Non-specific stimulation
- Opportunities for learning
- Pain management
- Stress management
- Early intervention

3.7.1 Non-specific Stimulation

The effectiveness of specific therapies is partly explained by the general benefits of social interaction and participation in familiar, everyday activities. Adequate social stimulation has been identified as necessary to reduce psychosocial stress (Brown, Gordon, & Spielman, 2003). These non-specific, but meaningful interventions create a platform for a gradual learning process whereby positive habits become embedded into the person's repertoire of skills (Kolb, 2004). For example, speech therapists not only provide training in language skills but also an opportunity for daily social interactions, which are invaluable for the acquisition of general conversational and behavioural skills. Kolb (2004) also asserts that the development of multi-dimensional programs comprised of non-specific stimulation integrated into daily routines may be superior to isolated and focused behavioural therapy.

Sensory stimulation provided randomly without an associated learning context should be kept to a minimum (e.g. the radio on in the background), as should inconsistent physical

stimulation (e.g. transfers occurring without cues to allow the patient to anticipate the movement). Such random and inconsistent stimulation is confusing for the individual and is more likely to trigger distress and challenging behaviours (Tierney, 2004) which in turn undermines the learning process.

These findings point to the importance of ABI:STR Programs facilitating the development of an integrated structure of activities that provide meaningful stimulation and social engagement over the course of a day and pitched to the level the person is able to process and manage.

3.7.2 Opportunities for Learning

Environmental enrichment studies in animals demonstrate the importance of providing opportunities for learning experiences in promoting recovery. Neuronal creation in the hippocampal region of the adult brain has been shown to be enhanced following learning, as is evident through its increased thickness, dendritic branching, and number of cells (Duffy, Craddock, Abel, & Nguyen, 2001; Kempermann, Kuhn, & Gage, 1997). Associative learning is maximised through learning skills that are inherently linked and this promotes the development of cortically integrated neural circuits that fire together (Elbert, Rockstroh, Elbert, & Rockstroh, 2004).

The potential for cortical reorganisation and remodelling of undamaged brain regions depends on the type of perceptual or behavioural activities involved. Importantly, cortical reorganisation typically emerges in response to intense training in behaviourally relevant, meaningful and rewarding tasks (Bao et al., 2004). For example, physical activity magnifies the positive effects of environmental enrichment on neurogenesis, synaptic plasticity and new learning capacity (van Praag, Christie, Sejnowski, & Gage, 1999). Engaging in “constraint induced therapy”, forces the use of the hemiparetic limb over an intensive period, and dramatic improvements have been reported in the affected limb (Taub & Morris, 2001). Increases of up to 50 percent in the area of cortex representing the paretic hand have been documented (Liepert et al., 2000). One explanation for this is that training increases the cortical area representing the paretic arm. Evidence has also been provided for the converse scenario whereby learnt non-use may develop as a result of neglected use of an affected function or skill (Elbert et al., 2004).

STR Programs have the potential to create an enriched learning environment by structuring training in meaningful and rewarding tasks. In the sensori-motor domain, this

could mean repetitive daily practice of existing skills (e.g. feeding oneself) or providing opportunity for exercise and activity. Various studies have pointed to the importance of consistent practice in skill development in order to reach a stage of 'over-learning' where the skill becomes more automatic and less reliant on conscious mental processing (Schmitter-Edgecombe, 2006). Creating opportunities for over-learning requires a highly structured program where carers are trained to provide a high level of consistent repetition throughout the day.

3.7.3 Pain Management

Pain is a common issue for survivors of ABI at various stages after their trauma. Brain injury may give rise to peripheral pain generators and perpetuators (Gardner, Martin, & Jessell, 2000). The experience of pain results from a cascading process that starts with the release of inflammatory chemicals and ends with information being transmitted from the peripheral nervous system to the part of the central nervous system that receives pain information from the skin, vision, hearing, and neuromuscular skeletal system (Galea, 2002). In the case of chronic pain there is ongoing firing of receptors and an unending pain signal (Galea, 2004). Pain can also be neuropathic in origin. In this situation, large fibres in the skin that convey information about touch become redirected to regions of the spinal cord that receive pain information, which causes touch to be perceived as pain. Sprouting of sympathetic fibres further compound inflammation and swelling, contributing to the feedback loop and thereby maintaining the pain. Furthermore, pain produces abnormal cortical connections and inhibits neuronal regeneration (Woolf, Shortland, & Coggeshall, 1992).

Effective intervention to address pain may be a pre-requisite to achieving other rehabilitation goals. Due to spasticity, poor mobility or reduced expressive communication, an individual may be stuck in painful positions where they cannot move themselves. This can lead to pressure areas and further abnormality in joints. Pain captures the individual's focus of attention and reduces their capacity to attend to other stimuli. This impacts on their ability to learn and acquire new skills, which in turn impacts on opportunities to make physical gains that could potentially attenuate their experience of pain. For example, if a person is in significant pain, they may be unable to recruit the necessary cognitive resources to follow instructions from a therapist to change their position or they may communicate their distress through challenging behaviours. Further, pain can result in negative learned responses, such as tensing and resisting in anticipation of pain during a transfer (Tierney, 2004).

It is extremely important that therapists and carers in STR Programs understand the pervasive and detrimental impact of pain on recovery. Being free of pain may be a prerequisite for the individual to be able to actively engage in therapy and to benefit from learning opportunities. Every effort should be made to reduce pain through appropriate equipment prescription, positioning, tone management and judicious use of medication.

3.7.4 Stress Management

Much of the work by Gould and colleagues has examined the effects of stressful experiences on the rate of neurogenesis occurring in the brain. Stress reactions induced in animal experiments have been shown to increase the levels of circulating adrenal steroids and, during these periods, neurogenesis is inhibited (Cameron & Gould, 1994; Gould, Gross, Gould, & Gross, 2002).

Another consequence of stress is elevated cortisol in the blood which has been shown to impair learning (Heffelfinger & Newcomer, 2001). Cortisol is adaptive in the short-term but leads to hippocampal atrophy if released over a prolonged period (Bremner, 2001).

While therapy may be focused around skill-building, the client's learning capacity may be reduced due to stress. This may be caused either directly by the therapy (e.g., if sudden movement triggers pain or fear) or indirectly by environmental circumstances (e.g., loud noises that trigger a startle response). Therefore, it is essential that in STR Programs a person's living conditions and therapy processes are monitored to ensure that they are not creating a stress reaction. Maintaining stress-free conditions ensures the individual obtains maximal benefit from the learning opportunities provided during therapy.

3.7.5 Early Versus Late Intervention

The notion that rehabilitation is wasted on patients in MCS or that recovery will cease within months to a couple of years after injury is now outdated. An increasing body of literature demonstrates that recovery can take place many years after catastrophic injuries (Wales & Bernhardt, 2000; Watson, 2001). However, if commencement of rehabilitation is left too long after injury, the window for cortical plasticity may have passed, resulting for instance in entrenched and irreversible physical impairments, (e.g. spasticity, pain, rigidity) or behavioural reactions that become increasingly challenging to manage. Studies have shown that early rehabilitation is crucial to more positive outcome (Mackay, Bernstein, & Chapman, 1992). In a recent study, patients who received

rehabilitation within 35 days of injury had 50 percent reduced need for medical intervention at later stages as well as higher discharge rates (Elliott & Walker, 2005).

If left too late, the patient may also have developed secondary issues that require intensive input. A number of studies have shown that, compared with those who receive early intervention, severely injured patients who do not receive rehabilitation show a higher incidence of infections, respiratory complications, and contractures, including non-injury related contractures (Rusk et al., 1966, 1969; cited in Cope, 1995). It is therefore critical that the waiting time for ABI-STR funded intervention is reduced to maximise the efficacy of rehabilitation and minimise secondary complications.

Research has shown that the outcome following MCS is not only determined by the time of intervention but also the form of rehabilitation. In a study that evaluated the effectiveness of two clinical training procedures, the treatment that consisted of an enriched environment, a collaborative multidisciplinary team and additional yes/no response training resulted in improved communication responsiveness in patients compared with the treatment consisting of a standard hospital environment and interventions (Barreca et al., 2003).

3.8 Rehabilitation Interventions in MCS

Andrews (2000) prefers to use the term disability management rather than rehabilitation as the person in MCS is unable to contribute to his or her own recovery. He outlines 3 objectives of a disability management program:

- 1) ensure the diagnosis is correct;
- 2) promote optimal levels of recovery; and
- 3) maintain the person's level once they have reached stability.

In the following sections these elements will be addressed.

3.8.1 Assessing Patients in Reduced States of Consciousness

Accurate diagnosis is crucial to long-term accommodation decisions and to the appropriate tailoring of rehabilitation inputs. Improvements from the initial stage of coma are often gradual, and small gains may go unnoticed unless detailed and accurate assessment takes place. A number of observation-based behavioural assessment scales have been developed in an attempt to document and monitor recovery from severe brain injury.

Depth of coma has traditionally been assessed in the acute hospital setting using the Glasgow Coma Scale (GCS), which measures eye opening, verbal and motor responses. Scores on the GCS can range from 3, indicating no response, to 15, indicating that the individual is alert and orientated. The lowest GCS score taken within the first 24 hours following injury is commonly used to categorise injury severity (Ponsford, Sloan, & Snow, 1995). A total GCS of 3-8 indicates a severe injury, 9-12 a moderate injury and 13-15 a mild injury.

The Wessex Head Injury Matrix (WHIM) (Shiel et al., 2000) covers a wide range of abilities that reflect emerging awareness. Compared with the GCS, it provides a more detailed assessment of conscious level. The WHIM can be administered by observation and its focus is on behaviours that the individual does or does not display in the areas of sensory, motor, cognitive and social skills. The WHIM does not require specialised training to use, and can be administered by family members, carers and health professionals. The WHIM is scored to provide a total number of behaviours observed, and also the highest level behaviour displayed. The WHIM is a useful tool to use over time. By completing the WHIM periodically, for example every 3 months, a formal measure of change in a patient's behaviours over time can be obtained. This is particularly helpful as changes that occur are often subtle and generally occur slowly over time. The behaviour profile can be qualitatively analysed to check for emerging strengths (e.g. movement compared with communication skills), which influences the rehabilitation approach.

Based on the preceding literature review and the mfmc report (Winkler et al., 2007), the following 3 sections provide a summary on the factors that are important in facilitating optimal recovery, fostering the development of emerging skills and maintaining improved functions following MCS or PVS.

3.8.2 Promoting Optimal Levels of Recovery

Promoting optimal levels of recovery firstly involves minimising the complications that can impede recovery and level of function. Issues that can arise and require monitoring and early intervention include the following.

Neurological complications (including epilepsy): Abnormal electrical activity can impair awareness and the ability to learn. Pharmacological interventions can be helpful in managing seizures but levels and combinations of prescribed medications will typically

be balanced with side-effects, particularly their potential impact on awareness. It is also important to identify any triggers to seizure activity, such as fatigue and stress and to incorporate management of these factors into the daily routine.

Musculoskeletal complications: Poorly managed tonal changes that lead to contractures and abnormal postures can have huge consequences for recovery. Loss of function in limbs poses a long-term risk to the potential for positive functional outcomes for the patient. Pain associated with musculoskeletal changes can result in increased levels of distress, and anxiety in individuals with emerging awareness, particularly during manual handling activities. This can snowball into the development of challenging behaviours. It is extremely important that a proactive approach is taken to the management of comfort, tone and positioning and that routines are established for all manual handling activities.

Skin conditions: pressure areas and rubbing can contribute to pain and increase the risk of further medical complications such as infections and gangrene. Positioning and equipment prescription are vital to maintaining skin integrity.

Respiratory complications: Chest infections severely compromise health and negatively influence recovery. Positioning, equipment and routines, particularly for managing oral intake and oral health are vital.

Digestive issues: complications with PEG feeds, reflux and constipation can all contribute to reduced comfort and general well being. Discomfort associated with these complications compromise awareness as well as the ability to learn and may also trigger challenging behaviours.

3.8.3 Encouraging Emerging Skill Development

The pattern of recovery commonly seen in severe brain injuries is of fleeting evidence of a new skill, in the right conditions, and perhaps with certain observers. Over time and with encouragement, the skill becomes more consistent and resilient to the environmental conditions and as a consequence is observed by more people.

In order to encourage the emergence of new skills and to consolidate learned behaviours it is vital that the individual is provided with consistent and repeated opportunities to practice and develop their skills. By ensuring comfort, structuring an environment with minimal distractions and providing consistent cues and routines and

reinforcement, behaviours can be shaped and developed into procedurally learned skills that can then be slowly built upon.

Consistency is a key to encouraging and shaping behaviours, and it is important to have the cooperation of as many caregivers as possible to provide the context for the behaviours to emerge and develop.

Minimising stress and anxiety is also a key to encouraging learning. Minimising unnecessary stimulation and maintaining structured routines with consistently provided prompts provides the context for the patient to begin to anticipate steps in the routine. This minimises stress by promoting predictability and a sense of security, allowing the opportunity for participation to whatever level the person is capable.

3.8.4 Maintaining the Person once Stabilised

A person who is in MCS or VS is unable to contribute to his/her recovery and therefore should be viewed from a disability management perspective (Andrews, 2005). Andrews highlights that the efforts employed through disability management plans are fruitless unless skills are maintained once they have emerged and reached stability. Without a focus on maintenance of functions, the individual will be unable to make consistent gains in physical and mental abilities, which in turn severely interferes with achievement of optimal recovery. In light of the gradual improvements that are likely to be made over several years, maintenance of core functions (e.g. prevention of infection, tone and posture management, pain management, nutrition, bowel and bladder management) is strongly recommended (Andrews, 2005).

3.9 Life Role Participation in ‘Slow to Recover’ Rehabilitation Programs

Earlier sections have considered the importance of managing the underlying conditions related to the individual's health and comfort and of creating routine learning opportunities to slowly build functional capacity. These routines create a platform on which the person's participation in meaningful life roles can be developed, thereby promoting a greater sense of well-being and quality of life. The following section will discuss the literature that informs an understanding of both the potential for, and the rehabilitation approaches that assist, life role participation in people with catastrophic injury.

3.9.1 International Classification of Functioning, Disability and Health

The International Classification of Functioning, Disability and Health (ICF) (World Health Organisation, 2001) provides a useful model to conceptualise the place of participation in the range of problems and outcomes associated following severe ABI.

As depicted in Figure 6, the ICF defines three levels of health: (a) body functions and structures, the physiological functions and anatomical parts of the body; (b) activities, the execution of tasks or actions; and (c) participation, the involvement in a life situation.

Health conditions negatively impact on each of these three levels, namely impairments, activity limitations and participation restrictions. The ICF model acknowledges the moderating influence of environmental and personal contextual factors on outcomes relating to activity and participation (World Health Organisation, 2001).

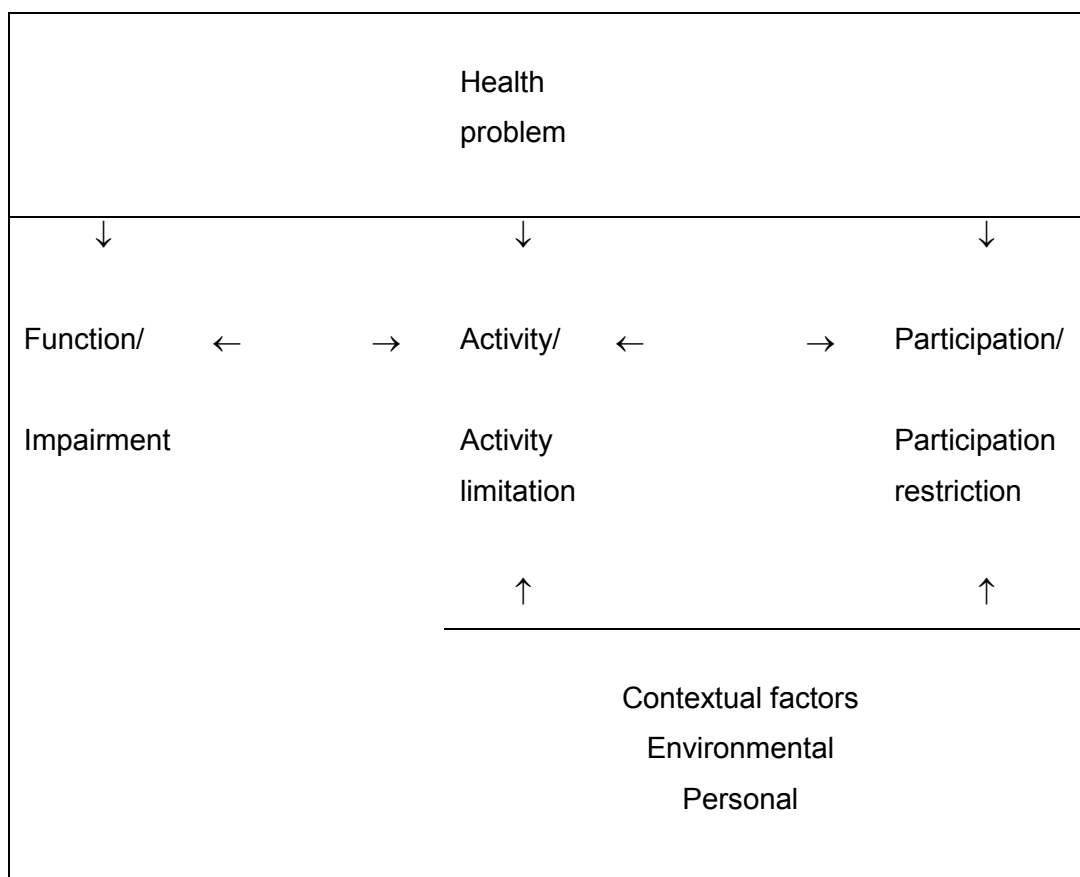


Figure 6: WHO Model of Impairment, Activity & Participation

Recent literature on best practice approaches to community rehabilitation subscribe to the World Health Organisation (WHO) model, outlined above. Within this framework, individuals are assisted to achieve their real world objectives and participate in their

chosen real world activities. The following issues have been drawn from the literature as crucial aspects to consider in a community-based, participation-oriented rehabilitation program.

3.10 Community Based Rehabilitation

Community based rehabilitation is a service model for people with TBI that addresses the functional sequelae of brain injury in the context of the person's home, their local community and/or society in general ("Department of Human Services (2001): Acquired Brain Injury Strategic Plan,"). Community based rehabilitation assists people with ABI, their families and carers to achieve maximum community integration, participation and quality of life through increased independence, choice, opportunity and access to appropriate and responsive services.

Research has shown that recovery rates for physical, cognitive, and behavioural problems are uneven and vary from person to person but that optimal functional recovery is more likely to take place in more naturalistic, community-focused environments (Evans & Ruff, 1992).

Research has shown that at least six months of community based rehabilitation has the potential to improve independence levels, increase social activity levels and reduce support needs (Wood, McCrea, Wood, & Merriman, 1999).

Community rehabilitation provided by specialist ABI programs has been shown to produce better outcomes compared with generic services without specialist ABI focus (Gerber, Boschen, & Gargaro, 2008). This includes better outcomes in areas of health status and functioning, as well as greater client satisfaction with the program.

Features of community-based rehabilitation that maximise outcomes are discussed below and include:

- Participation oriented approach
- Contextualised approach
- Long-term, flexible intervention
- Skill development
- Timing of intervention
- Interdisciplinary model of team work

3.10.1 Participation Oriented Approach

A top-down approach (McLaughlin-Gray, 1998) to the three levels of health proposed by the ICF characterises a community integration approach (see Figure 6). That is, participation / restrictions are the primary focus and direct an understanding of the underlying activity limitations / skills and the specific impairments / function displayed by the person. Environmental and personal factors (the presence or absence of which modify participation levels) also need to be identified and understood for either positive or negative impact on participation.

Based on this top down approach the Community Approach to Participation (CAP) Model was developed to articulate the aims and principles of a community based approach to the rehabilitation of people with severe brain injury (Sloan, Winkler, & Callaway, 2004). The aims of the CAP are to:

- Maximise the person's level of participation in valued life roles and their inclusion in home and community life
- Assist the person to maintain or develop a network of social relationships and supports
- Facilitate engagement in meaningful activity
- Support the development of independence in specific activities that underpin living skills
- Promote feelings of self confidence and empowerment to make everyday decisions and life choices
- Enhance adjustment and satisfaction with the changed life.

