

Preface

This document sets out the essential features of traumatic brain injury (TBI) rehabilitation¹.

In 1997 a collaboration began between the Accident Rehabilitation and Compensation Insurance Corporation (ACC) and the National Health Committee (NHC).

It aimed to develop TBI rehabilitation guidelines mainly for providers of TBI rehabilitation services wishing to improve the quality of their service. The Panel members appointed by ACC and the NHC recognise that improved services will lead to better rehabilitation of individuals with TBI.

ACC and the NHC advocate using these guidelines because they provide a basis for providers to be:

- explicit
- open and
- accountable in providing their services.

Format

Guidelines can take various forms but have certain characteristics in common:

- they set out the *processes* by which decisions should be made, rather than the decisions themselves
- they set out the *boundaries* within which competent practice should happen, rather than laying down rigid, step-by-step rules.

Guidelines are intended to guide decisions in usual circumstances. They require judgement in every step of their application and development.

These guidelines put individuals with TBI first, identifying their likely needs according to their injury severity. They do not attempt to indicate specific rehabilitation strategies for mild, moderate and severe injury.

Additionally, these guidelines do not prescribe what should happen at what time, or who should be responsible for the rehabilitation process at which stages. These are matters for service providers to decide, using these guidelines as a basis.

For more information a list of textbooks and other references is included at the end of the document.

- 1** *The guidelines do not divide the process or profession of rehabilitation into 'medical rehabilitation', 'vocational rehabilitation' and so on, but use the term broadly and inclusively. This broad use is intended to allow providers scope within which to use the term more specifically, when they develop their service specifications.*

The guidelines terminology

The Panel has used terminology about rehabilitation that reflects international clinical convention, such as the definitions of impairment, disability and handicap developed by the World Health Organization.

Varying definitions of rehabilitation are used, some being influenced by policy, governance and organisational orientation. These guidelines have been written as independently of the political and funding context as possible, while recognising that the nature, type, focus and extent of rehabilitation services are shaped by these factors.

Future expectations

It is anticipated that costs to ACC will increase in the short term as new TBI services are established and some established services become more comprehensive. However, in the medium to long term it is anticipated that effective TBI services will lead to reduced costs to ACC, family and whanau members and society.

Who should use these guidelines?

The guidelines are designed to be used by a wide range of providers with a corresponding range of awareness and experience of TBI and TBI rehabilitation.

To a lesser extent, consumers of services and their families wanting a basis for assessing service quality will find these guidelines useful. However, a fact sheet (see Appendix 7) is likely to be a more useful document for them.

Regular evaluation

These guidelines should be regularly evaluated to ensure that they:

- continue to be a sound basis on which to develop practices
- describe open and accountable practices
- have a consumer focus
- have a good evidence base
- are responsive to the needs of individuals
- incorporate an awareness of local community values
- are culturally appropriate
- can be useful in the face of competing claims on resources
- continue to be based on wide consultation.

The Panel recommends that they should be reviewed by October 2000.

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The panel

Panel members were selected according to the variety of their professional backgrounds and academic disciplines. They cover the spectrum of public and private service provision. Each contributed their individual expertise rather than the perspective of any organisation they represented.

Andrew Beattie

Registered psychiatric nurse, general and obstetric nurse. Experience in rehabilitation in UK, Australia and New Zealand. Currently Manager of a residential rehabilitation and assessment service for individuals with TBI.

Denise Brown

Rehabilitation expert with a particular focus on TBI. Work has included clinical practice, training, research and strategic planning over 20 years in Canada, Australia and New Zealand.

Libby Carr

Occupational therapist with over 10 years' specialist experience in brain injury rehabilitation with extensive involvement in consumer advocacy organisations. Currently working as Contracts Manager in purchasing health and social services.

Patricia Champion

Developmental psychologist and Clinical Director of the Champion Centre, Christchurch, and lecturer in Paediatrics, Christchurch School of Medicine. Clinical and research interests are with infants, and pre-school children with disability.

Joanna Curzon

Specialist physiotherapist with extensive experience with children with neurological disorders. Now with Specialist Education Services national service development team responsible for services for people with high and complex needs.

Hamish Godfrey

Senior lecturer in psychology and Director of the Clinical Psychology Training Programme at Otago University. Research and clinical interest in psychosocial aspects of TBI.

Janis Henry

Clinical nurse specialist with extensive clinical and managerial experience in TBI rehabilitation. Involved in developing TBI rehabilitation programmes in acute, residential and community-based settings.

Brigette Larkins

Speech language therapist with extensive clinical and teaching experience in brain injury rehabilitation. Special research interest in outcome measurement of TBI, particularly functional communication assessment.

Harry McNaughton

Senior lecturer in rehabilitation University of Otago, Wellington School of Medicine, with clinical experience in managing individuals with TBI in units in Scotland and New Zealand.

Gil Newburn

Neuropsychiatrist with 15 years' experience and special interest in working with brain-injured individuals and their families; publications in various areas of management and invited speaker at major international conferences.

Jenny Shieff

Project manager with wide experience in public and private sectors, with 17 years' teaching experience. Project manager representing ACC in 1995/96 for the development of guidelines produced by ACC and the NHC for managing acute low back pain.

Linda Thompson

Chief Executive of Te Oranganui Iwi Trust, registered and obstetric nurse with a background in community health, intensive care and psychopaedic nursing. 10 years' experience in community and Maori health development with a variety of clinical and health management positions.

Rod Watts

Manager of an acute rehabilitation service who has worked clinically in TBI services, trauma, palliative care and mental health, in settings that have ranged from acute hospital to community outreach.

Project Managers

Brigette Larkins, National Manager, Serious Injury, ACC

Jenny Shieff, member of the National Health Committee Secretariat



Standing left to right: Patricia Champion, Gil Newburn, Libby Carr; Harry McNaughton, Joanna Curzon, Rod Watts, Janis Henry, Denise Brown

Seated left to right: Brigette Larkins, Hamish Godfrey, Andrew Beattie, Jenny Shieff (Absent: Linda Thompson)

Executive summary

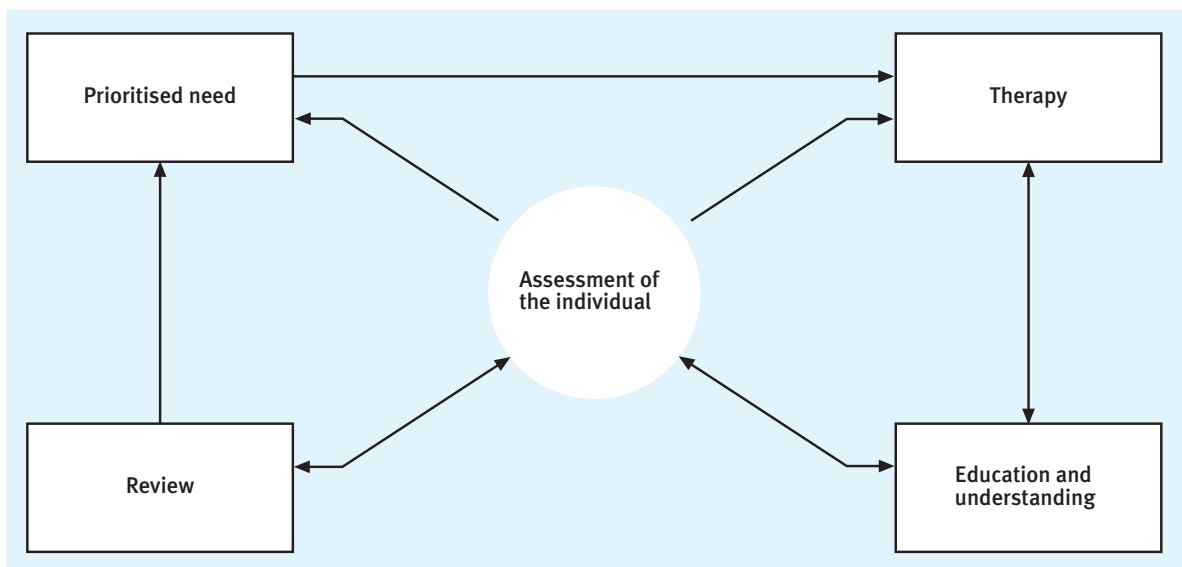
These guidelines are intended to help service providers improve rehabilitation services and results. They are accompanied by a sample fact sheet for people with brain injury, their families and friends (see Appendix 7). Copies of this fact sheet can be obtained from any ACC branch.

While individuals with TBI and their families are expected to find the guidelines useful, they are expected to be mainly used by providers of TBI services as a framework from which to develop their service specifications. Accordingly, the guidelines will become a basis for funders and providers who are drawing up contracts for services.

Effective TBI rehabilitation services will lead to decreased dependency, reduced costs relating to care, and opportunities for individuals with TBI to take their place as community members.