As progress towards the above aims is often variable, unpredictable and at times difficult to achieve, the resources required to support community participation change over a person's lifetime (Willer & Corrigan, 1994). For each area of need, a high level of initial intervention is recommended followed by a period of consolidation during which supports can be scaled back.

In a study of 51 severely injured individuals who received two years of CAP intervention, significant improvements in functional independence and life role participation was achieved and resulted in an overall reduction in daily support needs and costs of care (Sloan, Callaway, Winkler, & Anson, 2006).

3.10.2 Contextualised Approach

The context in which rehabilitation takes place has been shown to be an important factor in client outcomes. A holistic approach should ensure that the environmental context addresses emotional and motivational responses, thereby strengthening the therapeutic influence (Prigatano & Summers, 1997). A great advantage of community-based rehabilitation therefore is the ability to create a normalised environmental context whereby the individual can be involved in personally relevant activities.

The contextualised approach is particularly important for those who have severe and diffuse brain injuries, physical disabilities and challenging behaviour (Schutz & Trainor, 2007). As these individuals tend to lack insight, motivation, self-accountability and the ability to adapt their skills to new situations, a 'slow stream', contextualised approach to rehabilitation assists to gradually shape more adaptive behavioural responses within specific environments.

In a recent study on individuals with chronic cognitive-behavioural impairment, it was demonstrated that a contextualised approach is highly cost-effective (Feeney, Ylvisaker, Rosen, & Greene, 2001). Contrary to the traditional paradigm of cognitive rehabilitation, the contextualised approach emphasises the importance of compensatory strategies early in the rehabilitation process (Ylvisaker, Hanks, & Johnson-Greene, 2002).

Environmental modifications and contextual supports provided systematically by others are another effective way to compensate for cognitive impairment and facilitate performance of functional tasks. For example, the environment can be structured in such a way that the need to perform certain tasks or steps within tasks are eliminated, so simplifying demands placed on the individual. Graded exposure to distraction and provision of structure within the environment has been highlighted as an important way to assist individuals to function at their optimal levels (Hayden, Moreault, LeBlanc, & Plenger, 2000). That is, tasks are structured to reduce demands on impaired cognitive functions and prompts are embedded in the environment to cue adaptive responses.

3.10.3 Long-term, Flexible Intervention

It has been cautioned that strategies are tailored to the stage of recovery that the person is in, particularly with regard to insight and readiness to benefit from input (Prigatano, 2000a, 2000b). This requires that rehabilitation is structured as a flexible, dynamic process over an extended time-frame.

This is particularly relevant to those with severe and chronic impairment where the long-term goal is to achieve role participation. Such interventions are time intensive as they cover a wide range of domains including social, vocational and recreational participation. In order to modify routines of everyday activity, individuals who are part of these routines (e.g., family, workmates, carers) are integral in delivering the ongoing support required to enable participation.

The approach to intervention needs to be flexible so it is adapted to the individual's unique constellation of needs and timed for the greatest benefit. Frequently, several different techniques will be used with a given individual to deal with different problems encountered. Methods used will need to be altered as the injured person recovers and changes over time.

3.10.4 Skill Development

Research has shown that compensatory strategies that are adapted to the individual and designed to improve their functional skills, reduce memory failures and anxiety and improve interpersonal relationships (Carney et al., 1999). Such positive outcomes rely on the interventions being delivered within broader programs that address the full range of needs of the individual. Strategies taught are most likely to be of lasting benefit if they are applied directly in real-world settings, (Cicerone, 1999) and if they focus directly on functional skills relevant to the individual (e.g., Burke et al., 1988; Fryer & Haffey, 1987; Mills et al., 1992). This points to the importance of understanding the individual's personal motivations as well as their goals and tailoring input to support goal achievement.

It is suggested that compensatory strategies build on the skills that a person has learnt prior to the injury and has subsequently retained, as this reduces demands on new learning and reduces the person's confusion (Schmitter-Edgecombe, 2006). For instance, a person with severely reduced attentional and memory ability would be more likely to increase independence in personal care by performing the tasks in the same sequence as prior to the injury (e.g., showering, dressing, breakfast) or at the same time of day (e.g., showering in the morning or evening). Such an approach builds on residual skills and routines and minimises demands on new learning.

Another recommendation borne out of the literature is that compensatory strategies should harness existing, automatic and natural processes (Hayden et al., 2000). In this

way, less effort is required and therefore success is more likely (e.g. taking medication when sitting down to eat breakfast and dinner, or checking the diary before turning out the light before bed).

In the learning phase of acquiring skills, there is evidence that individuals learn better if they are prevented from making mistakes in the first instance (Wilson, Baddeley, Evans, & Shiel, 1994). This body of research emerged from the observation that once a task component (e.g., an error) becomes automatised it may be difficult to eliminate.

Such rigidity can also lead to difficulty adapting the skill to changed situations (e.g., differences between the environment of the hospital and home). It is therefore important to teach skills in the setting in which it will be required and to embed those skills within the functional routine.

3.10.5 Judging the Timing of Rehabilitation

The timing of rehabilitation commencement and the intensity of the rehabilitation provided is important to consider in maximising the impact of rehabilitation on the recovering brain.

A number of studies have shown that early rehabilitation is associated with better outcomes such as improved self care and mobility (Cullen, Chundamala, Bayley, & Jutai, 2007) and reduced length of stay (Mackay et al., 1992). Cullen, Chundamala, Bayley & Jutai (2007) suggest that the optimal timing of rehabilitation may be unique for each individual and that their stage of recovery may be the best determinant rather than a certain point in time post-injury.

3.10.6 Interdisciplinary Model of Team Work

The more complex and varied the array of issues, the more important it is to manage them within an interdisciplinary model of teamwork. An interdisciplinary team is person-focused and all team members share responsibility for supporting the individual in all problem areas. Collaborative, interdisciplinary assessment can reduce the burden of assessment for the individual. The gathering of information from different perspectives combined with a shared team approach provides a rich understanding of the key issues, minimises repetition and lays the foundation of integrated treatment approaches.

Interdisciplinary teamwork enables the individual to achieve reliable practice of key skills with the range of people involved in the team. The family also receive a consistent and

more coherent message, which assists in facilitating education and self-awareness (Ylvisaker et al., 2002).

3.11 Supporting families

It is not only the injured person who needs to be considered when developing rehabilitation programs. A common finding in the literature is that severe TBI causes significant carer strain and burden (Douglas & Spellacy, 1996; Koskinen, 1998) and high levels of unhealthy family functioning (Anderson, Parmenter, & Mok, 2002; Testa, Malec, Moessner, Allen, & Brown, 2006). The emotional and practical ramifications of looking after a family member with a catastrophic brain injury have been shown to be long-lasting, manifesting in terms of significant psychological distress (Allen, Linn, & Gutierrez, 1994) and health problems (Leathem, Heath, & Woolley, 1996).

A recent Australian study showed that levels of depression in carers reached 60% in a sample of 35 primary carers of individuals 3.5-10 years post-injury (Douglas & Spellacy, 2000). Due to resource constraints and limited service provision, care-givers are often required to assume the roles of nurse, physiotherapist, counsellor, carer in a lay capacity in addition to their pre-injury role of parent, spouse or sibling.

Qualitative evidence has indicated that carers report a sense of feeling overwhelmed by the daily demands of living with a brain injured individual. Rather than decrease, their responsibilities and demands increase over time and thus attendant care services are viewed as a “lifeline” (Douglas & Spellacy, 2000).

Psychological deterioration has been documented to take place in caregivers from 3 months and is still apparent at 5 years post-injury and beyond (Brooks, Campsie, & Symington, 1987; Livingstone, Brooks, & Bond, 1985). As a result of the high dependency of the injured individual and near-continuous supervision required, care-takers frequently become socially isolated (Lezak, 1978). Moreover, they are often forced to relinquish their own employment or education in order to meet their relative’s care needs (Douglas & Spellacy, 1996).

Douglas and Spellacy (1996) advocate the need for greater service provision to care-givers and increased practical assistance with the daily demands placed on them in order to function more effectively in their roles. As suggested in the recent literature, the

better the family members are able to cope with their situations, the better the patient's recovery (Verhaeghe et al., 2005). These authors assert that there is a need for models of long-term support and care that alleviate sources of burden on relatives.

The implications for developing STR Programs is that carers require education and support delivered in a climate of understanding of the devastating and ongoing emotional impact of caring for their injured loved one.

3.12 International and National Program Models

In an international context, European nations are considered to have the most comprehensive approach to the management of people with catastrophic brain injuries. As a consequence of increasing rates of MCS/VS in Europe, the Scientific Panel Neurotraumatology of the European Federation of Neurological Societies set up a task force on guidelines for quality management of patients in VS.

Based on class II or III evidence from the literature and clinical experience of expert task force members, the following best practice recommendations for rehabilitation programs were introduced:

- The establishment of special units for early rehabilitation (15-20 beds per 1 million population) in order to support spontaneous recovery and quicken restitution of impaired cortical function, preserve and support brain plasticity and prevent secondary and tertiary complications
- Inpatient rehabilitation for a period of 6 -12 months
- Ready access to investigations and management of co-morbid medical conditions
- Ongoing “activating” nursing management for those who remain in VS
- Availability of 6 monthly admissions for 3-week follow up assessments during the first 3 years post injury
- Minimum 3 years experience/ supervised training in management of VS/MCS for physicians and therapists

In the United Kingdom, the National Service Framework for long-term conditions was released in 2005 as a set of standards for the National Health Service. It sets out evidence-based markers of good practice for people with long-term neurological conditions and their carers. It aims to promote quality of life and independence by ensuring that individuals receive coordinated care and support that is planned around their needs and choices. The National Service Framework emphasizes the need to

provide lifelong patient-focused care from diagnosis to death for people with neurological conditions. It also emphasizes the need for "joined up" service provision. This includes close collaboration between healthcare and social services, as well as close networking across different service boundaries such as hospital/community care, specialized/local services, etc. to provide seamless continuum of care along the patient pathway. The slinky model uses the analogy of a child's "slinky" toy progressing down a staircase to describe a network of services that may be required to support an individual through the various stages of his or her recovery following brain injury. An essential feature of the model is excellent communication and flow of information from one stage to another so that the individual can move down the staircase in a "seamless continuum of care." The model also serves to highlight the fact that the goals of rehabilitation (and therefore the outcome measures used) will vary with the stage of rehabilitation.

At the Halvar Jonson Centre for Brain Injury, in Alberta, Canada patients with severe TBI are admitted for rehabilitation on a "slow to recover" program where the mean length of stay is 359.5 days. Patients show significant improvement in outcome on the Functional Independence Measure (FIM) and the Functional Assessment Measure (motor and cognitive subscales) as well as the Rappaport Disability Rating Scale (DRS) and level of independence. Discharge destinations are to community living situations in 85.6% of cases. The centre places a significant emphasis on training and when new staff members are introduced, a structured 4-day educational program is carried out. Thereafter, for both nurses and therapists, specialised, full-time supervisors follow the work of the new staff members and evaluate the attainment of predetermined skills. Financial support for the education of staff is continuously provided.

In Victoria, the TAC delivers a personal injury scheme that provides needs-based, no-fault benefits for medical, rehabilitation and disability services. The TAC is governed by the Transport Commission Act 1986, which legislates that people injured as a result of transport accidents receive effective rehabilitation.

In 2002 the TAC instituted a new lifetime support initiative based on the notion that a comprehensive system of care should include therapy, training, and supported living within the natural environment for extended periods or even across the entire lifetime. This approach moved the system of care from traditional rehabilitation practices to a model that assists clients to rebuild their lives and participate in the community.

The Lifetime Support model was built around person-centred planning and incorporated community focused discharge, the creation of more flexible community based support options, a greater focus on client outcomes and a new approach to client communications. The viability of the scheme was initially a concern from an economic perspective, however the continuing use of this model and results from a recent study indicate that this it is a financially sustainable scheme. Better outcomes have been achieved for clients of TAC by adopting an approach that places the individual with brain injury at the centre of the service delivery, rather than at the end of service and funding constraints.

Key Implications of the literature review for the ABI-STR Program

- In order to provide a comprehensive continuum of care, the systematic availability of slow stream rehabilitation across the entire life time following catastrophic brain injury is required.
- Individuals in minimally conscious or vegetative states may pass through various phases of consciousness at varying points post-injury. As such, the timing and nature of rehabilitation intervention will be influenced by an understanding of the level of consciousness of the individual.
- Functions and skills can emerge many years after catastrophic brain injury, highlighting the importance of long term intervention and the importance of minimising secondary complications that may otherwise hinder future progress.
- The brain's recovery potential is influenced by the physical and social environment to which the individual is exposed. This points to the need for environmental stimulation, opportunities for learning, minimisation of the experience of pain and stress, and early intervention.
- Optimal recovery can be promoted by minimising secondary health complications such as neurological, musculoskeletal, skin, respiratory and digestive issues.
- Skill development is encouraged by providing consistent and repeated opportunities for contextualised practise of personally meaningful activities.
- Disability management plans require that skills and routines which are developed in active rehabilitation phases are maintained over time when therapy input is reduced.
- Better health status and functional outcomes are seen following specialist ABI rather than generic programs, indicating that expert knowledge and experience in working with catastrophically brain injured individuals is crucial to outcome.

- Progress towards life role participation is an overarching long-term goal following catastrophic brain injury and requires a level of resources and rehabilitation input to achieve.
- The individual's changing levels of insight and readiness to benefit from therapy necessitates monitoring as well as long-term, flexible funding and dynamic intervention.
- Given high levels of family and carer distress, provision of education and training and support for care-givers is an essential component of ABI rehabilitation.

PART B: CONSULTATION: CONSUMER, THERAPIST & SECTOR

4. CONSUMER PERSPECTIVE

4.1 Aims

The aim of the consumer interviews was to obtain a personal perspective on the ABI:STR Program, including:

- Overall satisfaction with the program
- Experiences with community-based and hospital-based therapy, attendant carers & case management
- Waiting periods
- Funding & service availability
- Suggestions for improving the program

4.2 Method

4.2.1 Participants

An initial pool of 13 clients on the ABI:STR program was identified. Eight of these were selected by the ABI:STR manager, and the others were selected on the basis of clients most recently accepted onto the program who were agreeable to participating in an interview. An additional five waiting list clients were also selected. The interviewer attempted to contact all clients, but some could not be contacted or were unavailable to participate in the interview.

From the above pool, two individuals on the ABI:STR program and nine family members were interviewed. Nine people were currently in receipt of ABI:STR therapy services, and had been on the program for an average of 5 years (range 18 months to 9 years). Two people were on the waiting list for ABI:STR services. One, an 11 year old girl, had been on the waiting list for 28 months and the other, a 17 year old girl, had been on the waiting list for 18 months.

The average age of the ABI:STR recipients interviewed was 35.8 years (range 24 to 51 years).

With regard to current accommodation, nine STR recipients were living at home with 24 hour care, one lived in an Supported Residential Service and two lived in residential aged care.

4.2.2 Procedure

Eleven telephone interviews were conducted, each of 45 – 60 minute duration. The interviews were semi-structured (refer to Appendix 2 for interview questions) and sought feedback on the three key components of the therapy program: therapist's input, attendant care and case management. Interviews were audio-taped (with permission from interviewees). Notes were taken during the interview and during the play-back of audio tapes. Themes were identified on the basis of these notes, and key quotes were transcribed.

The interview included specific questions and ratings of satisfaction as well as open-ended questions designed to elicit and explore personally relevant themes.

The comments below should be considered in the context of the pitfalls that are inherent in seeking self-reports from clients and significant others. These individuals are influenced by subjective feelings of their own often overwhelming situations. This issue is particularly relevant where individuals are providing input or assistance that is not malfeasant. For example, while therapists or attendant carers may not necessarily be providing a service to the highest quality or standards, they are still seen in a positive light as families are grateful that they have access to any help at all.

4.3 Main Findings

4.3.1 Overall Satisfaction Ratings

Nine people who were currently receiving services were asked to rate their overall satisfaction with each of the rehabilitation services according to a five point scale. One family member felt unable to provide ratings.

5=extremely satisfied

4=very satisfied

3=neutral

2=dissatisfied

1=very dissatisfied

Satisfaction ratings were averaged and are displayed in Table 2.

Table 2
Consumer Satisfaction Ratings of ABI:STR program

ABI-STR Service	Average satisfaction rating	Actual Ratings
Occupational Therapy	4.1	4,4,4,5,5,5,5,5
Physiotherapy	4.2	4,4,5,5,5,5,5,5
Speech Therapy	3.9	1,4,5,5,5,5,5,5
Attendant Care	4	4,4,4,4,5,5,5,5
Case Management	2.4	1,1,2,3,3,3,4,5
Overall Program satisfaction	3.9	3,4,4,4,5,5,5,5

4.3.2 Community-Based Therapy

Respondents were very clear regarding the roles of each of their community-based therapists on the ABI:STR program. The overwhelming majority of respondents reported that the needs of their family member were satisfactorily addressed by the therapy team. The needs they were specifically asked about included: health care, oral hygiene, nutrition, swallowing, mental health, behaviour, communication, community and leisure activities, independent living skills, positioning and pain management, mobility and equipment.

“The OT works on how he is able to do things on his own, like in the kitchen ... the physio works on balance and walking ... the speech therapist helps with eating and speech.”

“Goals are very important ... we are all very focussed on this eating goal ... she is eating now as a result of the therapy input.”

Most of the people interviewed have been on the program for longer than three years. They worked with experienced community brain injury therapists, many of whom had more than 10 years experience. The majority of respondents had had the same community-based therapists since commencing on the program. The experience and approach of community therapists was overwhelmingly valued:

“They are experienced, they work with brain injuries all the time ... they know each other and work as a team ... experienced therapists can see the end result ... the broader perspective.”

“They care ... it’s all about the heart”

“They listen to me ... I listen to them ... it’s both ways.”

However, the therapy practises of some therapists were reported as unsatisfactory:

“I don’t like what she’s doing...my son says quite a few words and the speech pathologist has given up. All she’s doing with my son is teaching him how to communicate on a board etc etc...well that’s not good enough because I think my son has a lot of potential as far as speaking. I’m not happy with the speech therapist and I don’t want her on board.”

“I don’t really know what the old one (OT) did, the new one (OT) is helping me with work”

Where a change of therapist had occurred they had typically remained within the same private practice, so the change over was described as smooth.

“They (the therapists) have been with him now for 2 years ... they know him inside out ... I don’t have to explain myself 100 times.”

There was one exception

“Due to many therapy changes, the speech therapist and OT (were) not up to date with (my) progress”

4.3.3 Hospital Based Therapy

The generally positive feedback regarding the practice of the community based therapists stood in stark contrast to the feedback on institutionally based therapists. Respondents who had experienced living in residential aged care settings reported that in-house therapy staff were not able to satisfactorily address the complex range of

needs, and family members found it difficult to get details of the therapy program being conducted.

"We had the nightmare of the [nursing home] providing their in house service... the speech therapist was great...the OT had a lot to be desired. I believe they could have done a better job...I wasn't 100% happy with the in-house physio...I think there were a lot of admin hours being used, not so much the physical hours...I went from in-house to community therapists so I saw both sides..."

"Hospital based therapists' lacked experience with ABI and management of (his) complexities ... they were not experienced taking someone like my husband home."

"They didn't really do anything with him...it was more they would just tell me"

"We used to have monthly meetings with the therapists but they have fallen away because they say there is little change ... there is no accountability ... I'm not aware of what they do. Nothing has changed since he went onto STR."

"There's a lot of enthusiasm and then it drops away...there's a lot of talk about what could happen and then nothing happens. Chest care is not addressed properly...oral hygiene is not addressed properly...mental health...communication...dystonia. There's no routine and community and social activities have not been addressed."

STR Program Folders and therapy guidelines were highly valued.

"The folders are fantastic ... we keep everything in it ...it has all the details of his care ... it's made a huge difference. When new people come in I don't have to keep explaining the background"

4.3.4 Attendant Care

Most people seemed unable to distinguish the hours of attendant care funded under ABI:STR and that funded under other government packages (e.g., Support and Choice package).