The Panel emphasises that assessment is the key to developing a framework from which to develop services for rehabilitation after TBI.:

The key position of assessment



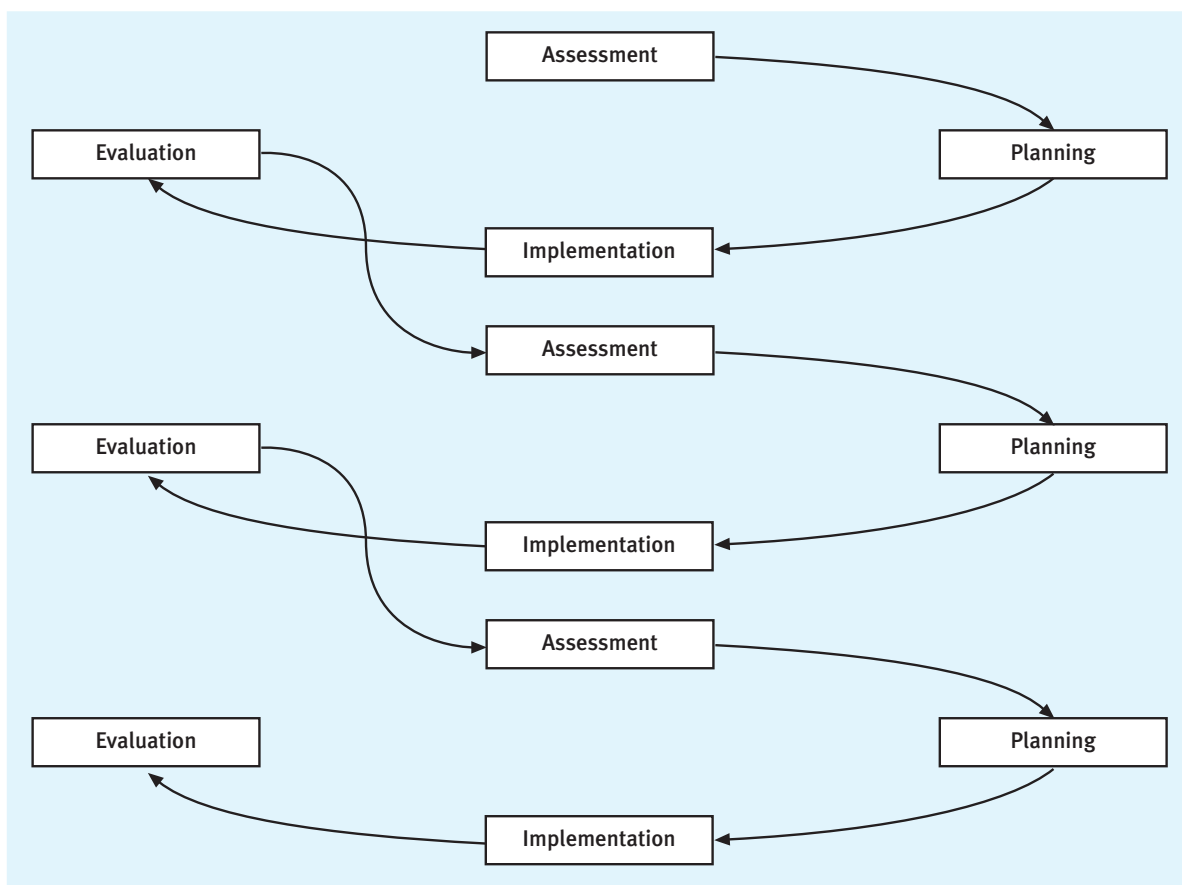
The Panel also emphasises it is essential to:

- address the goals of the individual and their family/whanau
- recognise that rehabilitation should happen in the individual's own community when possible and appropriate
- ensure that services are culturally appropriate
- have rehabilitation interventions that are based on functional goals and objectives
- have services provided by appropriately trained health and education professionals and an interdisciplinary team.

Principles specific to TBI rehabilitation include:

- acknowledging that the consequences of TBI are unique and there is no neat list of what is likely to happen
- assessment that is both general (including gathering baseline data against which change can be measured) and TBI specific (including considering the injury's severity indicators)
- planning based on the individual's actual and assessed abilities and needs
- implementing a plan that includes identifying those responsible for monitoring and evaluating the plan and takes a proactive approach to predictable changes in circumstances
- evaluation that includes questions targeted at the individual and programme levels.

These guidelines describe the principles underpinning the assessment, planning, implementation and monitoring stages of rehabilitation. The following diagram shows the cycle of assessment and re-assessment that will usually be needed:



The guidelines highlight that TBI rehabilitation must be a co-ordinated process and that there is a need to improve this in New Zealand. It also highlights:

- the importance of data gathering and New Zealand-based research
- the necessity to consider issues specific to TBI rehabilitation, including psychiatric consequences, substance abuse and issues of consent.

Recognising the age-specific nature of TBI rehabilitation, the guidelines describe principles for service development that are relevant to children, adolescents and adults.

In keeping with the approach taken by panels developing guidelines internationally, it is recommended that this guideline has a review date of October 2000.

Part One: 1.0

1 Origins

The preparation of these guidelines was motivated by:

- (1) the relatively recent recognition in New Zealand of TBI's seriousness and extent. This is the result of advances in medical care and surgical techniques and increased understanding and knowledge of the diverse consequences of TBI that affect individuals and their families
- (2) observations and anecdotal evidence relating to problems in effectively providing TBI rehabilitation in New Zealand.

The current problems in providing TBI rehabilitation service include:

- limited awareness and understanding of the problems associated with TBI
- service fragmentation
- a large variety of assessment procedures and services for people with TBI and their families
- minimal follow-through and integration of services, allowing little long-term management
- little or no support for carers of people with TBI
- little emphasis on re-integrating people with TBI into the community, including return to education, work and other 'purposeful activities' (see Section 13c)
- an assumption that re-integration will somehow happen on its own
- lack of awareness of TBI's developmental consequences for children
- lack of awareness of the effect of a child with TBI on their families
- limited skills and expertise of some current providers
- inadequate co-ordination of services
- lack of effective and co-ordinated data collection
- lack of integrated policy development among government agencies.

A number of previous initiatives have aimed to support the development of effective TBI rehabilitation services in New Zealand. They include *The silent epidemic* (Head Injury Society and ACC) (Carr L, 1993), *A review of the support needs of people with severe head injuries* (Central Regional Health Authority co-ordinating on behalf of the four RHAs, the Head Injury Society and ACC) and most recently in September 1995 a draft *Standards for Head Injury Services* prepared by ACC.

After extensive community consultation on the ACC draft document, many submissions were received.

These guidelines incorporate those submissions.

2 Purpose

These guidelines aim to:

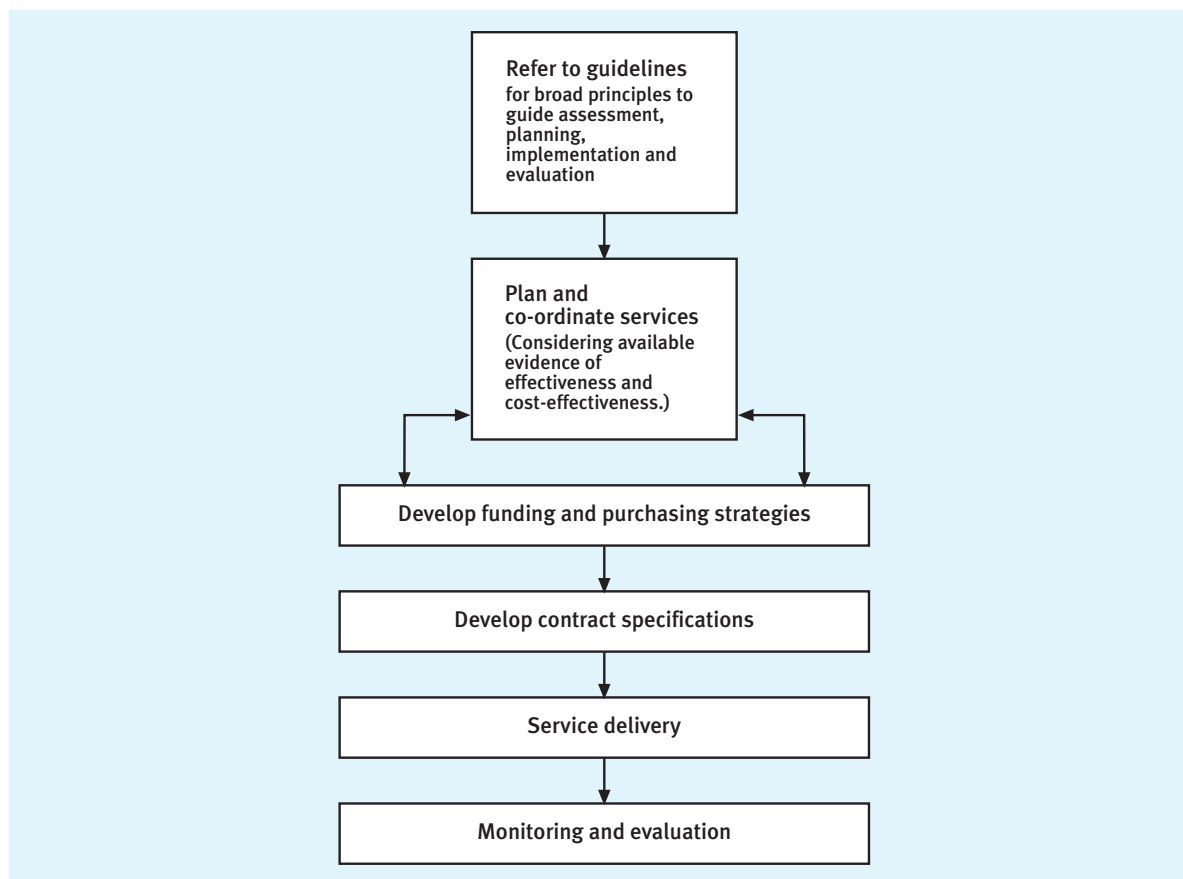
- raise awareness of the need for rehabilitation services for people with TBI
- describe essential features of a TBI rehabilitation service
- provide a basis for improving services
- identify areas where research is needed on TBI rehabilitation in New Zealand.