The hours of attendant care funded under ABI:STR varied for the recipients interviewed from 10 to 44 per week. Positive benefits of attendant care in reinforcing the therapy program were identified:

“Attendant carers play a huge role ... they follow though the program and repeat everything ... we are very strict here ... repetition is good for her and works for her because she has amnesia”

Reflections on attendant care were often qualified:

“Attendant care has been up and down over the years but we have a good team at the moment and it is well co-ordinated, so I’d give it a 5 (extremely satisfied).”

“It’s difficult to fill all shifts ... it’s so hard to get good carers ... we have learnt how to say ‘No’ to a carer and to remove them from the program ... we were sent any carers (at the start)... but you get a sense of who will work ... we have a team leader of carers and she talks to everyone.”

“It’s a huge effort to make sure the carers follow this (therapy) through.”

“The carers are really good but the agency is not that good”

“The agency are just hopeless ...they don’t train the carers or replace them when they are sick ... they just do the pays and they can’t get that right ... we have given them so many chances ... we do all the work ... we are in the process of changing agencies”

4.3.5 Case Management

The turnover of Case Managers assigned to individuals was the most common concern raised by respondents.

“We go through too many Case Managers ... we have had 7, no 8, Case Managers (in 9 years on the program) ... only one was good and she made a

difference ... each time I meet a new one I have to go through the story again ... I never hear from the new ones."

"They don't last long, there has been a huge turnover ... I've had at least 12 (in 9 years on the program)... It's hard to get anything done ... one said she'd organise a holiday but by the time she could get onto this she had left and the new one came and she said there was no record and she didn't follow through."

"We've had three case managers (in two years on the STR program), the first one thought I couldn't achieve things ... the second one was really there for my husband and played a huge role in getting him home ... I don't know the new one"

No one identified the Case Manager as the person in the team that co-ordinated therapy goals.

"The Case Manager doesn't coordinate the goals ... the therapists do that ... they (the Case Manager) do the submission, but they get all the information from the therapists."

"The therapists have worked as a team without the Case Manager."

"... they should not be so negative about goals... the case manager thought I couldn't achieve things ... it was only because I saw the (name deleted) family take their daughter (another STR client) home that I thought I could do it."

One mother described the goal setting process as:

"All three therapists are terrific and suggest certain things ... but because we are living with her and are close ... the instinct ... therapists suggest and the family follows through ... it's not part of the case management role."

Many people were unable to clearly state the role of the Case Manager.

"I don't know (the role of the Case Manager), we have a meeting every six months ... I can ring them up ... I haven't had a lot to do with them ... we do things in-house ... they apply for funding."

There were exceptions to the generally negative feedback received regarding case management practice. The roles appreciated included:

"I go to her if I need any information ... ask her opinion ... she makes me feel it's OK to have time to myself"

"I debrief with her and she tells me of opportunities and she did all the contact with the attendant care agency."

"Because I've had a good one, I know the difference, how do we get a good one like X (name)?"

4.3.6 Experience of the Wait List

People admitted to the ABI:STR program 5 or more years ago reported that they did not wait long for therapy services to commence.

For those admitted to the program within the last two years and for those still on the waiting list significant issues were identified.

One mother spoke of the inappropriate accommodation her son was placed in during the 12 months he was on the waiting list for ABI:STR services. She said,

"The hostel was horrific and he got really bad depression. When he wheeled himself onto the Nepean Highway (in a suicide attempt) he was moved home"

One wife spoke of the effect of the delay in services on loss of function

"He is very determined and I think he would have made more progress if it (therapy) was earlier... he got very bored...his speech went down... he spent a lot of time in bed ... his walking capability decreased ... I tried to do the therapy"

... like walk him ... but I'm too frightened because of the risk of falls ... I'm exhausted and too tired to do it now"

A brother spoke about the development of complications:

"they put him in a nursing home ... it was just a bed ... they didn't want to do anything with him ... mum and dad went in everyday ... he kept getting pneumonia... then he 'fell out of bed' and fractured his hip – actually they dropped him from the hoist ... when we got STR funding we brought him home ...his behaviour problems immediately reduced."

The uncertainty of being on the waiting list was a significant stress for people.

"We didn't get any feedback about the wait list progress ... we would have liked more information ... our biggest worry was that he might get too old and be ineligible ... not hearing made us more depressed."

Most people spoke of the extended period of time spent in acute hospitals waiting to be accepted onto the program so they could take their family member home.

"She spent 14 months in the (name deleted) hospital but her return home was delayed by a lack of funding... I can't say by how many months ... she couldn't come home until we got a package of funding for carers and built a fence around the home"

One wife spoke of the costs involved in the delayed return home:

"It cost us \$2,500 each month to be in (the nursing home) while the nursing home OT fiddled around ... the builders complained she didn't know what she was doing ... there were (also) issues with the wheelchair."

4.3.7 Lack of Funding & Services

The lack of information in the months after the injury and the confusion families experienced in trying to work out what services were available and what funding they were eligible for and able to access was a common theme.

A mother whose daughter has been on the STR waiting list for 18 months said, *"We had nowhere to go ... it was pretty scary ... what I found the hardest to accept was that, if my daughter had been in a car accident, even if she had caused it, she would have been entitled to more support and rehab...it was such a battle to get anything ... it was so frustrating that ... we couldn't get her home."*

She continued, *"After 14 months, we ended up with a package of 34 hours care per week ... speech therapy once a week through the local hospital and an OT to set up some community activities ... Support and Choice pays for a Case Manager in Warrnambool but they are so far away I do most of it myself... and we got an educational grant for a tutor ... I get paid to do some of the 34 hours care... I use that money to pay for swimming lessons and music therapy ... it's such a mish-mash ... I find things out by word of mouth."*

A mother whose daughter had been on the waiting list for 28 months said, *"I just need funding for a Case Manager ... I'm so stressed that I don't know where to go to get information ... it's difficult to access funding ... the bathroom modifications cost \$8,000 ... I didn't know what to do ... I called my local member of Parliament."*

4.3.8 Finding Therapists and Carers

People more recently coming on to the ABI:STR program spoke of the difficulties of finding therapists, particularly those in rural areas. Often they were accepted onto the program and faced long waits for therapists and carers to be identified or start work.

"We found a physio straight away ... but we had trouble getting an OT and we don't see her much ... overall it took about 3 months to start"

"There is a lack of availability of carers in small rural situations ... I do most of the (paid) care as well (as the gratuitous care) because of a lack of carers."

"I'm not happy with the speech therapist because she has given up on him talking ... but the Case Manager hasn't done anything about getting him replaced ... he says there is no one else available who'll come to (small rural town)."

4.3.9 ABI:STR Program as a Whole

People interviewed were overwhelmingly appreciative of the therapy services received under ABI:STR program.

Since starting on the program, "I'm starting to feel like a person again ... I don't have to do the rehab now ... I feel like I'm becoming a wife and mother again."

"Without STR my son wouldn't be anywhere. With all its (i.e., the programs) limitations it is extraordinary it has the power to be so responsive"

"If I look at where she (my daughter) is, I'd have to give it a 5 (extremely satisfied) – I'm grateful. But if I look at how it could be improved, I'd have to give it a 3 (neutral) because there is room for improvement for others."

4.3.10 Suggestions for Improving the Program

Many family members did not hold comprehensive and vital documents relating to the injury, treatments and progress of their family member. Some did not receive copies of ABI:STR program reports and care plans. All respondents indicated that they would like to receive copies of all documentation.

One mother commented that there was no mechanism for recording the personal history of the person and that, for each new service provider, the history had to be repeated.

The funding protocols for ABI:STR were seen by some as inflexible and not person centred

"It (therapy hours) should be the other way around ... in the beginning she never got to use her three hours (for speech therapy) because she was always asleep ... but it was given regardless ... and then she improved, it was reviewed and cut back ... when she needed it we had to fight for it. You have got to go with the individual ... not a general thing where you start with 3 hours and come down ... it depends on how the individual is recovering."

“People should be allowed to be individually looked at as a (whole) person ... I don’t understand why the money has to be segregated into little bits and pieces. I can’t understand why they can’t flexibly allocate the pot of money.”

“(the funding) needs to be more individual ... you need to work out what is going to be best to focus on ... there is so much there ... you have to get the timing right ... having more predictability about the long-term funding would be good.”

The challenges of getting approval and enduring long waiting times for customised equipment to arrive were considerable. People said that the equipment becomes obsolete, and there are difficulties getting it replaced or updated. Where families were in contact with each other, a number of examples were given of passing on unneeded equipment to other STR recipients on an informal basis. Two respondents suggested formalising this process through a register that allowed for an “*equipment swap*” or “*sharing of equipment*”.

5. THERAPIST & SECTOR CONSULTATION

5.1 Aims

Consistent with the project brief, a series of therapist forums were conducted to review current ABI:STR therapy standards and practices.

5.2 Method

5.2.1 Participants

Health professionals were asked to participate in the forum on the basis of the following criteria:

- Greater than five years experience in working on the ABI:STR program
- Currently providing service to ABI:STR clients as well as ABI clients funded through other programs (e.g. TAC)
- Greater than 10 years experience in their particular discipline
- Available to participate in a series of 6 forums, each of 2 hour duration
- Cover a broad range of professional disciplines

Input was sought from the ABI:STR program manager as well as experienced ABI:STR therapists in determining appropriate forum participants. All therapists that were asked to participate in the forum agreed to attend.

The membership of the Therapy Forum was as follows:

- **Michelle French** - Principle Occupational Therapist, Michelle French & Assoc.
- **Susan Gray** - Client Services Manager Topaz ABI, Care Connect
- **Leanne Healy** - Principle Occupational Therapist, Everyday Independence
- **Jan Mackey** - Principle Speech Pathologist, Applied Communication Skills
- **Joan Tierney** - Medical Practitioner
- **Sue Vincent** - Principle Physiotherapist, Neurological Rehabilitation Group

Additionally, the following ABI service providers were consulted and provided information, advice and feedback on the recommendations contained in this report:

- **Libby Callaway**, Neuroskills
- **Dianne Winkler**, Summer Foundation
- **Marg Darcy**, Marg Darcy and Associates

- **Jan Loewy**, ABI-Behaviour Consultancy
- **Katherine Hoskins**, ABI-Behaviour Consultancy
- **Jenny Todd**, ABI-Behaviour Consultancy
- **Bronwyn Harding**, ABI-STR Program Manager
- **Tom Worsnop**, Melbourne City Mission
- **Kerry Stringer**, Disability Services
- **Helen Harrington**, Epworth Hospital

5.2.2 Procedure

The forums consisted of six sessions, each of 2 hours duration. The forums were facilitated by the author of the review.

The first forum consisted of an open discussion of experiences of working on the ABI:STR program, with a focus on identifying what therapists perceived to be issues relating to current standards and practices. Based on this session, the following six themes emerged: 1) Therapy models; 2) Role definition; 3) Workforce issues; 4) Goal setting and outcomes; 5) ABI service systems; and 6) Therapy funding. Subsequent sessions addressed one or more of the above themes, as well as addressing additional themes that emerged through the course of sessions. The last two forums focused on discussing and refining recommendations of the review. When discussing specific themes, therapists were encouraged to generate ideas for addressing weaknesses and to collaboratively test ideas with the group, allowing for further refining of these ideas.

Each of the sessions was recorded on audio tape, and a summary document was produced by a research assistant. This document was then distributed to all participants prior to the subsequent forum. Forum participants were given a draft copy of the review document, and given the opportunity to provide further input into recommendations.

Further input was sought from ABI service providers (see list above) on issues relating to practices on the ABI:STR program, as well as proposed recommendations.

5.3 Main findings

The therapy forums identified a number of key themes relating to the provision of therapy services in the ABI:STR Program. In the following section a summary of the therapy forum discussions on each of these themes is integrated with the additional input of the ABI service providers listed.

5.3.1 Understanding Recovery in Slow to Recover Individuals

Participants recalled that when the ABI:STR Program commenced in 1996 the generally accepted notion of recovery espoused by the medical profession was that it was most rapid in the first year after injury and continued at a slower pace for a further year, after which the individual's potential for recovery "plateaued". It was believed that intensive therapy intervention after the two year window was ineffective and therefore wasteful. At that time, it was therefore seen as appropriate for the ABI-STR Program to offer "intensive" therapy services for the first two years and then reduce input to a "maintenance" level at that point in time.

Participants in the Therapy Forum agreed that in the past 10 years there has been an accumulation of scientific evidence that, without doubt, refutes this earlier notion. It is now known that recovery continues for many years following injury and that the timing of intervention needs to be assessed on an individual basis to gauge the person's readiness for specific inputs. It is also understood that the need for therapy services in catastrophically injured individuals needs to be conceptualised as extending over their lifetime. Clinical experience of the forum participants accords with the literature findings.

Participants noted that with the change of management in the ABI:STR Program the original funding model has been less rigidly adhered to and has adapted to the increasing evidence base. This has led to people on the ABI:STR Program often receiving active input for longer than the nominal two year period and, even when they have officially been moved to 'maintenance', some individuals continue to receive a significantly higher level of support than they would have in the earlier years of the program.

Forum participants argued that the funding model for ABI:STR individuals should be modified and aligned to the scientific evidence regarding recovery of function. It was seen as vital that these individuals, who have life-time needs, are funded for reasonable therapy in a timely manner and for as long as, or whenever, required over their lifetime.

There was strong debate within the Therapy Forum as to the ethics of decision making when allocating a limited funding pool to a high needs group. Do you limit the people coming on to the program and ensure that those fortunate enough to have been selected

are funded at an adequate level to maximise their outcomes? In this case, others not chosen for funding are denied those same opportunities. Or, do you distribute the funding equitably but in doing so reduce the outcomes obtained by all to a bare minimum?

It is extremely difficult to make such decisions but participants identified that we have come “full-circle” in that the same issues that led to the development of the ABI:STR program in 1996 are again present. That is, long-term high dependency catastrophically brain injured younger adults are not receiving the input they require and remain in acute hospitals or inappropriate accommodation for inordinate periods whilst on the ABI:STR waitlist. As occurred 10 years ago, the failure to provide adequate levels of therapy to this group will give rise to increased life-time costs and poorer quality of life for these individuals and their family members.

Participants compared the difference in opportunities for their catastrophically brain injured TAC clients with those falling within the non-compensable system. The inequity of the system is striking and may only be remedied by a universal compensation scheme that gives access according to need, rather than mechanism of injury.

5.3.2 Model of Treatment

The treatment model of catastrophically injured individuals has been termed ‘slow to recover’. This name depicts the reality of the individual’s situation in that, given an appropriate environment and tailored inputs, small changes in function are encouraged and shaped in meaningful ways over an extended time frame.

Participants noted that families new to the ABI:STR program usually have inadequate or incorrect information about their relative’s injuries and what to expect. In the experience of participants, information from the medical profession is often quite polarised – either overly bleak or unrealistically optimistic. One of the key roles for the therapy team is to provide / clarify information and gradually shape the expectations of the family throughout the duration of rehabilitation.

Participants believe that while ‘hands-on’ input (i.e., directly with the individual) is important, the work done ‘behind-the-scenes’ is equally important in the longer-term. Such ‘behind-the-scenes’ work includes:

- Meeting with the team as a whole to discuss progress and set goals and priorities

- Liaising and problem solving an approach to managing a complex problem with another team member or service provider
- Accessing resources and investigating equipment options
- Writing care manuals and therapy guidelines
- Training attendant carer workers and others
- Providing support and information to family members
- Writing funding submissions and reports

Participants argued that the value of this non-face to face work should be acknowledged as integral to slow stream rehabilitation practice and factored in to the amount of funded therapy time allocated. It was also seen as important that the individual and family are educated as to this more expansive model of therapy delivery. Participants expressed concern that families often place an inordinate value on hands-on treatment and discount the importance of the behind-the-scenes component of the therapy intervention. In such a scenario it becomes extremely difficult to reduce / withdraw therapy services as, over a number of years, families and individuals have become used to, and perhaps dependent on, the physical presence of the therapist, particularly if appointments are always held at the same time on a set day of the week.

Two key components of slow stream therapy intervention were identified:

- management of core, basic needs and
- specific rehabilitation interventions.

Basic, core issues include health care, comfort, positioning, manual handling, oral care, nutrition, behaviour and communication. Management of core needs focuses on structuring the person's external (e.g., accommodation, daily supports and task cues) and internal (e.g., health and medication) environment to ensure that day-to-day factors that positively influence a person's function are maximised.

Participants described that, when an individual first comes onto the ABI:STR program, the establishment of routines and strategies for the management of these core issues are at the foreground of practice. This was described by participants as 'the set-up phase'.

Over time, as the person stabilises and improves these core issues move to the background. However, they remain integral to the ongoing daily routines and create a therapeutic platform from which additional goals can be created.

When core needs are well managed, foreground issues move to a focus on the opportunities for skill development and community participation. Careful observation of progress enables the therapist to identify windows of opportunity in which specific rehabilitation interventions may be pitched.

When an ABI:STR client moves to a “maintenance level” of funding this should not be taken to imply that the person has plateaued in their function. The reality is that their situation will continue to be dynamic, with opportunities to continue to both improve or decline in function depending on a range of factors and circumstances.

Forum participants identified that a ‘maintenance’ level of STR funding is usually not adequate to provide the therapist with the time to work on new goals (although in many cases one or two new goals may be managed). However, at the very least, management strategies and routines established for the core issues need to be sustained and refined so that gains are maintained and skills are consolidated.

5.3.3 Funding for Therapy

A major concern voiced by all those consulted was the formulaic model of allocation of STR therapy funding. Typically a high number of therapy hours in each of the three disciplines (OT, PT, SP) is requested in the first 1 to 3 years of acceptance onto the program and therapists have a high degree of certainty they will be funded at these levels. Even if the need for these hours has not been expressly identified or where the allocation is clearly more than needed to achieve the desired outcome they may be applied for with the mind set that ‘you might as well apply for them now, because you won’t get them down the track’.

Care Plans detail requests for therapy hours according to a weekly allocation (e.g. three hours speech therapy per week for a six month period). This method encourages a rigid pattern of service delivery that is not tied to measurable outcomes. It is important to avoid the possibility of conflict of interest or external pressure to use up all the allocated hours, where they are not required.

Participants reported inconsistency in advice as to whether excess therapy hours can be banked. However, even if instructed to do so by a case manager, therapists are reluctant to bank hours due to a possible perception of corrupting the system as, hours have to be billed for in the designated funding period, when that service has not yet been provided.

A similar mind set is apparent when therapists suggest discharging people from the program. They may be advised that the individual will never get back on the program so it is best to keep them on it. Further, families may also fight to keep people on ABI:STR as there are no clear options within the existing service system for obtaining the support they believe their family member requires. Participants all reported that a huge amount of effort is expended fighting to keep hours people might not benefit greatly from now, but may need again in the future.

Participants argued for a more flexible funding model based on the individual's specific needs and readiness. A system where hours are allocated flexibly would allow for the fact that not everyone is ready for the same level of intensity of therapies within the same time frame post injury.

Comparisons with the more targeted TAC funding model were made by participants who work in both sectors. TAC requires therapists to link the requested therapy hours to measurable outcomes, backed-up with a strong clinical rationale. The request is reviewed by a clinical panel member from the same discipline as the therapist making the request. Although there were some concerns raised regarding the TAC model, it was generally felt to provide for greater accountability and evidence-based practice. This model is also more flexible as, from one funding period to another, hours of input can increase or decrease depending on need.

5.3.4 Model of Teamwork

In order to achieve effective outcomes, individuals with complex problems require an interdisciplinary model of team practice. In this model, therapists work as a co-ordinated team and share person centred goals. This is a dynamic process whereby therapists share assessment information, provide joint treatments and together develop strategies and techniques that best suit the individual in goal attainment.

However participants identified that, in practice, ABI:STR teams are increasingly segregated on multidisciplinary lines, whereby therapists provide discipline-specific input centred around each of their own therapy goals. Participants identified that the absence of a co-ordinated, holistic approach impacts adversely on the individual's ability to achieve potential gains.