They are intended to contribute to further understanding and development of TBI rehabilitation services and lead to:

- improved decision making as a result of the support they provide
- continuous improvement in TBI rehabilitation services
- improved results for individuals and their families/whanau
- the most effective use of available resources.

The following diagram illustrates how these guidelines are intended to be used for developing service specifications:

The place of these TBI guidelines in the service development cycle



3 Who are these guidelines for?

While individuals with TBI and their families will find the guidelines useful, they are expected to be mainly used by the funder(s) and providers of TBI rehabilitation services as a framework from which to:

- develop service specifications
- draw up contracts for service.

As services develop it will be possible to promote research and link evidence-based TBI rehabilitation with education, audit and review. This will involve six key groups:

- funders
- providers
- professional organisations
- educational bodies
- consumers
- policy makers.

It follows that the target audience for these guidelines includes, but is not limited to:

- Ministers and Ministries of Health, Education and Justice
- Minister and Department of Social Welfare
- Minister for ACC
- ACC as funder of TBI rehabilitation services
- the Health Funding Authority and regional health divisions
- the National Health Committee
- universities and other tertiary education providers
- professional associations
- current and potential service providers
- community support groups
- individuals and their families.

4 What is traumatic brain injury?

TBI is commonly caused by impacts to the brain in car accidents, falls, assaults and sports. It may happen at the time of the impact or subsequently through mechanisms such as haemorrhage, brain swelling, changes to blood flow, lack of oxygen (via altered blood flow, blood loss and chest injury) or chemical changes in the brain.

Injury severity ranges from very severe (which usually results in a 'vegetative state') to mild injury. Functioning levels, service needs and results will vary according to this severity.

Individuals in a 'vegetative state' may make a recovery over a prolonged period of time, so it is important not to allow serious complications to set in. Large studies have shown it is only in the situation of brain death that there is no prospect of recovery.

A 'severe' classification describes injuries that may require longer-term rehabilitation, typically focusing on developing independent living skills. Many people with severe brain injuries are unable to return to their usual activities. Those who can, do so after a number of years, often in a reduced capacity and/or with supervision.

The level of disability in the 'moderate' brain injury range is highly variable. An individual may take at least six months to return to usual activities, although some research suggests up to two-thirds of people are unable to return to work a year after injury (Winthrop, 1996).

Most brain injury falls into the 'mild' category. People with mild brain injury often receive little or no medical attention and return to usual activities within a few days. However, Carr (1993) notes that 5% to 10% of people with mild brain injury are unable to maintain their pre-injury performance level.

Two parameters are commonly used to define TBI severity:

1. the Glasgow Coma Scale (GCS)
2. Post Traumatic Amnesia (PTA).

The GCS measures eye opening, verbal response and motor response, with scores ranging from 3 to 15 (3 being deepest coma). 'Mild' refers to scores 13 to 15, 'moderate' 9 to 12 and 'severe' below 9. Individuals rating 13 to 15 may develop serious complications in the next 48 hours.

PTA is the time from injury to the recovery of a continuous memory thread (although memory impairment may, and frequently does, remain). 'Mild' commonly refers to less than 24 hours but usually minutes to a few hours, 'moderate' one to six days and 'severe' seven days and over. More than seven days is commonly regarded as extremely severe.

These are arbitrary definitions with considerable overlapping results. Whatever measure is used, increasing injury severity is generally associated with increasingly significant consequences. It is clear that a proportion of those with mild brain injury continue to suffer consequences that significantly influence their ability to function as previously.

Incidence of TBI

International figures suggest a TBI incidence rate of 132 to 430 per 100,000 head of population per year. Figures from acute hospital care in New Zealand (1993) show about 6,000 people with TBI annually, a rate of approximately 180 per 100,000 per year.

However, many more individuals suffer a brain injury than are admitted to hospital. United States data indicate a rate of 618 per 100,000 per year (Sosin et al, 1996). Applied to New Zealand, this rate would indicate more than 30,000 people in New Zealand sustain a mild, moderate or severe brain injury every year.

There is a lack of data on the incidence of TBI in New Zealand. Data collection is needed as improved TBI rehabilitation services must be informed by accurate and reliable information.

Brain injury affects all age groups in a trimodal distribution: children; young adults; and the elderly. Incidence data indicate that males aged 15 to 30 make up the largest group, followed by children under 15.

5 Common consequences

TBI may have a profound impact on all areas of an individual's life. Common consequences include impaired attention and concentration, learning, memory, speed of information processing, communication and other cognitive skills (Prigatano, 1986).