The reasons for this shift in the model of teamwork were seen to occur due to a loss of experience in both the therapists and case managers engaged in ABI:STR work (discussed in more detail below). It is also felt to be due to a reduction in the frequency of the clinical meetings that were the hallmark of past ABI:STR practice. This critical practice has diminished for two possible reasons. Firstly, therapists' time to attend meetings is not funded and therapists are now less able to absorb these costs (see below) and, secondly, therapists report that meetings are not as useful due to the absence of clinical case management leadership on programs and the focus of meetings often centering on 'updating the new case manager'. Teams that operate without regular meetings and clinical leadership typically provide fragmented and reactive interventions characteristic of the multi-disciplinary model.

Participants identified that therapy teams on ABI:STR programs should always operate on interdisciplinary principles as defined above. An experienced therapist or case manager on the program, who has frequent contact with the individual and family should be nominated to provide team leadership. This leadership role involves the drawing together of the expertise of the team to fuse the various inputs into a coherent plan based on person-centred goals. This model is discussed in more detail in the recommendations section.

5.3.5 Expertise of the Therapist

Community rehabilitation following catastrophic ABI is an area that is not covered in undergraduate or post-graduate clinical health courses as the proportion of students who go on to practise in community settings is small in comparison to the proportion who work in acute or sub-acute settings. Further, there is only a recently emerging literature in this field and there are few written resources (none comprehensive) that provide guidelines for treating people with such complex injuries. Without training and guidelines for practise, less experienced therapists can become overwhelmed and easily lost amongst the myriad of problems and possible interventions.

Participants identified that specialised skills and knowledge is only amassed through years of clinical practice. When it was initially set up, the ABI:STR Program sought to attract experienced therapists and, over the years, an extremely skilled and knowledgeable workforce of community based therapists has developed in Victoria.

For reasons discussed below, it is now more difficult to recruit experienced therapists and participants believe that a greater proportion of STR work is undertaken by inexperienced / generic therapists. This situation is even more prominent in rural areas and also in paediatric ABI. ABI:STR programs funded within institutional settings may be delivered by hospital-based therapists and the same concerns regarding inexperience were expressed.

Therapists who lack the necessary clinical background benefit from supervision and mentoring from an experienced therapist. Without a system of supervision there is very little opportunity for feedback, which can result in errors in applying particular therapies to the wrong patient group and suboptimal therapy being practised for long periods, without detection. This problem is further exacerbated in rural communities where therapists are isolated and there is less opportunity to conduct joint therapy or consult with other professionals on best practice methods.

The key concerns participants raised were that therapists inexperienced in ABI may not:

- Have an understanding of the common sequelae of different aetiologies of ABI (e.g., tonal issues associated with TBI versus hypoxic injury) and therefore the different treatment approaches
- Have the capacity or interest in keeping up with the emerging evidence base regarding treatment of catastrophic brain injuries, so provide out-of-date or discounted interventions
- Have a knowledge of the typical long-term trajectories of various brain injuries and take an alarmingly short-term view in constructing programs
- Have experience in dealing with rare conditions or unique combinations of problems and so tend to offer generic rather than individually tailored therapy input
- Understand the complexity, resulting in becoming overwhelmed by the person's problems and not knowing how to select a relevant starting point for intervention or how to progress the intervention to the next level.

In Therapy Forum discussions, a number of anecdotal examples were detailed which highlighted the consequences of providing therapy without a knowledgeable frame of reference. Due to insufficient knowledge, therapists have unintentionally acted outside of the bounds of the client's best interests by providing therapy interventions that have interfered with the attainment of important therapy goals or, at worst, caused long-term harm to the client. Issues raised included:

- Prescription of medications with adverse long-term side-effects in order to withstand the pain of physiotherapy interventions,
- Inappropriate equipment prescriptions resulting in unusable items of equipment, serious safety issues or poor postural alignment,
- Prescribed manual handling techniques that trigger challenging behaviours or result in OH&S risks for carers,
- Over/under stimulation of people in a minimally conscious state,
- Stretching and casting programs that resulted in fractures, pain and muscle tears,
- Repetitious input with no clear goal and no lasting gain for the client.

Forum participants identified a strong need to retain expertise within the ABI:STR Program and also to build workforce capacity.

This need to build workforce capacity is particularly apparent, although not limited to, rural and remote areas. The numbers of catastrophically injured people living in outer metropolitan and rural areas do not support specialised practices in all regions for all therapy disciplines. It is a reality that therapists will be drawn from locally based generalist practices and they will require support to ensure they are able to provide appropriate therapy input.

Participants emphasised the need for junior therapists or those less experienced in catastrophic brain injury to feel comfortable to admit their shortcomings and to actively seek and receive assistance from others without the fear of being judged as being inadequate or incompetent.

It was also felt that best practice guidelines should be developed according to different client profiles. For instance, there are common approaches to working with a client in a minimally conscious state that differ significantly from working with someone who is fully conscious.

A framework proposed in the Therapy Forum and discussed with those consulted was the establishment of an ABI:STR Clinical Resource Panel (CRP), which would provide clinical guidance and structure to this mentoring process (see page 94 onwards for further detail). Participants felt that it is essential that the CRP is staffed by the appropriate people, both in terms of personal qualities as well as clinical expertise and experience in slow-stream community based ABI rehabilitation. Given that one of the primary functions of the CRP would be to mentor and support less experienced therapists, it is vital that members are respected clinicians who are flexible in their work practices and have the ability to pass on knowledge and skills to others without judgement.

5.3.6 Funding of Therapists

The hourly rate for STR clients was initially set in 1996 at the private practice rate then charged by community-based therapists. Participants recalled that this was a deliberate decision, taken in order to attract experienced providers. The rate however has not kept pace with the increasing costs of private practice, nor has it maintained parity with hourly rates funded by other organisations (e.g. TAC).

In the ABI:STR program there have been only two CPI rises in the 12 years of the program. The hourly rate for Occupational Therapy for instance was \$80.00 in 1996 and today is \$85.40. This failure to keep pace, even with inflation, has occurred at a time when there has been a greatly increased demand for community based therapy from private individuals as well as other organisations (e.g., TAC). The impact of the low hourly rate is compounded by the failure of ABI:STR to pay for non-face to face client contact (i.e., travel time, meetings, liaising, resourcing and report writing, and preparation of guidelines and manuals).

Participants noted that whilst, for many years, the non-funded activities and increasing costs of service were absorbed by the private practitioners, it has come to the point where it is not viable financially for some practices to take STR work and, if they do, to only take a greatly reduced number of referrals. This has led to the current situation where case managers have difficulty recruiting therapists to programs. Anecdotally they may make between 3-9 phone calls before finding a therapist (experienced or not) who agrees to accept the referral. This problem has been disguised by the minimal number of new STR referrals in the past few years while the waitlist has grown, however the

workforce problem will be revealed with the expected increase in program funding in the middle of 2008.

The anecdotal reports of therapists taking reduced STR referrals was assessed via a questionnaire sent to 11 community-based practices in Melbourne which have historically provided a high level of service to ABI:STR clients and have significant expertise in slow-stream rehabilitation for people with severe ABI. The survey revealed that 3 out of 11 practices are no longer accepting referrals and 8/11 are restricting intake due to funding issues and challenges of working with inexperienced case managers and team members. Details are provided in Appendix 3. With the trend towards experienced therapists reducing STR caseloads, there is a looming workforce issue that will affect future clients of ABI:STR. Due to medical advancements, this population is surviving longer therefore raising the question of whether in the future there will be adequate, high quality therapy services available to meet the rehabilitation needs of individuals with catastrophic brain injury.

5.3.7 Neuropsychology

Most forum participants and therapists consulted felt that there is an overall lack of neuropsychological input into ABI:STR programs. As a result, teams may operate without a clear understanding of the person's level of awareness and their cognitive strengths and weaknesses, particularly in regard to their learning ability. Also formal behaviour programs are often absent, which is of particular concern given the high incidence of challenging behaviour in this group and the adverse impact of challenging behaviour on accommodation placement, social relationships and community participation.

The ABI Behaviour Consultancy is the key agency that provides neuropsychology services to STR individuals and their service is supplemented by a small number of referrals to private neuropsychologists. The ABI Behaviour Consultancy reported that they are not specifically funded to provide services to individuals with ABI:STR funding and expressed concern that they are unable to meet the many demands placed on their service. As a result, they offer core intervention on a time limited basis to ABI:STR individuals referred to the service. Intervention includes a behavioural assessment, secondary consultation to the team and education in the management of the behaviour as well as written guidelines. More extensive or extended input is beyond the scope of

their current resources but could possibly be provided in the future on a fee-for-service basis.

5.3.8 Attendant Care Therapy Support

An effective Attendant Care program model involves allied health professionals setting up goal-oriented programs that can be implemented on a day-to-day basis by attendant care workers. The rationale for this model is that the individual experiences an appropriate and consistent care routine to manage their core needs and they also achieve the level of practice required to consolidate new skills. The ongoing input of allied health professionals is essential because attendant carers usually have little or no training in the management of complex care needs. They require guidance in adapting programs to changing needs and there is a high turnover rate of carers necessitating continual training of new workers.

The ABI:STR Program usually allocates 10 hours per week of attendant care for people living at home and 15 hours per week for those in institutional settings. These hours are in addition to the hours of attendant care funded through other packages (e.g., 34 hours per week for a person living at home on a Home First package).

The comments below regarding attendant care are limited to those hours funded by ABI:STR, which are allocated specifically for following through the therapy program.

To be effective, this attendant care model of therapy support relies on the skill and motivation of the carer and the ability of the therapist to provide ongoing training and support necessary to effectively guide the carer.

Overall, forum participants believe that this model can be extremely effective and should be retained. Participants all provided examples of significant gains in function achieved by individuals who had good carer support teams. They identified that the model works well when suitable carers are selected, they remain in the position for an extended time and there is funding for regular carer training. Therapists also felt that despite the difficulties of setting up and managing attendant care programs, it is vital for the individual to be appropriately supported across the day in core areas such as positioning, manual handling, eating and psychological/behavioural support. Therapists rely on carers to implement their programs and the forum participants emphasised the

importance of developing positive relationships with carers and continually assisting them to build their knowledge and support of the clients.

However, there were concerns with the current model raised by participants which included:

- Unless the carer has an interest or a particular skill and a capacity to learn, they often don't have a well-defined sense of their goals or how best to achieve them. As a result not all carers do what the therapist have instructed.
- The turnover of carers on programs is increasingly very high and each new carer has to be trained. There is a high, ongoing level of loss of expertise from programs and a continual need to train new carers. Therapists rarely have the funded hours to maintain the necessary training.
- Without the required training and guidance, the attendant care hours are typically used for unfocused activities such as outings and family respite, with no meaningful therapeutic gains for the client.
- Some attendant care agencies have a philosophy of client directed care, even when the client lacks decision making ability. In these cases, carers may not for instance implement programs that require setting of boundaries (e.g., on behaviour, manual handling routines, diet or activities). Perhaps, believing they are acting in the best interests of the person, individual carers may make up their own rules and routines, which may directly conflict with the therapy goals. The resulting inconsistency is a significant barrier to learning and attaining desired outcomes.
- Carers often "forget" to implement the older goals when new goals are developed, so skills and routines that have been established aren't always maintained.
- There are significant workforce issues. Carers are low paid, relatively untrained, often poorly supported by their agencies and asked to undertake extremely demanding work in often isolated and difficult environments. Programs are having increasing difficulty recruiting carers and individuals often don't get a choice of who works with them.

5.3.9 Allied Health Assistants

Allied health assistants (AHAs) are not commonly employed to work on ABI:STR Programs. However, they were discussed by participants as a potential alternative to the use of attendant care workers (ACW's) in the provision of therapy support.

The suggested AHA model of therapy support would yield a number of benefits to clients, as listed below:

- By virtue of their skills and experience, AHAs are more amenable to specific training and thus more capable of delivering therapy support, yielding the opportunity for greater progress for the client.
- A close working relationship between AHAs and therapists would enable timely feedback that would assist in refining therapy strategies.
- With a more satisfactory rate of pay, greater level of job support, provision of professional guidance and a career trajectory, AHAs would have less reason to feel overwhelmed and disenfranchised, resulting in lower turnover rates in comparison with ACWs. The retention of a more skilled workforce would enhance therapy outcomes.
- With a lower number of therapy support workers exiting programs, therapists would not utilise so many of their therapy hours training frequently changing staff. Therapists would thus have more time to develop and refine therapy strategies and work directly with the client to achieve their goals.

Although this workforce does not yet exist in great numbers, it could be developed by encouraging therapists to employ AHA's. Strategies therapists may take to identify appropriate people include:

- Identifying and supporting attendant carers who demonstrate requisite skills, so providing them with a career path
- Employment of students of therapy training programs
- Employment of qualified allied health assistants

5.3.10 Equipment

Equipment is vital for maintaining health (e.g., to achieve correct positioning during eating to avoid aspiration) and minimise discomfort as well as enabling access to everyday and community based activity (e.g., a wheelchair that enables the person to be taken outside). Participants noted that it is extremely difficult, if not impossible, to progress forward with therapy unless appropriate equipment has been prescribed and is adequately maintained.

Concerns with the current system for equipment prescription and approval were raised by participants. Often therapists experience significant delays in placing orders due to the extended process required for trialling and providing rationalisation for choices.

Whilst it is important to have checks and balances in the system, it is reported that within the Aids and Equipment Program these are currently often onerous and applied unevenly.

Further, it was the experience of participants that if an equipment request is initially denied, the family, through strong advocacy, will usually end up with approval for the desired piece of equipment. However, apart from risking inequitable outcomes for clients, this process leaves families angry and exhausted and shapes a way of dealing with “the system” that may be unhelpful in the longer term.

Anecdotally, it was revealed that much of the equipment that is prescribed eventually ends up lying obsolete in the family’s garage. Participants suggested an internet based registry open to all that can track equipment and let families and therapists know what is available. It may be that a single system could be developed in partnership with other funding bodies.

5.3.11 Program Outcome Measurement

Participants felt strongly that it is very important to track and document program outcomes and identified that this was a different process to evaluating individual client outcomes (which is discussed further under goal setting).

The use of selected, standardised outcome measures across the client group as a whole enables the effectiveness of the program to be determined and provides an evidence base for modifications to improve the ABI:STR program and justify funding. Discussion was held as to the potential measures that could be selected and they are explored further in Section 9.

5.3.12 Role of the Case Manager

The importance of case management in the team was stressed by all participants.

Anecdotally it was identified that workforce issues have impacted on case management services to the extent that there is a high turnover, long vacancy period and erosion of the original STR selection criteria.

Virtually everyone who was consulted for this review expressed concern that the current standard of case management practice varies markedly and, in many cases, is falling well below expected levels.

As such, participants identified that the role of the case manager within ABI:STR therapy programs has significantly deviated from that which was originally described and provided when the program commenced in 1996.

A tertiary background in a therapy discipline was stipulated in the original ABI:STR guidelines and was deemed by the participants as essential in enabling case managers to fulfil their role, which is expected to include:

- sourcing community supports and services for the client and family,
- preparing and coordinating care plans and therapy programs
- liaising between the family and the therapy team
- eliciting client goals from the individual and family
- providing information to the family as needed
- facilitating the family's understanding of the therapy goals and long-term vision of the therapy team
- managing team meetings that involve problem solving and decision making regarding the client's nursing, social, community development and welfare needs.
- Other, more general aspects of a case manager's role, eg. Supporting mental health issues, are not covered in this review

To fulfil these roles, case management agencies are currently funded to the level of 2.4 hours per week for 'intensive' clients and 1.1 hours per week for 'maintenance' clients. Table 1 shows that, per person, this equates to an average level of case management funding of \$6,367/annum, for each year the person remains on the ABI:STR Program.

In essence, the role of a case manager incorporates not only administrative skills but the ability to think and reason within a clinical framework. The task of preparing and coordinating a care plan is a good illustration of the high level of clinical skills required by a case manager. For a catastrophically injured ABI client on the STR program, issues regarding transfers and mobilisation, hygiene, grooming, social stimulation, continence and bowel care, splinting, nutrition and hydration, skin/pressure care, PEG feeding, communication and challenging behaviours would likely need to be addressed in the care plan. While this information is primarily gathered and documented by individual therapists, it is currently expected that the case manager summarises the progress of the client in these areas over the past six months/year, highlights the key goals for the next funding period, anticipates the impact of the client's changing circumstances on

short-term and long-term goals, and organises and structures the care plan in a coherent manner so that the goals of the team are clearly prioritised and understood by all stakeholders. Written and communication skills are paramount to effective completion of this single task. More importantly, it is essential that the case manager harnesses those skills within the context of ABI knowledge. To this end, it would seem that the skills afforded by a tertiary background of study in a therapy discipline and experience in community-based brain injury rehabilitation should be mandatory for case managers.

Families, individuals and forum participants and others consulted for the current STR therapy review indicated that, on the whole, the case management functions described above are not being fully achieved.

Whilst it is acknowledged that there are exceptions, the issues raised by the current review are as follows:

- While some case managers have tertiary therapy qualifications and ABI experience, it is increasingly common that people with general disability qualifications and little clinical background in ABI are appointed to these positions. Despite being funded for at a level of \$94,000/annum (\$45.00/hour) for a case management position, by the time on-costs and overheads are allowed for the hourly rate of pay for most case managers falls within the \$25-26/hour range. This rate of remuneration would appear to be inadequate to attract and retain skilled and experienced therapy graduates.
- Experience working with people with ABI is fundamental to providing clinical leadership to the team. However, participants reported that it is now very rare to find this function performed by case managers on STR teams. Therapists consulted for this review commented that most case managers are not able to effectively synthesise information from therapists in order to formulate care plans or submit funding requests. Rather than highlight and prioritise the key issues, information forwarded by therapists tends to be paraphrased in a way that often loses the therapy rationale for the care plan or funding request.
- Therapists and many family members reported that contact between the case manager and the family typically occurs irregularly and infrequently which limits the capacity to achieve the high standards of team coordination, planning, liaising, reporting and service quality maintenance. As a result, other members of the therapy team may perform many of the tasks currently expected of case managers. For instance, while it is currently the role of the case manager to alert

the rest of the team to changes in the client's circumstances, it tends to be the team member who is regularly visiting in the individual's place of residence who takes on the role of communicating with the family and team.

- Participants expressed concern that team meetings less often serve their original purpose of providing a forum for team planning and problem solving and instead may be predominantly spent updating the case manager on progress.
- Case managers are often lacking in knowledge of the ABI service sector and therapists report that their hours are often taken guiding the case manager as to services, procedures and funding opportunities.
- All of the above issues are compounded by the high turnover of case managers on teams, which is particularly disruptive for clients and leads to a loss of service continuity and client knowledge.

Participants identified that case management services in rural and remote regions suffer from additional difficulties. Often, case management is provided by Melbourne based agencies. When this is the case, it was reported that the frequency of face to face contact with the individual and family is very low, perhaps as little as once every 12-18 months. Metropolitan based agencies also lack the local knowledge of services and service providers, which is a particular issue given the difficulties recruiting in rural areas. Participants observed that this leads to situations where funded hours are allocated to a person who is not in the position to perform the role and someone else on the team, who does not have funding, is expected, or feels obliged to perform those duties. In the forum, participants' reported case management as more effective when it is undertaken by a locally based person.

Participants discussed the personal attributes required to effectively facilitate clinical leadership and co-ordination within the team and identified years of experience working with individuals with ABI as a key factor. If the current workforce capacity situation is to continue, it cannot be expected that case managers will always have the necessary background to perform a clinical / facilitative role in the therapy team. The participants suggested that this leadership role be delegated within the team to the person most capable of performing the role and that the additional workload is acknowledged and allocated funded hours. This would require a greater level of flexibility in both teamwork and funding arrangements.

5.3.13 Goal Setting and ABI:STR Reports

Setting goals with families and individuals with catastrophic injuries was described by participants as a key to the therapeutic process. Therapists assist individuals with severe cognitive and communication difficulties to articulate the long term goals they aspire to, but also identify the short term, attainable steps that build towards longer term goals. Typically, there will be broad participation goals which help set the general direction of the team and from which shared team goals and individual goals are derived. Intertwined with the goal setting process are opportunities for therapists to provide feedback on progress, educate the individual regarding the impact of their injury and assist long-term adjustment to the changed life. The process of reviewing and adjusting goals is dynamic one as expectations are shaped and effort is directed towards personally meaningful and achievable ends.

Given the severity of the injury and the generally extended time before the person is able to express their own goals, forum participants felt that therapists may need to set the initial direction of the therapy and this will typically involve a focus on management of basic, core needs. For instance the client in a minimally conscious state will not be able to express goals and the focus in the earlier stages post-injury should be on activities such as a positioning, nutrition, safety, hygiene, equipment, comfort and pain management, oral care, swallowing and chest care, monitoring of changes in awareness.

As the routines for managing these core issues are established, rehabilitation goals can slowly be introduced in a managed way. These specific rehabilitation goals will often focus for instance on

- Developing communication skills that allow the person to have choice and a level of control over their daily life and to express their wishes
- Developing independent living skills that increase the person's ability to actively participate in personally meaningful activities
- Developing coping skills that enable the person to come to understand what has happened to them and learn strategies to manage these changes.

Documenting goals and reporting on progress in relation to goals is integral to the therapy process and a necessary process to obtain funding.

Currently case managers perform an intermediary role between therapists and the ABI:STR management in obtaining funding for therapy services.

In practice, therapists report some variation but essentially within the ABI:STR Program this process occurs in the following way:

- Case managers obtain the goals of the individual and the family,
- Case managers inform therapists of the new goals
- A meeting may be held with the team and family / individual to update the case manager on progress and discuss tailoring the therapy program and funding requests around attainment of these goals.
- Therapists write individual reports and make specific funding requests for hours of therapy input.
- These reports are sent to the case manager who then “cuts and pastes”, paraphrases and reinterprets those individual reports into a single document proforma organised around a SMART methodology. SMART is a mnemonic that represents an objective that is: specific, measurable, achievable, relevant and time-bound.

Participants gave many examples of the pitfalls of this approach including:

- Case managers encounter significant difficulty generating meaningful goals when they may not yet have developed a therapeutic relationship with the individual or when they have limited understanding of the individual's capacities and potential.
- There is a tendency of case managers to accept all the goals stated by the person, which can lead to many more goals being generated than is possible for a therapist to address in the funding period.
- Therapists experience difficulty working with the goals generated by a person who is not conversant with that therapist's history of working with the individual and the way therapists anticipated building on goals previously addressed
- Therapists experience difficulty in knowing how to structure therapy when presented with goals that are clearly unattainable (e.g., a wish to ride a motor bike or travel). The ‘meaning’ of the expressed goal and the small steps that could be worked on that lead towards goal attainment have usually not been identified with the client.
- There is a tendency when paraphrasing therapists' requests for case managers to misinterpret or lose the essence of the request or stipulate that the allocated funding is to be used for another purpose

- Concern over the length of the documents and number of hours case managers spend preparing the ABI:STR reports was expressed.
- Given unworkable goals, therapists will tend to generate alternatives, which results in the Case Plan report failing to reflect the actual therapy being undertaken.

Overall, it was the opinion of the therapy forum group that there are more time-efficient and helpful processes for developing and documenting a comprehensive, person-centred therapy plan and these are explored in Section 10.

5.3.14 Discharge

Participants identified three key barriers to discharge from the ABI:STR Program:

- Lack of alternatives in the existing/generic service sector. The level of ongoing funding provided to people who have been on the STR program for many years (see Table 1) and the associated blow-out in the waiting list demonstrates the difficulty of discharging people into the existing, generic service system. Discharge and throughput will only be possible with corresponding improvements in the existing service sector that enable people to have their considerable ongoing needs met.
- The potential loss of 10-15 hours of attendant care support. Whilst an individual is on ABI:STR program they receive up to 44 hours of attendant care if they are living at home (typically, 34 hours funded by Home First or other programs and 10 hours funded by STR). Despite access to rehabilitation, it is likely that the majority of STR individuals will continue to require 20-24 hour care over the long-term. If people are discharged from ABI:STR they therefore not only lose access to therapists but also 10-15 hours of funded care. The responsibility to cover this shortfall typically rests with the family. In such a situation the family would be providing up to 134 hours of gratuitous care per week. For most families this is not sustainable and the cost burden (e.g., mental health and lost vocational participation) would be substantial. If discharge from ABI:STR is to be possible, the responsibility for funding the attendant care hours, previously funded by STR, needs to be assumed by another DHS program.
- Active discouragement to discharge. Participants reported that even when individuals reach a point where discharge could be possible they are actively discouraged from doing so as there is no possibility of re-entry into the system if needs develop in the future. Everybody who was consulted identified that an enormous amount of resources (especially case management time) are devoted to retaining the hard

fought therapy hours that, although not specifically required, may be needed in the future.

5.3.15 Funding Lifetime Care

The development of a universal insurance scheme that provides life-time therapy input according to reasonable need was highly recommended by the Therapy Forum participants. This scheme would address the current inequities between people with compensable and non-compensable injuries in terms of funding and access to services. A universal model would also respond to the increasing evidence base acknowledging people's life time needs for services and their ongoing potential to benefit from targeted therapeutic input. Victoria is in a unique position to build on the experience of the TAC model, which is internationally recognised as an effective and innovative model in providing life-time support to people injured in road accidents.

This review recognises however that, in the absence of a fully funded, needs-based model, the life-time requirements for therapy and support for people with non-compensable brain injuries cannot be fully met.

Key Findings from Therapist/Sector Consultations and Implications for the ABI-STR Program

1. Understanding recovery: Given the scientific basis for slow recovery and life-long needs following catastrophic brain injury, senior therapists concur that individuals should be able to access timely and necessary rehabilitation over the course of their lifetime.
2. Model of treatment: Two primary components of slow stream rehabilitation are - the management of core needs and the provision of specific rehabilitation interventions, As well as hands-on intervention with the individual, therapists provide information and support to families, train carers, prescribe equipment, establish routines and write guidelines, source activities and resources and liaise with team members.
3. Funding for rehabilitation: Therapists suggested a more flexible model of rehabilitation funding that is tied to measurable outcomes and that is based on the individual's specific needs and readiness for intervention.
4. Model of teamwork: Therapists emphasised the importance of interdisciplinary team work, which can be promoted by increasing the frequency of meetings with a strong

person-centred rehabilitation focus, facilitated by team leaders with sound clinical acumen.

5. Expertise of the therapist: Less experienced therapists working with catastrophically injured clients benefit from supervision / mentoring from experienced therapists and this is vital to quality service provision.
6. Funding of therapists: The anticipated workforce crisis due to a diminishing pool of senior therapists working with ABI:STR clients may be avoided by increasing the hourly rate paid for working with STR clients. Adequate fee rates assist to attract those therapists with the necessary expertise and experience to achieve effective rehabilitation with clients, thus achieving optimal outcomes through the most cost-effective means.
7. Neuropsychology: The high risk of challenging behaviours in ABI:STR clients may be mitigated by neuropsychological input that includes behaviour management programs. With adequate funding, the ABI Behaviour Consultancy would be well placed to provide such services in an ongoing manner
8. Attendant care therapy support: Implementation of goal-oriented plans is extremely effective when suitable carers are selected, who remain with the client for an extended period and receive regular training and supervision. This emphasises the importance of adequate pay rates for attendant carers and ABI:STR funding for ongoing training.
9. Allied Health Assistants (AHAs): Replacing attendant carers with AHAs is an alternative solution for obtaining high quality therapy support, as AHAs are generally more skilled and experienced. However they would still require therapist supervision.
10. Equipment: Equipment can provide maximum benefit to ABI:STR clients if it is appropriately prescribed and maintained and supported by a system of requesting items that is straightforward and standardised. Wastage of obsolete equipment can be ameliorated by implementing an internet-based registry that re-issues equipment that is in good condition.
11. Role of the team leader: Team leadership and provision of clinical coordination/facilitation is vital to effective rehabilitation provision. It may take the form of a clinical case manager or a lead therapist.
12. Goal setting in ABI:STR reporting: Initial and subsequent measurable rehabilitation goals should be set by the therapist in conjunction with the individual and family, with team goals developed to guide the overall direction of the therapy program.
13. Discharge: Improved ABI:STR discharge rates or transition to maintenance level STR funding can be achieved by the provision of ongoing attendant care and case

management funding by other generic sources or DHS programs.

14. Funding lifetime care: The life-time requirements for therapy and support for people with catastrophic brain injuries could be met through the development of a universal insurance scheme.

PART C: RECOMMENDATIONS

This section contains recommendations relating to the following areas:

1. Referral and eligibility for ABI:STR therapy programs
2. Best practice therapy services for ABI:STR clients
3. Flexible funding and resource allocation
4. Program outcome measurement
5. ABI:STR program therapy reporting

Each section contains a summary of key issues, which includes issues raised in the ABI:STR Review (2004), as well as feedback provided by consumers and therapists. This is followed by a discussion of recommendations, which are based on research findings, and suggestions identified by consumers, discussion through the Therapy Forums, and in consultation with ABI providers. Each section ends with a summary of key recommendations.

As part of the recommendations, a revised clinical pathway for clients on the ABI:STR program is suggested. Figure 7 provides a representation of the key elements of the proposed ABI:STR pathways and will be referred to throughout the recommendations section of this report.

PROPOSED ABI STR PROGRAM SERVICE MODEL

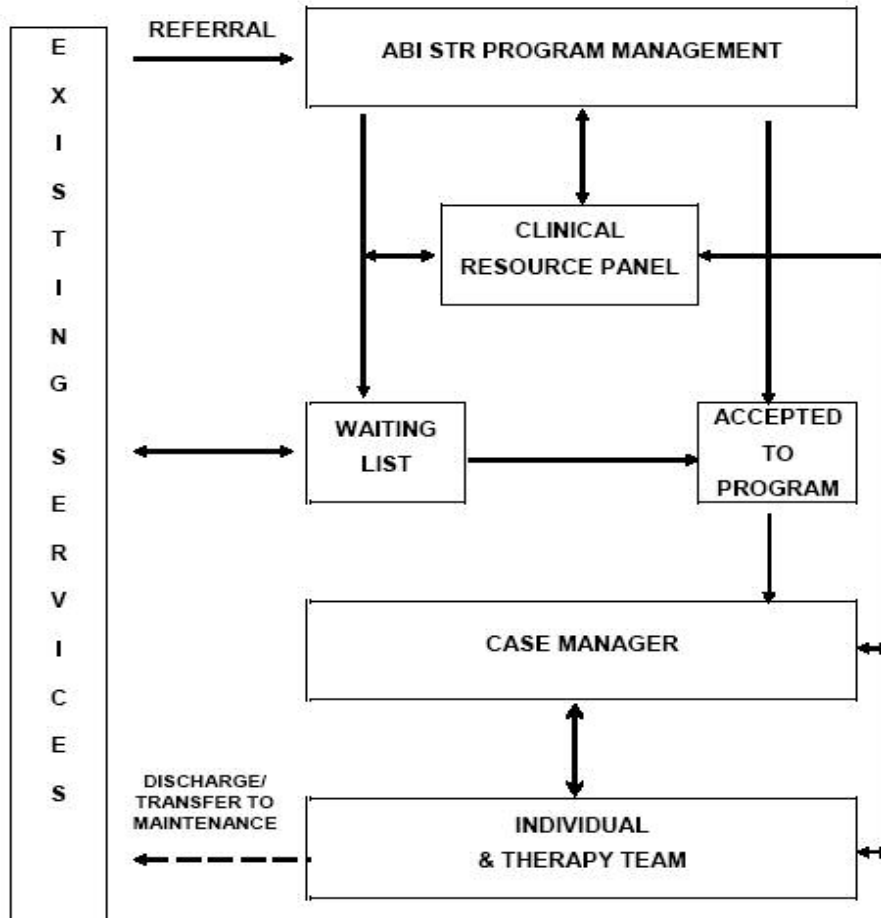


Figure 7: Proposed Pathways for Accessing and Monitoring ABI:STR Therapy Services

6. REFERRAL AND ELIGIBILITY FOR ABI:STR THERAPY PROGRAMS

Key issues identified

- Not all potential referrers are aware of eligibility criteria
- Lack of clear policies and procedures in relation to eligibility
- Long waiting periods

As depicted in Figure 7, referral from the existing service system to the ABI:STR Management is the first step in enabling a non-compensable, catastrophically injured person to access ABI:STR therapy services.

It is recommended that referral to the ABI:STR Program be preceded by completion of the Disability Service Register (DSR) application as well as a formal assessment of level of care needs.

Given that the ABI:STR program targets those with catastrophic levels of injury, the assessment of level of care requires the individual to demonstrate the need for a high level of ongoing care.

It is suggested that one of two tools are utilised to assess whether the individual meets this hurdle for eligibility and they are:

- **ACAS assessment.** The ACAS assessment is a standard, widely used and understood tool that, in this case, would be undertaken to establish that the individual requires high level residential aged care. A High Care resident is classified at a level between 1 and 4 on the Residential Classification Scale (RCS).
- **Care and Needs Scale (CANS).** If verification of the RCS level is required or an ACAS assessment cannot be performed for any reason, an assessment on the CANS would be appropriate. The Care and Needs Scale is an eight-category scale, which measures the type and extent of support needed in daily life and was developed specifically for application with people with ABI in the post-acute rehabilitation stage (Tate, 2004). To be eligible for the ABI:STR Program a rating of

Group A, Level 7 or 8 on the CANS would be required. This rating reflects the fact that care and support is required for 20-24 hours a day and thus is in line with ABI:STR program eligibility criteria of an individual having sustained a catastrophic acquired brain injury.

Ideally, the DRS would be completed prior to an ACAS assessment. If the DSR cannot be completed at this time, it should be completed on admission to the program by the Case Manager. The referrer should arrange for ACAS assessment or completion of the CANS, but if these could not be satisfied, the CANS should be completed by a member of the ABI:STR Clinical Resource Panel.

Following completion of the DSR application and ACAS/CANS assessment, Disability Services would have notification of the individual's need for services and a plan could be developed, one element of which would be a referral to ABI:STR.

It is recommended that the ABI:STR Program referral form proforma be revised and extended to elicit information regarding:

- ACAS/CANS assessment results
- Information on other specified eligibility criteria as outlined in the 2004 Review (refer to page 16 of this report for details)
- Wherever possible, specific details including:
 - pre-morbid health conditions
 - date of injury
 - cause of injury
 - acute management of injury
 - Glasgow Coma Scale at time of injury and on referral
 - duration of PTA, if applicable
 - results of radiological investigations
 - current medical condition(s) and their treatment
- Current circumstances (eg family, accommodation, existing funding packages and / or therapy support)
- Discharge plan including other referrals made / rejected
- Anticipated immediate and likely long-term needs.

The proforma and updated instructions should be available on the website.

Eligible individuals would be placed on a waiting list for ABI:STR therapy services. Individuals and referrers would be notified of the outcome of the referral.

Individuals who are accepted to sub acute rehabilitation services should still be eligible for ABI:STR therapy upon discharge to community. Referral at this point would still require an ACAS or CANS assessment to determine that they still meet ABI:STR eligibility criteria (as previously noted).

The individual could therefore be referred at any point within a two year period following injury.

Program funding should be adequate to enable people to receive timely intervention to facilitate discharge from acute and sub-acute hospital settings and to avoid the development of secondary problems stemming from an extended time waiting for therapy to commence.

Recommendations

Referral & Eligibility

- Revise and extend referral proforma
- Update website with guidelines for referrers
- Document methods for determining injury severity
- Document criteria for determining eligibility

7. BEST PRACTICE THERAPY SERVICES FOR ABI:STR CLIENTS

Key issues identified

- Loss of the original service panel structure to inform program funding allocation
- Need for greater transparency and accountability regarding allocation of funding for therapy services
- Inconsistent evidence-base to service planning and therapy interventions
- Limited skilled workforce capacity in catastrophic brain injury
- Absence of mechanisms to monitor and maximise effective service provision
- Lack of program induction and benchmarks for new workers

A key recommendation of the ABI:STR Therapy Review Project that addresses many of the 2004 review recommendations, is the development of a service panel, hereafter referred to the Clinical Resource Panel (CRP).

Figure 7 depicts the place of the CRP within the ABI:STR Program structure.

The primary aim of the CRP would be to provide consultation to STR Management and to therapy teams to develop and extend cost effective, best practice therapy services for people with catastrophic brain injury.

To address the issues identified in the 2004 Review, the CRP would have several specific roles, which are outlined in more detail below. However, a key purpose of the panel is to ensure that the knowledge and experience of senior therapists in community-based brain injury rehabilitation is harnessed towards the development of rehabilitation skills in less experienced therapists and within the broader service sector.

It is recommended that the CRP is comprised of at least seven core members, one representative from each of the following disciplines: physiotherapy, speech pathology, occupational therapy and neuropsychology, as well as a case manager, medical specialist and the ABI:STR Program manager. Additional secondary consultant members would be identified who have specific expertise not held by CRP members, and their input could be sought as required.

In order to meet the objectives of the group, all CRP members should have a minimum of 10 years experience in ABI, five of which involved working with catastrophically injured clients in community-based settings. All panel members should also have current, evidence-based knowledge of best practice in this highly specialised field of rehabilitation.

Members of the CRP would have a range of specific, specialist knowledge and experience in areas such as: equipment prescription; tone management; positioning and seating; pressure care and wound management; assessment and management of cognitive function; management of challenging behaviours; swallowing; PEG feeding; continence; medication prescription; mental health; and role participation and community integration opportunities for people with catastrophic ABI.

It is suggested that the core members of the CRP meet as a panel for one day each month and that a further day each month is available to enable client assessments, clinical consultation, training and mentoring, research and program documentation activities.

It is recommended that CRP members are paid a sessional rate commensurate with their advanced skills and experience. It is recommended that the rate currently paid to TAC and MACNI panel members is used as a reference point in setting the rate. Direct employment of panel members was considered but it was felt that this would be an inflexible, cost prohibitive model that fails to capture the necessarily broad range of specialist expertise required. Further, it would not achieve the desired outcomes as the people with the necessary backgrounds (i.e., community-based private practitioners) would likely not be attracted to such a position.

7.1 Key functions of the CRP

It is recommended that seven key functions are undertaken by the CRP members:

- ☐ Review new referrals
- ☐ Monitor waitlist clients
- ☐ Assist the Case Manager to construct a therapy team
- ☐ Advise therapy teams on appropriate rehabilitation
- ☐ Develop and implement training programs

- ☐ Provide program documentation, proformas and develop database
- ☐ Research and analysis of program outcome data

These key functions will now be explained in detail.

Review new referrals

STR management, having screened for eligibility, would refer each new waitlisted individual to CRP for discussion (estimated at 4 referrals per month). The CRP members would review new referrals and allocate the most appropriate CRP member to assess the individual, within four weeks of the panel meeting. This assessment would enable eligibility to be confirmed and, for those not eligible, to be advised of other services for which they may be eligible.

It is recommended that the CRP develop clear criteria to prioritise individuals for acceptance to the program. Factors to consider are:

- the individual's age
- availability of alternative options for rehabilitation and support,
- expected impact of delaying provision of rehabilitation,
- accommodation setting as well as social circumstances.

The CRP member's initial assessment would enable priority to be established and program outcome data to be collected (see below for more detail on measuring program outcomes). As depicted in Figure 7, the CRP member would liaise with the family and existing service sector to create a plan and source the necessary supports to ensure the individual was managed in the best way possible whilst on the waitlist.

Monitor waitlist clients

The CRP would monitor and conduct a 6-12 monthly review of the individual on the waitlist. Eligibility and priority could be reevaluated at necessary intervals. On a limited basis, a CRP member would be available to provide secondary consultation or expert input to the family and hospital team. Importantly, the family and existing team could be guided in the commencement of processes for discharge from acute hospitals such as accommodation waitlisting, support funding applications, referrals to existing services such as attendant care agencies, home modifications and equipment prescription, as necessary. This would assist to ensure that discharge was not unnecessarily delayed. During the monitoring process, the CRP member could collect and compile relevant

documentation related to the client. On acceptance to the program, compiled information along with a summary of any additional information obtained through monitoring the client on the waitlist could be given to the case manager.