Changes to physical and sensory functions are common. These include hemiparesis, impaired balance and co-ordination, and partial or complete loss of vision, smell and taste. There may also be a decreased ability to function as before in social situations owing to, for example, impulsive behaviour, mood swings, anger outbursts, fatigue and depression², and an impaired ability to 'read' and respond appropriately to social signals.

A slow healing process is common, during which the safety of individuals with TBI may be at risk because of impaired judgement, decreased awareness, poor impulse control and memory dysfunction.

Neither the individual nor the family/whanau is likely to be fully aware of all the consequences or their effects on day-to-day functioning. Some are more obvious than others, particularly impairments and disabilities related to physical and sensory functioning. Others may be masked by the more obvious impairments and/or will begin to emerge over time. It is important to be aware of as many consequences as possible and, with them in mind, include adequate and appropriately timed assessment soon after injury and throughout the rehabilitation process.

Brain injury rehabilitation is complex and challenging. All providers must consider and integrate cognitive, behavioural, communicative, physical, sensory and psychosocial needs when providing services. These complexities must also be considered throughout the rehabilitation process, from the acute setting to life-long support, and through changing life circumstances.

6 Evidence for effectiveness

A literature review was carried out to evaluate the evidence for rehabilitating people with TBI. The review did not aim to examine and assess every piece of relevant work in the field, but to summarise review articles that have evaluated studies of the effectiveness or cost-effectiveness of TBI rehabilitation. The Panel then scrutinised the identified articles. They identified several studies of specific elements of TBI rehabilitation, such as computer-assisted cognitive rehabilitation (Chen, Thomas, et al, 1997). However, these were not included as they did not evaluate the effectiveness of *comprehensive* TBI rehabilitation. For this reason, only three review articles which deal mainly with severe TBI rehabilitation were assessed. The conclusions should be considered within that context.

2 Refer to Appendix 2 for a list of consequences of TBI that may influence recovery.

Evidence for the effectiveness of TBI rehabilitation

Reviews by Cope (1995) and Malec and Basford (1996) included relevant studies of effectiveness up to the end of 1995. These reviews are summarised below and the full appraisals are in Appendix 5. The reviews are not strictly systematic but are comprehensive and consistent summaries of the current state of evidence. Broadly speaking, their conclusions are:

- the weight of current evidence supports rehabilitation for individuals with TBI and suggests it is cost effective
- the current level of evidence supporting the efficacy of rehabilitation programmes is at Grade 3 (non-randomised historical cohort studies and other studies with non-experimental designs such as case-control studies)
- rehabilitation increases independent living, results in a higher rate of return to independent work, training or home-making and a lower level of unemployment
- in most cases, early rehabilitation is more effective than delayed intervention
- no consistent relationship has been shown between treatment outcome and either length of stay or cost.

Evidence for the cost-effectiveness of TBI rehabilitation

The review by McGregor and Pentland (1997) assesses the quality of previous cost-effectiveness studies of TBI. While individual studies demonstrate some economic benefit from TBI rehabilitation, there is a lack of reliable and methodologically sound evidence on its cost effectiveness. However, there is increasing awareness of, and emphasis on, economic efficiency in health care services. As rehabilitation services are relatively high cost, the review provides a timely reminder that future research in this area needs to have a sound methodological base.

It is recommended that providers:

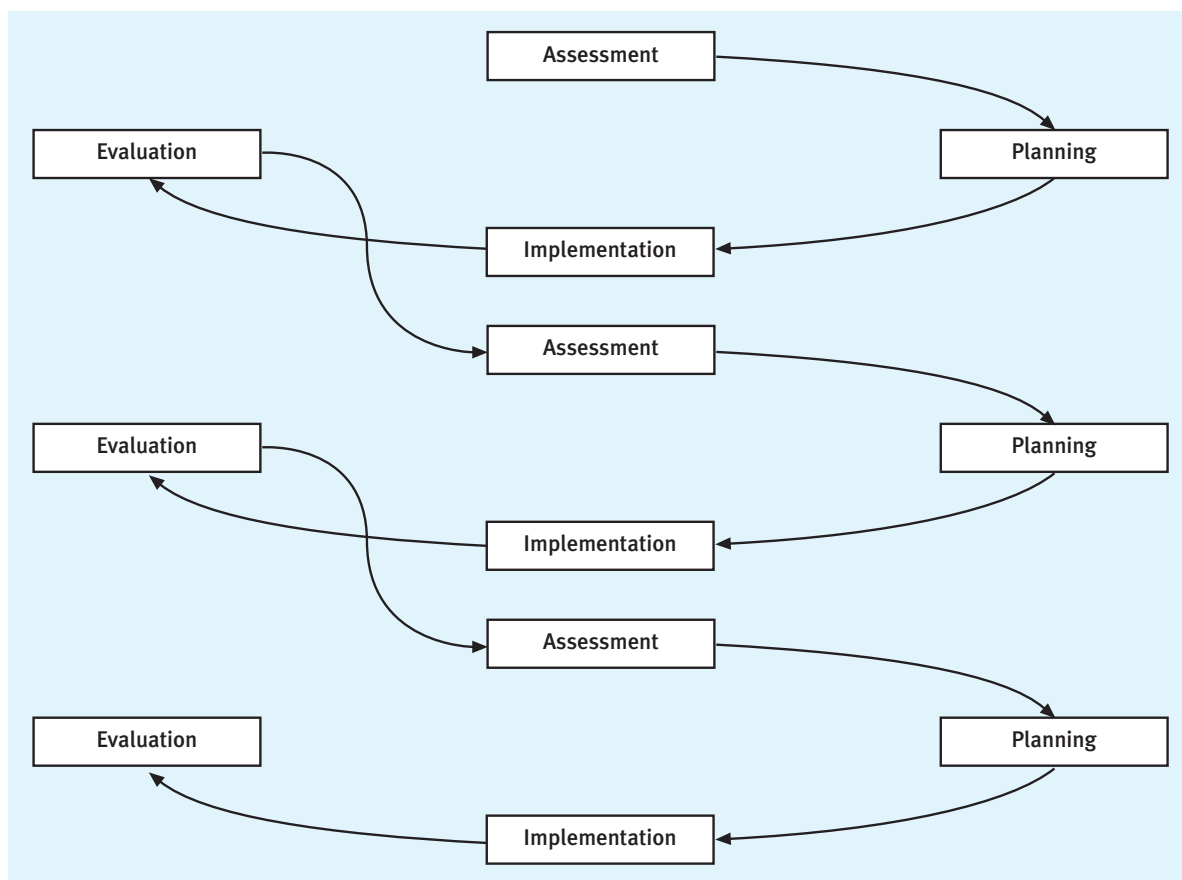
- collaborate with other New Zealand providers to ensure a consistent and co-operative approach to measuring results. Care must be taken when comparing results between service and service types. Results will depend on specific service goals, the level and nature of the impairment/handicap and other factors
- use measures to make direct comparisons with overseas providers to ensure a well established record of outcome measurement
- include measures that show whether planned rehabilitation strategies are actually being carried out.

This will bolster the importance and place of evidence-based practice in TBI rehabilitation in New Zealand.

2.0

Part Two: The rehabilitation process

The process of traumatic brain injury rehabilitation

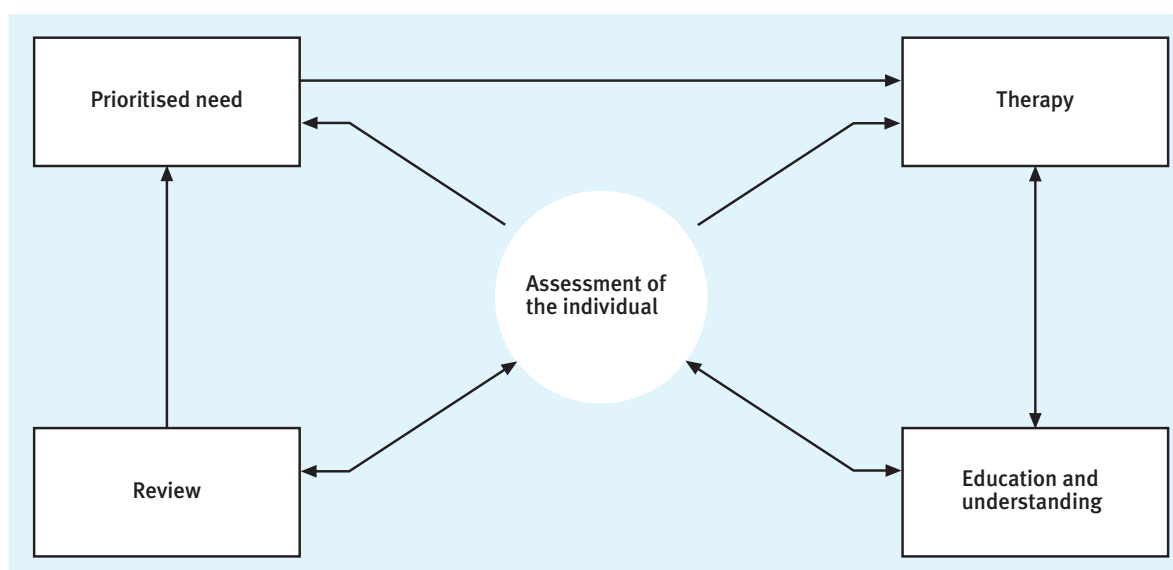


TBI rehabilitation should not be considered a one-off event but a continuous process that manages the changing needs of people with brain injuries and their families. To get the best results service providers and caregivers must take a consistent approach. This requires co-ordination.