Assist the Case Manager to construct a therapy team

Once accepted onto the program the case manager could draw on input from the CRP, to source a therapy team. The CRP input is seen to be important to ensure the case manager is:

- offered secondary consultation regarding urgent care / management issues that require immediate attention to minimise the risk of secondary complications developing
- able to select the right mix of therapists (given the individual's needs and readiness for input)
- therapists with the appropriate background relative to the individual's specific impairments and circumstances
- able to consider available natural supports in the individuals existing network and how these can be harnessed or complimented by the constructed team

Advise on appropriate rehabilitation

The CRP would have an ongoing role in reviewing rehabilitation plans and advising STR Management, the therapy team and family as to appropriate rehabilitation.

At each Clinical Resource Panel monthly meeting it is envisaged that a specified number of written STR therapy plans would be reviewed and feedback provided to the team. This process of peer review would provide an informed and evidenced based framework for intervention and for the allocation of therapy funding.

If issues with the therapy plan are identified, a member of the CRP could be allocated to follow up with the particular therapist / team. This follow up may include telephone contact, face to face meeting and/or joint session(s) with client and therapist. Again, this process is similar to that currently occurring within other service systems (e.g., TAC) and thus is familiar to many practitioners specialising in brain injury rehabilitation.

A selected number of case conference reviews would be timetabled to problem solve the management of particularly contentious, problematic or unique issues. The constitution of the discussion panel should be individualised for the particular issue and enable

additional secondary consultant members of the Resource Panel to be invited to attend for that case discussion. The full team including therapists, case manager and family should be invited and encouraged to actively participate in these meetings. The aim would be to develop a management plan for the therapy team and family to implement. There may be follow up by a member of the CRP to track the implementation of the plan and to provide face to face support if necessary.

It is recommended that flexible funding is available for CRP members to travel to visit clients, particularly in rural areas and work jointly with therapists to assist in the development of treatment plans, provide advice on specific therapeutic interventions and to support training of carers.

Develop and implement training programs

It recommended that an induction program to the ABI:STR Program is developed. Each therapist, new to treating STR individuals, would receive a comprehensive resource manual detailing procedures, proformas and program guidelines. The therapist would also meet with their professional counterpart on the Clinical Resource Panel to receive introductory training.

In order to emphasise the importance of professional development, it is proposed that the introductory training be a hurdle requirement for therapists who accept STR clients onto their caseload.

Further, the Clinical Resource Panel members would provide periodic, formal education sessions on identified topic areas relevant to brain injury rehabilitation. Appropriate training modules would be identified through liaison with the sector, professional therapy bodies and universities. Therapists would be expected to attend a specified amount of training each year. This would assist to screen and select preferred providers.

Family members would be encouraged to attend education sessions provided by Clinical Resource Panel members. Education sessions should also be offered via video-conferencing or podcasts for people unable to attend due to distance or carer commitments.

It is also recommended that families receive an information package that assists them to understand the ABI:STR therapy model and rehabilitation principles. It is vital that they

receive information at the beginning in order to shape realistic expectations of the program, including timelines for availability of funding etc.

Provide program documentation, proformas and develop database

Over time, the CRP would document the philosophy and principles of STR rehabilitation, as well as information relevant to understanding the stages of care pathways. Specific categories of individuals would be identified and protocols for managing their complex care needs could be documented as program guidelines.

The CRP would also develop proformas to streamline report writing and care plan development with an emphasis on measurable and evidence-based treatment objectives.

As the CRP becomes aware of resources, information or services it is recommended that updates are provided to the Summer Foundation Knowledge Network. The Summer Foundation Knowledge Network is a centralised resource that is currently under development and aims to provide comprehensive and up to date information relevant to younger people either living in aged care or at risk of admission to aged care. All people will be able to access this database over the internet.

Research and analysis of program outcome data

It is recommended that a methodology for program evaluation is developed and that outcome measurement data is collected at set intervals. Potential measurement tools are listed in section 9. It is recommended that the CRP in conjunction with the ABI:STR program Management utilise the outcome data to evaluate the effectiveness of the program and to answer specific research questions.

Recommendations

Establishment of a Clinical Resource Panel to Oversee and Promote Best Practice Therapy Services, including:

- Provide secondary consultation by a senior therapist in each discipline to
- Provide access to a range of clinical expertise for case review and rehabilitation planning.
- Provide secondary consultation to waitlist clients to prevent deterioration
- Streamline case managers access to therapy providers
- Develop program information for practitioners
- Document detailed program standards and proformas to streamline report writing and promote evidenced based care plans and specific measurable treatment objectives
- Develop criteria and processes for accreditation of practitioners
- Develop and provide program induction to ABI:STR
- Offer an increase in ABI rehabilitation service workforce capacity via secondary consultation process
- Develop a research and evaluation program

8. FLEXIBLE FUNDING AND RESOURCE ALLOCATION

Key issues identified

- Limited flexibility in allocation and delivery of therapy services
- Lack of clarity of roles of case manager
- Varying levels of effectiveness of case management in clinical / facilitative role within therapy team
- Remuneration for therapists time is inadequate
- Variability in effectiveness of the attendant care model of therapy support

The recommendations provided in this section acknowledge the extended time frame of recovery following catastrophic injury and also the importance of providing an appropriate mix of therapy inputs at various stages post-injury. However the recommendations also place time limits on intensive funding to ensure that ABI:STR program through-put is increased, resources are allocated equitably and therefore the program becomes available to a greater number of people than is the case currently. Modification of the existing funding model is vital to ensure that waiting times for acceptance are kept to a minimum, hence circumventing the deterioration and associated escalation in costs in that result from absence of early rehabilitative input.

8.1 Development of funding bands

As detailed on page 19 of the report there are currently two levels of rehabilitation support within the ABI:STR Program: intensive and maintenance. Despite limitations, it is recommended that this terminology be maintained to clearly articulate that rehabilitation services funded through the ABI:STR Program will decrease over time.

Overall, it is recommended that people are accepted onto the ABI:STR program with the view to receiving time-limited intensive and goal-oriented therapy services. From the time of acceptance onto the program, referral back into the existing service system should be planned for and articulated to the individual, their support network and service providers via written program policy and education. More generic service provision should be pursued particularly for the elements of ongoing support that become less specialised / goal-oriented over time (eg, attendant care and case management). The

aim should be for progression from the ABI:STR intensive program to a maintenance level of funding at the end of the fifth year on the program. The person would then have access to maintenance level of ABI:STR funding over their lifetime, coupled with mainstream or disability specific services.

It is proposed that ABI:STR Program funding bands be established within which a flexible allocation of therapy services is planned for. The proposed bands are designed to be cost neutral relative to existing ABI:STR Program service costs. Figures previously provided in Table 1 that document the current funding allocations for each year of the program were used to derive the funding bands detailed below. However it is acknowledged that the figures below are based on limited and incomplete data and therefore only provide a general indication of a possible structure. Further investigation and development of this model is recommended.

As a starting point for development of this model five possible bands have been identified and are detailed below.

Band 1: \$70,000 - \$60,000 per annum

Band 2: \$59,999 - \$45,000 per annum

Band 3: \$44,999 - \$32,000 per annum

Band 4: \$31,999 - \$20,000 per annum

Band 5: \$5,000 - \$2,000 per annum

It is recommended that the bands be adjusted to accommodate increases in allied health remuneration as well as CPI each year.

It is recommended that maximum limits be set on funding in the first 5 years on the program, with a total of approximately \$300,000.00 being considered as the limit. As was described on page 21 and depicted in Figure 4 this represents the approximate current spending per person for the first five years they are in receipt of the program. This limit would allow the individual to have for instance, two years of funding at the Band 1 level, two years of funding at the Band 2 level and 1 year at Band 3 level, but many variations would be possible. Table 3 and 4 below provide examples as to how funding may be flexibly allocated over 5 years. Total funding costs for the first five years in example 1 are \$267,000, and in example 2 are \$252,000.

It is recommended that for each 6 or 12 month reporting period, the individual is assigned a funding band by the ABI:STR Program Manager, in consultation with the individual's team and the CRP.

The allocated funding band would be based on individual clinical need. Flexibility should be allowed so that the highest levels of funding are provided at the time when the person is most able to benefit from specific rehabilitation inputs. This may not correlate to the time post injury.

Criteria which would influence band level allocation would include

- The nature and complexity of the injury sequelae
- Types and levels of specialist input required
- The accommodation setting and other supports available
- The goals of the individual and family
- The person's readiness to benefit from specific inputs
- Whether the person lives in a rural, remote or metropolitan area
- Whether generic supports are available
- Whether the individual is due to undergo an accommodation transition
- Anticipated clinical outcomes in relation to requested therapy inputs
- Risk of adverse outcome if specified intensity of service is not provided

The model would enable transparency in the allocation of the funding band level, expectations of a finite resource and encouragement to flexibly tailor the allocation of funds between various services according to need. This gives teams, including individuals and their families, greater empowerment over decision making as well as realistic expectations regarding the capacity of the program.

This self-brokerage-type model also discourages the current formulaic approach to allocating therapy hours as well as the mentality of spending the maximum amounts available in anticipation of funding levels being reduced over time. If individuals are encouraged to think about how to spread their intensive program resources over a five year timeframe, according to need and with consultation from the Clinical Resource Panel, it is expected that therapy funding will be utilised in a more efficient and effective manner. It will also nurture opportunities for greater creativity as individuals, families and therapists would be encouraged to consider mainstream and generic supports to supplement, or over time replace, ABI:STR Program funded services.

It is recommended that the team develop a budget for their allocated funding band that includes an appropriate mix of a comprehensive range of therapy services and also therapy aids (eg whiteboard), therapy materials (eg splints), group fees and gym memberships, as appropriate relative to therapy goals. Please refer to Appendix 4 for examples of possible therapy services within each funding band.

It is recommended that program policy and systems be established to manage the risks of this more flexible and transparent model including the possibility that interventions with no credible evidence base may be requested or that individuals may wish to focus solely on one treatment modality at the expense of all others.

There would be an expectation that at the end of the 5th year of program participation the individual would be managed on Band 5 (maintenance) funding levels. By this time, the existing service sector should be able to assume responsibility for the majority of the service elements (eg attendant care, case management). It is expected however that the existing service sector will not have capacity to meet the need for long term ABI specialist therapy services and the cost of this maintenance input would continue to be borne by ABI:STR Program for as long as required over the individual's lifetime. The calculations of Band 5 (maintenance) funding levels allows for between 22-54 hours of therapy funding per year (see Table 3 for an example).

In cases where the existing service sector cannot meet the ongoing attendant care and case management support costs of the individual, they would continue to be funded by ABI:STR Program at Band 4 levels (e.g., Table 4). Band 4 funding levels allows for up to 54 hours of therapy per year, 15 hours of attendant care per week and one hour of case management per week. In contrast, in some cases where the person did not require ongoing specialist therapy input, they could be discharged from the ABI:STR program.

Table 3*Example 1 of Resource Band Funding Allocation for an Individual*

	Year of STR Program for individual					
Funding Band	1 st Year	2 nd Year	3 rd Year	4 th Year	5th Year	6 th + Year
Band 1		\$68,000	\$62,000			
Band 2	\$55,000					
Band 3				\$40,000	\$42,000	
Band 4						
Band 5						\$4,500

Table 4*Example 2 of Resource Band Funding Allocation for an Individual*

	Year of STR Program for individual					
Funding Band	1 st Year	2 nd Year	3 rd Year	4 th Year	5th Year	6 th + Year
Band 1		\$68,000			\$64,000	
Band 2			\$55,000			
Band 3				\$36,000		
Band 4	\$29,000					\$31,000
Band 5						

It is recommended that this system be considered initially for new clients of the ABI:STR Program and that it be transitioned to existing clients, as is possible over time. In particular it would be very important to work with the existing service sector to explore ways of moving individuals to Band 5 funding levels and shift generic service costs (e.g., community access attendant care support) to the wider disability service system. This would require that all of the attendant care hours as well as case management services be funded and provided by an expansion of current programs within the existing service system. Unless there are pathways for individuals to exit the ABI:STR Program it will continue to be difficult to ensure timely access to services for those on the waitlist.

The above funding model addresses several limitations of the current model. Of primary importance, it enables flexibility to meet client needs over time by providing periods of greater intensity at times when the client can most benefit from input, and lower intensity when the client does not have high therapy needs (as determined by goals and outcomes that can realistically be achieved). Consistent with this flexible approach, a client can remain on, or return to, a higher funding band if there are outcomes to be achieved, even if this is after 5 years on the program. There is also flexibility for a client currently considered a 'maintenance client' to be funded at Band 4 or Band 5 at any stage while on the program if they do not have high therapy needs (i.e. earlier than year 6).

Although this model addresses many of the key funding issues relating to providing quality care to ABI:STR clients, it is recognised that it is a starting point and that further development and economic modelling is required.

8.2 Funding for Case Management

Stringer (2007) describes case managers as providing a single point of contact for people requiring a complex range of services and/or intensive levels of support. Stringer (2007) cites the Case Management Society of Australia (2004) definition of case management being a "collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual's health needs through communication and available resources to promote quality, cost-effective outcomes". The ABI:STR program stipulates that case managers hold tertiary qualifications relevant to allied health, community care and health settings and have demonstrated extensive experience in case management within a community or health setting.

This review has identified two key roles expected of case managers within a therapy program; one role encompasses a range of administrative activities and the other is a clinical / facilitative role within the therapy team.

It was identified in the Therapy Forum (pages 63 to 85), by the individuals and their family members (pages 51 to 62) and other consultations that this clinical / facilitative role requires a high level of skill and also experience in ABI. Without this there is a significant gap in provision of co-ordinated, interdisciplinary therapy services. It was

identified that the clinical / facilitative function is often not part of current case management practice.

Without clinical leadership the team will naturally revert to a fragmented and segregated mode of operation where, as previously noted in the 2004 Review, there is a lack of co-ordination of various therapy inputs and outcomes are less effective or efficient.

To address this issue it is recommended that the funding model for case management be reviewed and restructured to accord with a flexible, person-centred approach. That is rather than block funding case management at an average level of \$6,367.00 per annum per ABI:STR client, specific funding would be attached to the goals and activities identified as relevant for the particular individual.

To this end, it is recommended that the case manager completes the same pro-forma report as therapists (see Section 10 below) and that case management hours are requested for identified tasks aimed at achieving specific outcomes, linked to each individual's goals.

As is the case for therapists, this methodology provides more clarity around the roles and expectations of the case manager on the team and also provides greater accountability for the allocation and expenditure of funds.

This methodology would also address the situation where the case manager lacks the necessary background or skills to perform the clinical / facilitative role within the therapy team. In such a case, the tasks associated with this role and the funded hours would be flexibly allocated to the person in the team who has the relevant skills.

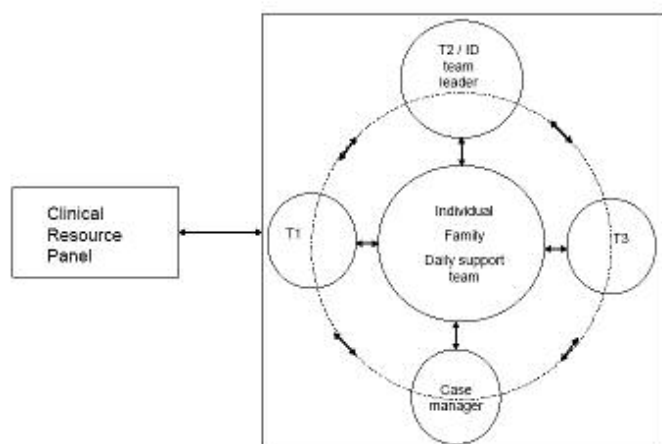


Figure 8: Transition phases of reduced consciousness following coma

The person who takes this clinical / facilitative role within the team (i.e., therapist or case manager) could be identified as the Team Leader and they would have the added responsibility of ensuring that the therapy intervention was person-focused, goal oriented and coordinated.

The model is represented in Figure 8.

This methodology also allows flexibility to implement the allocation of a family member as the individual's case manager as raised in the 2004 Review.

It is strongly recommended that case management is provided by a locally-based person. This is particularly important in rural areas where distance is a barrier to contact with the individual and family and where a metropolitan-based provider lacks knowledge of local resources and services. In these situations case managers could be drawn from a local case management agency or from within the relevant DHS regional office.

As is recommended for therapists, it is important that case managers from generic services are supported in the specialist aspects of their work by the Clinical Resource Panel.

The above model of case management as a person-centred, time-limited and goal-oriented service is similar to that adopted by the TAC (refer to Appendix 5 for the TAC case management policy). More recently the TAC has switched from external provision of case management to one where the case managers sit within TAC. Early feedback regarding the TAC initiative is positive as the case managers have a detailed knowledge of the organisation's policies as well as the relevant service system. Further, they are proving to be effective advocates, able to provide direct feedback to the organisation

regarding the needs of individuals with ABI. Such a model may be considered by the ABI:STR Program.

8.3 Funding for Therapists

It is recommended that the hourly rate of funding for therapy services is reviewed. Following the review, it is recommended that rates rise by the CPI each financial year. Without an increase in the hourly rate, it is likely significant workforce issues will escalate in the future, as it becomes less viable for private practitioners to provide services to ABI:STR individuals. It is recommended that there is parity in the rates paid for all types of therapy services.

The right of individuals to choose their therapists should be paramount. However, an outcome of fewer experienced therapists accepting STR work will be a smaller pool to choose from. The individual may not obtain the therapist with the experience and personal qualities that suit their specific needs. It is therefore recommended that, within the bounds of the flexible funding model previously discussed, individuals and families should be able to select therapists who charge more than the rate currently set by ABI:STR. Based on previous calculations ("Submission to STR dated 23 October 2006,"), it is recommended that this hourly rate be capped at \$125.00/hour for all therapists.

It is also recommended that the value of non-contact therapy time (e.g., spent in resourcing equipment, writing guidelines and training carers, liaising with other allied health providers, preparing resources for carer-implemented therapy etc.) is recognised as integral to provision of effective slow stream therapy and sound interdisciplinary practice. In order to encourage teamwork and documentation of therapy programs it is vital that these services are funded.

It is also recommended that therapists are paid for report writing time but that this is capped at the levels suggested in Section 10.

It is recommended that therapists, particularly in rural areas, are able to negotiate payment of travel. As a general guide, it is considered unreasonable to expect a therapist to undertake unfunded travel time of greater than 20 minutes, each way.

Given the above, it is recommended that therapists provide recommendations for therapy hours as a block of hours required to achieve each identified measurable outcome within the funding period. Both contact and non-contact interventions would be detailed and, as previously suggested, funded. These hours would then be utilised in a flexible way over the funding period.

Rather than risk being used up irrespective of need, unused hours could be banked, reallocated to alternative activities within the individual's program, or returned to the Program.

Agencies administering the funding would need to adapt their accounting practices to enable this more flexible approach.

8.4 Allied Health Assistants



Figure 9: Allied Health Assistant Model

It is recommended that the option of replacing some attendant care and/or therapy hours with allied health assistants is trialled, with a longer-term view of developing a well trained therapy support workforce.

The effectiveness of this model of therapy support should be guided and evaluated by the Clinical Resource Panel.

Figure 9 represents the relationships of the AHA's to therapists and attendant care workers within a slow stream model of rehabilitation.

The AHA's role would be to take the strategies developed by therapists (as represented by the arrows between AHAs and the therapy team in Figure 9) and integrate them into the everyday life of the client in order to manage their basic needs and improve their level of skill in selected tasks. At such a time when the client's skill level has expanded, become more established and resilient, and the guidelines have been refined, it would be feasible to transfer the AHA therapy role to the ACW program. In this way the input of the AHA provides a stepping stone to the daily routines implemented by the attendant care workers.

The non-ABI:STR funded support hours (e.g., Home First) would be filled by ACW's who would be trained, as they are now, to implement routines and strategies in activities throughout the day.

In order to attract AHA's to this role, they would require remuneration that is commensurate with the costs of employing a more skilled person (estimated to be between \$42-45/hour). By paying AHA's at a higher rate than ACW's and reducing attendant care hours proportionately, the use of AHA's in supporting therapy could be achieved without any increase in STR expenditure. Given more effective therapy support

from AHA's it is anticipated that progress in therapy would be achieved with fewer hours than is currently approved by STR.

It is recommended that AHA's be linked into the therapy practices of individual therapists. The therapy practice employing the AHA would provide them with training, guidelines, professional liability insurance and a career structure.

By working under the auspices of a therapy practice and coming under the guidance of the therapists, the AHA's work could be carried out as an adjunct to therapy. The therapy team could decide on how AHA's would spend their hours with clients, based on therapy rationale and clinical reasoning. In some cases, collaborative therapy/AHA sessions may be delivered, which integrate the skills of the therapist and AHA, thus bringing maximum benefit to the client.

It is recognised that it may be feasible for only larger practices to employ AHA's, limiting the scope for AHA involvement. If the proposed AHA model is considered successful following a trial phase, other models for employing AHA's would need to be explored.

8.5 Neuropsychology & Psychology

It is recommended that the range of therapy services be broadened to more comprehensively address the cognitive, behavioural and emotional sequelae of catastrophic brain injury.

Neuropsychological assessment of the individual's state of awareness and cognitive capacity is seen as vital to an understanding of their readiness to benefit from particular therapy interventions. Strategies to maximise learning and minimise the development of challenging behaviours should be integrated into all therapy interventions.

A flexible model which enables teams to allocate funding within identified funding bands, would enable teams to allocated funding for neuropsychological input as needed.

Psychology input may also be requested and may be utilised to address emotional issues and adjustment in the individual or family members. This strategy is seen as particularly important to address the level of carer burden and emotional distress that was identified in the literature review as well as in the 2004 review.

While it is recognised that neuropsychology and psychology services are already available within the ABI:STR program, findings from consumer and therapist consultation indicates that there is a strong focus on physical needs, and relatively limited integration of cognitive and behavioural planning into therapy programs. In conjunction with the treating team, the CRP could facilitate identification of cognitive, behavioural and emotional support needs of clients and support referral and re-referral to neuropsychology or psychology when indicated.

Recommendations

Flexible funding and resource allocation model

- Development of a structured, transparent and flexible funding model to cater for individual client needs
- Strengthening the interdisciplinary 'care team' approach and communication between team members and families by the appointment of a Team Leader.
- Person-focused care plans and allocation of resources within 'intensive' and 'maintenance' service funding bands
- Defining case management parameters
- Trialling the use of Allied Health Assistants
- Improved access to case management and therapy services in rural areas.
- Provision of neuropsychological and counselling assistance to individuals and families

9. PROGRAM OUTCOME MEASUREMENT

Key issues identified

- Absence of systematic and comprehensive ABI:STR Program evaluation and documentation
- Lack of profiling of ABI:STR recipients and identification of subgroups of people with specific support needs

ABI:STR Program outcome measures

Comprehensive program outcome data collection is vital as it provides for the ability to:

- Demonstrate the impact of the program as a whole
- Document the profile of the group as well as their needs and change in needs over time
- Examine costs of program and potentially analyse cost benefits
- Inform future funding allocations

In determining appropriate outcome measures, a wide range of measures were considered through a review of the literature and discussion within the Therapy Forum meetings. The following criteria were used in selecting measures:

- Assessment tool has been widely used and is validated within an ABI population
- The assessment tool is sensitive to change over time
- The tool can be completed on the basis of the knowledge of the client, and does not require engaging the client in long assessments and re-assessments.
- The measure can be completed by any therapist on the team
- The measure does not require a long period of time to complete
- The assessment tool emphasises measurement of activity and participation (rather than impairment)

On the basis of the above criteria, the following measures are recommended:

- **Disability Rating Scale (DRS):** Provides a general measure of disability that spans a full spectrum of function and tracks an individual from coma to community (Rappaport et al. 1982). Sections include awareness, level of disability and handicap.

The maximum score a patient can obtain on the DRS is 29 (vegetative state). A person without disability would score zero.

- **Care and Needs Scale (CANS):** Measures the type and extent of support needed in daily life (previously discussed).
- **Overt Behaviour Scale (OBS):** The Overt Behaviour Scale (OBS) (Kelly, Todd, Simpson, Kremer, & Martin, 2006) measures a range of challenging behaviours frequently observed following neurological conditions. These behaviours include:
 - verbal aggression
 - physical aggression against objects
 - physical acts against self
 - physical aggression against other people
 - inappropriate social behaviour
 - perseveration (repetitive behaviour)
 - wandering or absconding
 - inappropriate sexual behaviour
 - lack of initiation.

A brief version is suggested that measures the presence or absence of these nine key behaviours.

- **Community Integration Questionnaire (CIQ):** The Community Integration Questionnaire (CIQ) (Willer, Rosenthal, Kreutzer, Gordon, & Rempel, 1993) measures community integration. The CIQ is the most widely used and researched measure of community inclusion in the rehabilitation literature (Cusick, Gerhart, & Mellick, 2000; Hall, 1996; Sander et al., 1999; Sander et al., 1997; Seale, 2002; Tepper, Beatty, & DeJong, 1996; Willer, Ottenbacher, & Coad, 1994). Responses on the CIQ can be used to derive a total score and a score on each of three subscales: home integration, social integration and productivity, representing level of community integration experienced by the individual.
- **Role Checklist (RC):** The Role Checklist (RC) (Oakley, Kielhofner, Barris, & Reichler, 1986) elicits information about participation in everyday roles (e.g. friend, family member, hobbyist). The RC lists ten life roles and elicits information regarding the person's past, present and future participation in each role (Part 1). Present role participation is the suggested measure.
- **Barthel Index:** Consists of 10 items that measure a person's daily functioning. The items include feeding, moving from wheelchair to bed and return, grooming, transferring to and from a toilet, bathing, walking on level surface, going up and down

stairs, dressing, continence of bowels and bladder. The FIM was also discussed but not recommended at this time as it requires specific day-long training to utilise.

- **Medical Conditions:** The presence or absence of the following conditions in the previous 6-12 month period would be recorded: epilepsy, diabetes, chest infection, urinary tract infection, cellulitis, swallowing problems, altered muscle tone, pressure areas, heart or blood pressure problems, other.
- **Carer Burden:** A measure such as the Burden Interview (Zarit 1980) would be selected.
- Data should also be collected as to the **hours and costs** of therapy, attendant care and case management provided.
- **Other data** including readmission to acute hospital, residential environment, and quality of life indicators should be collected and based on specific research questions to be developed by the Clinical Resource Panel.

Outcome data should be collected at the following time points:

- 1) After receipt of referral and after 12 months if still on the waiting list
- 2) On admission to the ABI:STR program
- 3) Every 12 months after admission
- 4) On discharge or death

Every therapist providing services in the ABI:STR Program should be aware of the outcome measurement tools and the client's performance in relation to each of these measures. The team member identified as the person to collect and collate the data would largely complete these measures based on their knowledge of the individual, but would request additional information from the individual, therapists and family as required. It is estimated that each measure would take between 5 and 10 minutes to complete.

It is anticipated that a total allocation of three hours would be required to collect and enter the data into a custom built internet based survey such as (Zoomerang, 2007) or Survey Monkey ("Surveymonkey," 2008). The data from this survey could then be exported to the Statistical Package for Social Sciences (Microsoft, 2007) software package and aggregated for analysis.

Collating the data would require a significant time allocation and research expertise. It is suggested that resources are allocated to analyse the aggregated program data, liaise

with the Clinical Resource Panel and provide a report of the analysis to ABI:STR management on a yearly basis.

Given the recommended role of the CRP in utilising outcome data to address research questions, it is suggested that the CRP review the abovementioned outcome measures and modify the list as required.

Recommendations

Program Outcome Evaluation

- Development of a research protocol
- Common use of a comprehensive range of program outcome assessment tools, including a carer assessment tool
- Clinical Resource Panel to develop a research and evaluation program and protocols to commence a prospective study

10. ABI:STR PROGRAM THERAPY REPORTING

Key issues identified

- Inefficient and repetitious program care plan documentation and progress reporting
- Inconsistent documentation of measurable outcomes
- Lack of mechanism for linking funded hours to specific treatment goals and outcomes

It is recommended that new reporting proformas are developed to streamline and guide documentation of rehabilitation plans and requests for funding.

The framework for reporting should emphasise:

- The importance of a person-centred approach where the individual's desires are central to treatment planning
- The development of therapy plans based on measurable outcomes
- The identification of evidenced based interventions and strategies to attain goals
- The coordination of inputs to achieve shared team goals
- Documentation of progress and steps to achieve long-term aims

The following timetable of reports is suggested with further detail provided below:

Initial Reports On acceptance into program	Interdisciplinary background report (prepared by team leader) Discipline specific initial reports (one for each discipline) Interdisciplinary initial report (Brief overview prepared by team leader)
Progress Reports Annually, or every 6 months for Years 0-5 on program & at time of discharge	Discipline specific progress reports (one for each discipline) Interdisciplinary report (Brief overview prepared by team leader) Discharge report
Progress Reports Annually Year 6+ on program	Maintenance report (single, annual report prepared by team leader or remaining therapist)
Equipment and home modifications	Submission for equipment and home modifications to Aids and Equipment Program to be provided by relevant therapist as necessary.

Each proforma would utilise a format with the following headings as a basis for developing evidenced based care plans with specific measurable treatment objectives:

Funding request proforma:

Practical goals	Interventions & strategies	Measurable outcome(s)	Timeline	Total therapy hours requested to achieve outcome

Progress report proforma:

Practical goals (as stated in previous report)	Progress in relation to measurable outcomes and barriers to achievement

The following section provides more detail as to the key components of each of the reports. It is recommended that team members are funded for the time spent on report writing and that an estimated time allocation for each report is provided.

It is recommended that, based on the following outline, the Clinical Resource Panel develop a computerised template for each type of report. The CRP would also provide case examples of reporting using the new format and run a training session for therapists and case managers in the new reporting format.

10.1 Initial reports

An **interdisciplinary background report** would be prepared by a nominated team member to provide a comprehensive document that would form the platform for all subsequent funding and service applications. This would negate the need for the family to be asked essentially the same questions by all team members and eliminate the duplication of this information in therapist's reports. Therapists could supplement this background report with additional information specific to their field. Families would retain a copy of this document for their records.

The Interdisciplinary background report is estimated to take up to three hours to complete and would include:

- Background on the person
 - Accommodation history
 - Education history
 - Vocational history
 - Friendship / social networks
- Past history
 - Medical
 - Mental health

- Background regarding ABI (including date of injury, type of injury, severity indicator where possible, medical intervention and course post injury)
- Current situation
 - Medical / medical conditions
 - Functional capacity
 - Behaviour
 - Drug and alcohol
 - Mental health
 - Family
 - Financial
- Available funding sources
- Pending funding applications
- Tick box to state client is on DSR
- Family and client goals

Discipline-specific initial report (2 hours each allowed for completion)

Discipline specific initial reports would be prepared by all team members (i.e., therapists and case manager) following the initial assessment. They would include:

- Discipline-specific assessment findings
- Goal for client / strategies to achieve goal / measurable outcome (may include customised or published outcome measures) / number of treatment hours required to address issue / timeframe
- Total discipline-specific hours requested for funding period

Brief interdisciplinary initial report (1 hour to complete)

This interdisciplinary report would be completed by a nominated team member. This would be a one-two page covering letter to the discipline specific reports and would provide an overview of the key goals of the individual and team as well as proposed intervention. It would also note plans for discharge. Key elements would include:

- Identification of three to four key interdisciplinary areas of focus for the next funding period (e.g., eating, communication, community access)
- Overview and integration of team inputs to achieve key goals and the schedule of timing of commencement of inputs
- Summary of individual therapist / case management funding requested in specified period (block of hours within funding period)
- Discharge planning

10.2 Progress reports: Years 0-5 on Program

Discipline-specific progress reports (1 hour for each team member)

Discipline specific progress reports would be prepared by all team members ie therapists and case manager at nominated review periods (i.e., 6 or 12 months).

- Descriptive detail and review of measurable outcome/s of progress relating to previously stated goals
- List of: goal for client / strategies to achieve goal / measurable outcome (may include customised or published outcome measures) / number of treatment hours required to address issue / timeframe
- Total discipline-specific hours requested

Brief interdisciplinary progress report (1 hour)

This interdisciplinary report would be completed by a nominated team member. Again, it would be a one-two page covering letter to the discipline specific reports and would provide an overview of the persons current situation, the key goals of the individual and team as well as the team focus of intervention. It would also note plans for discharge.

- Brief descriptive overview of progress, social and accommodation situation, and issues during previous block of funding
- Review and description of the three to four key interdisciplinary areas of focus and progress made (i.e., talking about the client and the progress they have made as a result of program input)
- Barriers to progress and significant changes in circumstance or function.
- Brief descriptive overview of plan for next block of funding
- Identify three to four key interdisciplinary areas of focus for the next funding period
- Summary of individual therapist / case management funding requested in specified period (block of hours within funding period)

10.3 Discharge reports

Discharge (ie from intensive levels of program participation) reports would be completed when the individual moves to Band 4 or 5 level funding by Year 6 of the program, or on actual discharge. The key purpose is to document the outcomes of the intervention, the level of function the person has achieved, and what elements the program needs to actively continue to maintain.

Discipline-specific discharge reports (1 hour)

- Descriptive detail and review of measurable outcome/s of progress relating to previously stated goals
- Provide a functional description of the individual's current level of function in selected areas that need to be maintained when discharged from active programs (e.g., communication, manual handling, positioning, mobility, oral care, eating, community access, behaviour, equipment, socialisation, mental health).

Interdisciplinary Discharge report (2 hour)

Summary report by nominated team member

- Brief descriptive overview of progress, social and accommodation situation, and issues during previous block of funding
- Brief description of progress made whilst on STR program
- Ongoing supports in place (funded and gratuitous)
- Referrals to other agencies / services
- Wait listing for funding packages

10.4 Progress reports Years 6+ on Program

Only one **interdisciplinary** report per year would be required when the person is on Band 4 or 5 level therapy funding (and 6+ years on the program) and it is estimated to take 2 hours to complete.

- The report would be completed by a nominated team member.
- The goal of the program at Year 6+ is to keep the person at the level of function that they achieved on discharge from the more active program. Progress would be noted in relation to new goals, as well as changes in the individual's circumstances.
- The report would focus on strategies and outcomes in relation to the level of function in selected areas noted above (i.e., communication, manual handling, positioning, mobility, oral care, eating, community access, behaviour, equipment, socialisation, mental health).

10.5 Initial and annual data collection and entry (3 hours)

A nominated team member would collect data on the outcome measures previously described and enter the data into an internet data base: Role Checklist, CANS, Overt Behaviour Scale, Disability Rating Scale, Community Integration Questionnaire, Bartel, Medical Conditions, therapy and attendant care hours utilised.

10.6 Equipment & Home Modification requests

It is recommended that proformas for these requests be developed by the Clinical Resource Panel.

Recommendations

Therapy Reporting

- Therapy report proformas to be developed to promote person-focused, discipline specific plans that relate to achievement of specific measurable treatment objectives
- Interdisciplinary report to provide overview of the direction of the individual's program, identify key team goals and document methods by which strategies will be integrated
- Report writing time to be funded at specified, capped levels.

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APPENDIX 1: PROFILE OF STR CLIENTS

A number of ABI:STR clients have participated in previous research examining outcomes following catastrophic brain injury. In 2003, a retrospective outcome study of the ABI: STR program was conducted by Dr John Olver and colleagues. The 2007 *my future my choice (mfmc)* report on 105 people under the age of 50 years who lived in residential aged care facilities also involved 35 individuals under 50 years of age who had had a catastrophic brain injury, with about half of those in receipt of STR programs. Table 5 is a summary of the client profiles documented by these two studies.

Table 5

Summary of demographic data for the 35 clients from the my future my choice (2007) study & ABI:STR clients in the Olver et al. (2003) study

Outcome measure	2003 Study	2007 MFMC Study
Number of individuals with catastrophic brain injury	35	35
Proportion of catastrophic ABI on STR program	100%	46%
Male/female ratio	33:67	NA
Mean age	41 years	NA
Mean time post-injury	5 years	NA
ABI due to stroke	33%	NA
ABI due to heart attack	14%	NA
ABI due to substance use	14%	NA
ABI due to assault	12%	NA
ABI due to accident	6%	NA
ABI due to medical	6%	NA
ABI due to surgical	6%	NA
ABI due to near drowning	6%	NA
ABI due to unknown	3%	NA
Living in residential aged care facility	34%	100%

The data obtained from these two studies relates to the disability levels, health issues and support needs of individuals with catastrophic brain injury, as summarised below.

Level of Dependence

As shown in Table 6, clients receiving ABI:STR funding have extremely high level needs. A large proportion of this group requires 24 hour daily support, including support of carers awake overnight. As such high level needs cannot be met by the funded carer hours, there is commonly a high level of family involvement on a daily basis.

Table 6

Percentage of the 35 my future my choice (2007) clients at levels 7 and 8 on the Care and Needs Scale (CANS)

Outcome measure	Percentage of participants
CANS level 8 (cannot be left alone at all)	74 ^b
CANS level 7 (cannot be left alone for 20-23 hours)	26 ^b

^b (Winkler et al., 2007)

Awareness

'Full awareness' is the term used to describe a person who is fully aware of their environment and is oriented to time, place and person. A person is classified as 'partially aware' if they are conscious and awake but have profound memory difficulties and significant levels of confusion. 'Minimally aware' individuals show severely reduced conscious state. There may be inconsistent behaviours that suggest some awareness of self and/or the environment. This includes people variously described as in a minimally conscious state, vegetative state and post-coma unresponsiveness. In providing STR clients with support, it is vital to tailor input to their

individual's awareness and capacity to understand and respond. Those in a minimally aware state require specialist assessment and input.

Table 7

Level of awareness data for the 35 participants in the my future my choice (2007) study

Outcome measure	Percentage of participants
Full awareness	37
Partial awareness	46
Minimal awareness	17

Medical Issues

The *my future my choice* study (Winkler, Sloan & Callaway, 2007) found that the average number of health problems of each individual was 2.6. The number of health problems across the group ranged from 0-7^b. Multiple and complex medical conditions require frequent medical specialist input, daily nursing and complex care plans. Medical conditions are potentially unstable and may be deteriorating, requiring continual adjustment of the care plan. Table 8 details types of medical conditions experienced by the ABI:STR group.

Table 8

Medical conditions experienced by the 35 clients from the my future my choice (2007) study & ABI:STR clients in the Olver et al. (2003) study

Outcome measure	Percentage of participants
Hypersensitive to sensory stimuli	29 ^b
Altered muscle tone, spasticity or muscle spasm	66 ^b
Contractures	51 ^b
Chronic pain problems	29 ^b
Pressure areas or pressure care	40 ^b
Epilepsy/seizures	31 ^b
Diabetes	14 ^b
Incontinence	26 ^b
Difficulty sleeping	57 ^a
Increased tiredness	89 ^a
Balance problems	94 ^a
Poor eyesight	69 ^a

^a Olver et al. 2003

^b MFMC, 2007

Physical Issues – Positioning

Positioning is a prominent issue for STR clients. It is crucial that individualised daily care plans are developed and consistently implemented for these individuals in order to prevent the risk of secondary complications. Extremely high physical support needs may require the assistance of one or two people for positioning requirements.

Table 9

Data on positioning for the 35 clients from the my future my choice (2007) study

Outcome measure	Percentage of participants
Positioning is critical for the individual	64
Positioning is critical in bed	100
Positioning is critical in a wheelchair	100
Positioning is critical in a chair	100
Incorrect positioning causes pain issues	100
Incorrect positioning causes challenging behaviour	100
Incorrect positioning causes respiratory tract infections	100
Incorrect positioning causes pressure sores	100
Incorrect positioning causes choking	100

Physical Issues – Mobility

Table 10 details the impact of physical disability of mobility status of ABI:STR clients in the Oliver et al. (2003) and MFMC studies. The data indicates reduced mobility for a high proportion of participants.

Table 10

Mobility data for the 35 clients from the my future my choice (2007) study & ABI:STR clients in the Oliver et al. (2003) study

Outcome measure	Percentage of participants
Bedfast	11 ^a
Independent in a wheelchair or requires help in a wheelchair	69 ^a
Ambulant with walking aids	20 ^a
Cannot transfer or move around inside residence without help	77 ^b
Cannot get in and out of residence without help	88 ^b
Cannot get around local community without help	94 ^b
Immobile in bed	57 ^b

^a Oliver et al. 2003

^b MFMC, 2007

Physical Issues – Swallowing

Given the high incidence of swallowing problems in STR clients (see Table 11), routine reviews of swallowing and the development of measures to prevent chest infections is paramount.

Table 11

Percentage of the 35 clients in the my future my choice (2007) study with swallowing difficulties and requiring an alternative feeding method

Outcome measure	Percentage of participants
Swallowing difficulties	49
Requires nasogastric or PEG feeding	34

Equipment Needs

According to the CANS, the average number of different types of consumables used by each person was 5.2. The number of consumables used across the group ranged from 0-13.

The average number of pieces of equipment used by each person was 6.2, but ranged from 0-12

^b. This highlights the importance of adequate funding for customised equipment prescription and supply (e.g. seating, pressure care).

Table 12

Types of equipment commonly required by the 35 participants in the my future my choice (2007) study

Outcome measure	Percentage of participants
Shower trolley	14
Shower chair	69
Hoist	63
Pressure care mattress and overlays	66

Community participation

A large number of STR clients require assistance to access the community, impacting on community-based activities and roles (see Table 13). This emphasises the importance of

recreational support and adaptive recreation equipment to assist people to develop and pursue interest both at home and in their local community.

Table 13

Community activity / participation data for ABI:STR clients in the Olver et al. (2003) study

Outcome measure	Percentage of participants
Reduction in leisure and social life	94
Less sociable	63
Able to participate in leisure activities, visiting friends and relatives, and going on shopping outings	68
Less interested in children	58

Daily living activities

STR clients experience dramatic changes in their ability to manage their daily routines and activities (see Table 14). Given their potential to develop skills and reduce support needs over time, many people will benefit from therapy input and opportunities to integrate skills into everyday routines. Ongoing training and support of staff is also important in order to maximise skill development, safety during manual handling and implementation of consistent routines. Specific and individualised training of staff is also necessary for the development of personal care routines (e.g., structured oral care, manual handling routines).

Table 14

Assistance required for activities of daily living for ABI:STR clients in the Olver et al. (2003) study

Outcome measure	Percentage of participants
Dependence on others for shopping, meal preparation, housework & childcare	62
Less active in household tasks	83
Need more much more help with self-care routines	80

Cognitive Changes

High levels of cognitive and communication impairments (see Table 15) require speech pathology and neuropsychological interventions that draw on the strengths of the individual in order to compensate for their difficulties in thinking speed, memory deficits and fluctuating concentration. Basic personal care and routine domestic tasks are likely to require specialised cognitive and communication support.

Table 15

Cognitive and communication difficulties experienced by the 35 clients from the my future my choice (2007) study & ABI:STR clients in the Olver et al. (2003) study

Outcome measure	Percentage of participants
Slowness problems	86 ^a
Memory difficulties	83 ^a
Reduced concentration	94 ^a
Comprehension difficulties	51 ^a
Finding the correct word	80 ^a
Difficulty speaking	97 ^a
Difficulty communicating basic needs due to language impairments	66 ^b

^a Olver et al. 2003

^b MFMC, 2007

Mental Health

STR clients demonstrate high levels of mental health problems, including clinically significant depression and complex co-morbid conditions (see Table 16). As mental health issues compound the management of other disability related impairments, specialist expertise is required for accurate diagnosis and management. Monitoring and periodic input is critical for managing depression, anxiety and other psychiatric conditions.

Table 16

Mental health issues experienced by ABI:STR clients in the Olver et al. (2003) study

Outcome measure	Percentage of participants
More passive	74
More anxious/tense	69
More depressed	51
Reduced sexual functioning	85

Challenging Behaviour

Complex challenging behaviours are common for STR clients, as shown in Table 17. With the high incidence of poor initiation and aggression, it is crucial that individuals receive specialist behavioural intervention to develop individualised strategies. The effective implementation of such behaviour management plans hinges on ongoing training of staff, improved living environments, development of communication skills and enhanced participation in meaningful occupation.

Table 17

Challenging behaviours displayed by the 35 clients from the my future my choice (2007) study & ABI:STR clients in the Olver et al. (2003) study.

Outcome measure	Percentage of participants
Irritability	46 ^a
Verbal aggression	41 ^b
Physical aggression	21 ^b
Inappropriate sexual behaviour	29 ^b
Perseverative/non-purposeful repetitive behaviour	35 ^b
Wandering/absconding	6 ^b
Inappropriate social behaviour	38 ^b
Lack of initiative	53 ^b

^a Olver et al. 2003

^b MFMC, 2007

APPENDIX 2: ABI:STR THERAPY REVIEW SURVEY QUESTIONS

Date			
Name of STR recipient Place of residence			
Name of respondent / relationship			
Date of brain injury			
Can you tell me about the lead up to being referred to STR?			
Length of time on STR waiting list			
What was the experience of waiting like at this time?			
Were there any secondary issues / complications that emerged during?			
Length of time in receipt of STR therapy			
Tell me about your experience of therapy services under STR:			
Therapy 1 What therapies have you received from STR Describe each of the therapists roles 2 Are you still seeing each of these therapists / how many hours 3 Have you had any change of therapists – when, how was this managed 4 Maintenance – have you gone to maintenance, how did this go 5 Overall how satisfied are you with your 5 = extremely satisfied 4 = very satisfied 3 = neutral 2 = dissatisfied 1 = very dissatisfied Refer to list of issues	OT	1 Y N 2. Y N 3. Y N 4. Y N 5.	
	PT	1 Y N 2. Y N 3. Y N 4. Y N 5.	
	SP	1 Y N 2. Y N 3. Y N 4. Y N 5.	
	NP	1 Y N 2. Y N 3. Y N 4. Y N 5.	
	Other	1 Y N 2. Y N 3. Y N 4. Y N 5.	

<p>General comments about therapy (what has been the most helpful input / why, what would you have liked to have more of / less of, were you able to choose your therapists, did your therapists work as a team with common goals or were the goals fragmented / were there any adverse effects of cutting back on therapy / did you feel you understood the purpose of various therapies / were you ever dissatisfied by a therapist on your team / what did you do about it?)</p>		
<p>Attendant care</p> <p>Tell me about your general experience of attendant care under STR</p> <p>What do you see as the role of the carer?</p> <p>How many hours of AC do you receive per week under STR</p> <p>How many hours of AC do you receive per week under other funding packages</p> <p>What types of tasks do the carers perform</p>	<p>STR hours:</p> <p>Other AC hours:</p> <p>Total AC per week:</p>	
Is your team of carers stable	Y N	
Do your carers work under guidance of the therapists?	Y N	
Are there written guidelines in place for carers	Y N	
Are they up to date	Y N	
Does someone coordinate the attendant care program	Y N	Who
Do you have someone to call if there is a problem with the AC program	Y N	Who
<p>General comments about attendant care (what has been your experience of dealing with the care agency)</p> <p>Overall how satisfied are you with the therapy part of your attendant care program</p> <p>5 = extremely satisfied</p> <p>4 = very satisfied</p> <p>3 = neutral</p> <p>2 = dissatisfied</p> <p>1 = very dissatisfied</p>		

managing the persons life other Can you tell me about the impact of providing this care on yourself and others in the family (eg work, family life, health)
Do you have concerns about the future What would be the role of STR in helping you address these concerns Do you have any suggestions as to how STR could improve its rehabilitation services
Overall how satisfied are you with the therapy program under STR 5 = extremely satisfied 4 = very satisfied 3 = neutral 2 = dissatisfied 1 = very dissatisfied
Any other comments

List of issues addressed by therapists in your team

	Not relevant	Relevant but not addressed	Addressed but not satisfactorily	Addressed satisfactorily
Medication				
Health care				
Oral hygiene				
Nutrition and swallowing / digestive issues / PEG				
Mental health Stress Anxiety Depression				
Behaviour				
Managing cognitive problems				
Communication				
Community activities				

Leisure activities				
Social activities				
Independence in PADL				
Independence in DADL				
Having a routine (daily / weekly)				
Positioning and comfort				
Pain management				
Equipment				
Planning for the future				
Prevention / management of joint contractures / tone / other physical (splinting)				
Mobility				
Fitness				
Other				
Other				

APPENDIX 3: THERAPIST SURVEY RESULTS

Eleven therapists were surveyed with the following questions:

1. How many therapists do you have in your practice?
2. Do you **currently** have STR clients on your practice case load?
 - 2a. If so approx. how many?
3. How many years experience have you, as principle therapist of your practice, had in treating STR clients?
4. Do you take **NEW** STR referrals: Yes or No
 - 4a. If No, briefly state your reasons
 - 4b. If Yes, do you have any restrictions on who you would accept and if so briefly state your reasons.
5. Any other comments?

The following table is a summary of the responses:

Practise	EFT in practice	Years experience of principle therapist	Number of current clients caseload	of STR on	Take new STR referrals Y / N / Y under certain circumstances
1	1	11	3		Y, under certain circumstances
2	1	6	15		Y, under certain circumstances
3	7.2	11	33		Y, under certain circumstances
4	5	12	13		N
5	4	12	31		Y, under certain circumstances
6	Not provided	9	Not provided		Y, under certain circumstances
7	2.4	12	17		Y, under certain circumstances
8	4	12	22		Y, under certain circumstances
9	2.5	10	14		Y, under certain circumstances
10	5	9	6		N
11	7	12	4		N

Those who do not take any new STR clients refuse to do so for the following reasons:

“The practice is unable to afford to have STR clients as the ratio of unfunded to funded work is too great to absorb into the hourly rate and cover all the on-costs and overheads of the practice”.

“It’s too frustrating to work in poorly coordinated teams where the case manager keeps changing”

"All other funding bodies pay for travel and behind-the-scenes work, so they are prioritised".

"As the principle therapist in my practice with over 20 years experience, my hourly rate is \$140. By the time you do all the unfunded hours for STR clients and pay for petrol etc it works out at less than \$20-25/hour. The practice cannot afford for me to spend my time this way."

"...my ability to take on new STR referrals will continue to diminish, given that I place lower priority on accepting these referrals over others. I can certainly envisage that within a few years I will be in a position where I will no longer take on STR referrals at all".

"Travel and time costs are increasing more and more, and are out of proportion with STR funding fee rises... we have younger therapists...considerable supervision time is required, which adds substantially to these costs."

Conditions that influence whether a practice will or will not take new STR clients:

"...if they live close by, are very interesting, or if I have been invited by the [allied health] team to do so."

"In the country areas, we only take on clients if our travel time is funded. In the city we consider whether the client is within close proximity to the office or to another client receiving regular OT input".

"...ethically, we can't refuse"

"...provided they are within a reasonable travel time...i.e. no more than 20-30 minutes each way."

"...if we know who the other therapists are...we have taken on clients with therapists we do not know (i.e. they do not normally treat in this area of severe brain injury) and it has not been a pleasant experience"

"We feel that we have a responsibility to see these clients (i.e. severe, minimally responsive)... but we do have restrictions now..."

"...if I have capacity to accept only one referral and I receive two referrals at the same time, then an STR referral would be declined"

"We take into account...the other team members. Our role can be impacted quite significantly by roles and responsibilities taken on by other team members...e.g. case managers."

"...try to avoid maintenance clients as they often have no set-up done"

"Travel is a primary consideration"

"Living situation...if in a hospital type setting where carry-over is unlikely to be achieved, we do not take the referral".

"We would say 'no' to STR clients if they are geographically out of our area"

Some of the 'other comments' received were as follows:

"The STR program was a great initiative but there are fundamental difficulties...the clients accepted to the program often need very intensive therapy for many years and will require very large amounts of care support to go home or to be able to sustain the functional level they achieve by the intensive program."

"...This population of clients have a right to be treated with dignity, respect, and to be provided with therapy that is meaningful and appropriate for them."

"The program cannot provide the amount of ongoing input these patients require and hence there is always pressure to cut back services just when the patient is making progress and needs the therapy support to continue making progress."

"Therapists spend 4 years in training and ...years gaining the necessary experience to deal with these difficult clients and it is not reasonable to hand them on to a carer to work with...it means the client gets very poor care and this leads to very poor results of treatment."

"Many of the STR clients are not screened for their potential...they enter the STR program when a place becomes available rather than when the client is ready for the program...often the intensity of therapy is too low to support sustainable improvement"

"The equipment program for STR is a shambles with constant arguments ensuing with the equipment provider."

"I have had clients discharged home when they require 24 hour care, and they only have 38 hours a week care...this puts a huge burden on the family and is setting them up to fail.."

"Essentially it is a great program and without this funding, many non-compensable clients would not receive any therapy and would live with pain and an inability to engage. However, the provision of a quality service to these complex cases is becoming extremely difficult".

"I think the STR program could be one delivering an economic service to clients, to make a difference to the lives of severely disabled people. Instead I see the wasting of resources in poorly focused plans, and the gradual loss of experienced therapists to the program. I see therapists taking on more management roles in coordinating teams and sourcing services that I think should happen within the case management portfolio. I see an uneven distribution of resources that I do not believe stands up to objective scrutiny in terms of best meeting the needs of all clients of the service."

**APPENDIX 4: EXAMPLES OF SERVICES THAT COULD BE FLEXIBLY PURCHASED
FOR EACH FUNDING BAND**

Band 1: Maximum \$70,000 per annum						
Example 1				Example 2		
	Hours/wk	Rate \$	\$ Per week		Hours/wk	Rate \$ Per week
AHA	5.00	40.00	200.00	AHA	4.00	40.00 160.00
OT	3.00	85.40	256.20	OT	3.00	85.40 256.20
Physio	2.00	92.60	185.20	Physio	4.00	92.60 370.40
Speech	3.00	85.40	256.20	Speech	3.00	85.40 256.20
AC	5.00	30.00	150.00	AC	7.00	30.00 210.00
NP	2.00	100.00	200.00	NP	0.00	100.00 0.00
CM	1.00	45.00	45.00	CM	2.00	45.00 90.00
Band 2: Maximum \$60,000 per annum						
Example 1				Example 2		
	Hours/wk	Rate \$	\$ Per week		Hours/wk	Rate \$ Per week
AHA	3.00	40.00	120.00	AHA	0.00	40.00 0.00
OT	2.00	85.40	170.80	OT	3.00	85.40 256.20
Physio	3.50	92.60	324.10	Physio	3.50	92.60 324.10
Speech	2.00	85.40	170.80	Speech	2.00	85.40 170.80
AC	10.00	30.00	300.00	AC	10.00	30.00 300.00
NP	0.00	100.00	0.00	NP	0.00	100.00 0.00
CM	1.00	45.00	45.00	CM	2.00	45.00 90.00
Band 3: Maximum \$45,000 per annum						
Example 1				Example 2		
	Hours/wk	Rate \$	\$ Per week		Hours/wk	Rate \$ Per week
AHA	0.00	40.00	0.00	AHA	5.00	40.00 200.00
OT	1.50	85.40	128.10	OT	2.00	85.40 170.80
Physio	2.00	92.60	185.20	Physio	2.00	92.60 185.20
Speech	1.00	85.40	85.40	Speech	0.50	85.40 42.70
AC	10.00	30.00	300.00	AC	5.00	30.00 150.00
NP	1.00	100.00	100.00	NP	1.00	100.00 100.00
CM	1.00	45.00	45.00	CM	0.00	45.00 0.00
Band 4: Maximum \$32,000per annum						
Example 1				Example 2		
	Hours/wk	Rate \$	\$ Per week		Hours/wk	Rate \$ Per week
AHA	0.00	40.00	0.00	AHA	4.00	40.00 160.00
OT	1.50	85.40	128.10	OT	2.00	85.40 170.80
Physio	2.00	92.60	185.20	Physio	2.00	92.60 185.20
Speech	1.00	85.40	85.40	Speech	1.00	85.40 85.40
AC	10.00	30.00	300.00	AC	0.00	30.00 0.00
NP	0.00	100.00	0.00	NP	0.00	100.00 0.00
CM	0.50	45.00	22.50	CM	0.00	45.00 0.00
Band 5: Maximum \$5,000 per annum						

Example 1				Example 2			
	Hours/yr	Rate \$	\$ Per Year		Hours/yr	Rate \$	\$ Per Year
AHA	0.00	40.00	0.00	AHA	0.00	40.00	0.00
OT	12.00	85.40	1,024.80	OT	16.00	85.40	1,366.40
Physio	12.00	92.60	1,111.20	Physio	24.00	92.60	2,222.40
Speech	12.00	85.40	1,024.80	Speech	16.00	85.40	1,366.40
AC	0.00	30.00	0.00	AC	0.00	30.00	0.00
NP	0.00	100.00	0.00	NP	0.00	100.00	0.00
CM	0.00	45.00	0.00	CM	0.00	45.00	0.00

APPENDIX 5: EXCERPT FROM TAC CASE MANAGEMENT POLICY

The TAC can authorise the provision of case management services as an authorised disability service, for clients who, as a result of injuries suffered in a transport accident, have a [disability](#) and are assessed by a TAC Support Coordinator as requiring the specific expertise of a Case Manager. Services must be delivered by a provider of case management services in accordance with the [TAC Case Management Model](#).

All case management services require prior approval in writing from the TAC Support Coordinator.

Background

The TAC recognises that some clients with a disability, as a result of injuries suffered in a transport accident, may at certain times require assistance beyond the support coordination role of a TAC Officer or the role of treating health care providers. Case management is a time-limited, episodic service to achieve client outcomes.

Guidelines

Who can recommend or request case management services?

Case management services can be recommended by the client's hospital treating team, community based therapy team, TAC Support Coordinator or requested by the client's legal representative, family members or the TAC client.

Who is eligible for case management services?

Clients who are assessed as eligible for TAC disability services are eligible to receive case management services. The TAC can approve the provision of reasonable case management services for a client who, as a result of injuries suffered in a transport accident, has a disability and requires the specific expertise of a Case Manager to assist with:

- planning discharge from hospital to the community
- transition planning (eg. transition to residential care)
- re-establishing their role in the community, at home, in school, at work and in leisure activities
- proactive contingency planning and crisis intervention
- developing self-management skills and strategies.

What information does the TAC consider when approving case management services?

The TAC reviews and considers the following information when approving case management services:

- Whether case management is the most appropriate service to meet the client's needs and goals?
- Whether the service promotes progress towards independence, participation in the community and self-management?
- The goals submitted - are they specific, measurable, achievable, realistic and timely?

Can the TAC approve the provision of case management services for non-accident related client needs?

The TAC can approve the provision of a Case Manager to assist a client to identify and access services, including those for which the TAC is not liable. However, the TAC is unable to fund the cost of identified support services which are not related to the client's transport accident, and therefore are not the TAC's liability.

Who can provide case management services?

The TAC has a professional, appropriately skilled and experienced Case Management team to provide these services to TAC clients. A TAC case manager will be automatically allocated to all eligible new clients in the Community Support Division upon claim acceptance.

Case management services can be provided by a TAC Case Manager, or a Case Manager appointed by the TAC in accordance with the [TAC Case Management Model](#). Both require prior approval in writing from the TAC Support Coordinator.

Can a Case Manager approve any services?

Case Managers do not have any delegation under the *Transport Accident Act 1986* to approve services funded by the TAC. All services recommended by a Case Manager require prior approval by the TAC Support Coordinator.

The TAC will determine its funding liability under the legislation and the policy applicable to the services recommended.

In relation to case management services what will the TAC not approve the provision of?

The TAC will not approve the provision of:

- services for a person other than the injured client
- services that are not required as a result of injuries suffered in a transport accident
- services for a client who is not entitled to receive disability services
- services in respect of which the TAC has no liability to fund the costs of the service
- other services which are already being provided by another provider involved in the client's care
- services received by the injured person outside the Commonwealth of Australia
- activities provided when acting under a legal authority whether as a guardian, administrator, attorney or signatory to any of these for the client
- services to assist with the making of decisions on behalf of a client or the client's family or guardian
- services to coordinate and facilitate legal processes for a client to review decisions made by the TAC
- services not payable under the *Transport Accident Act 1986*
- services which are hospital, medical or [Authorised Rehabilitation Services](#) as case management services
- services provided more than 2 years prior to the request for funding. Refer to [Medical and Like Expenses - Application for payment more than 2 years after service](#) policy.