TBI rehabilitation aims to:

- minimise disability and handicap
- reduce dependency and, where possible, long-term costs
- enable functional recovery where possible
- introduce effective compensatory techniques if functional recovery is not possible
- maintain and enhance ability.

The key position of assessment



Brain injury affects every individual differently, so rehabilitation must be supported by documentation that clearly identifies the problem and indicates how and when any decision-making will take place in relation to assessment, intervention, monitoring and evaluation. Providers must keep accurate records that can help identify aspects of the environment or the individual's condition that are affecting rehabilitation (positively or negatively).

The individual's special needs will also change according to their responses to rehabilitation, their stage and level of recovery and their interpretation of their TBI and self in everyday life.

Rehabilitation must:

- take place in the individual's own community when possible and appropriate
- address individual and family/whanau goals
- operate in an environment conducive to achieving the best possible results
- be culturally appropriate
- include interventions based on functional outcomes and objectives³
- consider the individual's interpretation of their TBI
- keep abreast of and incorporate developments in the field
- include timely transition and discharge planning
- include intervention with the family and carer as appropriate.

- 3** *The term 'functional' as used here means pertaining to an individual's everyday, real world activities or behaviour. It refers to those skills necessary for an individual to participate (function) in their own daily living, work/play, social, academic, leisure or community life. In this document, 'functional' describes activities or behaviour change that are observable and measurable, and combines three different ideas: effectiveness; relevance; and integration:*
- *Effectiveness* refers to the importance of achieving a result regardless of technical correctness, eg, via compensatory strategies.
 - *Relevance* emphasises the importance of choosing tasks relevant to the individual.
 - *Integration* highlights the notion that activities are integrated events, eg, making a telephone call. This requires the individual to plan, remember, speak and listen, all within one activity.

Rehabilitation has many definitions, but it must be understood as an *approach* to meeting the specific needs of the individual client. So it is possible for effective rehabilitation to take place in a variety of environments – acute hospital wards, specialised rehabilitation units, at home, at school, at work and in the community.

The most appropriate environment depends on the client's needs and preferences at the time. However, rehabilitation is most likely to result in sustainable gains in an environment where the activity takes place and the skills are actually used.

TBI rehabilitation recognises that the injury has left the individual with some aspects of their performance unimpaired. Accordingly, effective TBI rehabilitation must ensure that the individual:

- is provided with the tools and skills to enable them to 'do for themselves' rather than be 'done to'
- has services provided according to their assessed needs
- has access to appropriately trained professionals and providers of non-professional services
- has access to rehabilitation services provided by an interdisciplinary team⁴.

TBI rehabilitation should be managed by a team that may include but not be limited to:

- the individual and:
- family/carer/whanau
- general practitioner
- neuropsychologist
- neuropsychiatrist
- occupational therapist
- physiotherapist
- psychologist (clinical and/or educational)
- registered nurse
- rehabilitation medicine specialist
- social worker
- speech language therapist
- teacher and teacher's aide
- vocational rehabilitation specialist
- work placement specialist.

4 *Refer to Appendix 3 for an explanation of this.*

Individual service providers will often emphasise the need for involving some professional services above, or prior to, others; consequently it is to be expected that their service specifications will reflect their judgement of the best mix of services.

7 The process

TBI rehabilitation services include elements of generic rehabilitation services and some special features. They need to be specific according to:

- special client groups, eg, Maori, children, clients with prior or co-existing conditions, the elderly
- the TBI severity
- the rehabilitation models used
- the programme philosophy
- available funding
- geography
- time since injury
- the individual's age and developmental stage.

At all stages of TBI rehabilitation, providers must ensure that:

- the environment is conducive to meeting the cognitive, communicative, behavioural, physical, social and cultural needs of individuals with TBI
- they consider specific needs related to fatigue levels, rapid cognitive overload and slowed information processing
- they plan for and manage a smooth and timely transition through the phases of care, including ICU/acute neurosurgery, inpatient rehabilitation, outpatient, community and residential care settings
- they liaise with all relevant services
- the environment has appropriate safeguards and mechanisms in place to protect clients who may be a danger to themselves through confusion or wandering, and to protect staff against violent or sexually inappropriate individuals.

Rehabilitation includes preventing, or at least minimising, secondary impairments, disabilities and handicaps⁵. Early assessment and intervention are therefore critical as are uninterrupted monitoring and appropriately timed intervention.

Rehabilitation and related support needs may continue over a lifetime. The specific needs and extent will depend on the injury severity, types of impairment and disability and the context, including changes in circumstances.

Providers must recognise and manage any further problems, such as those associated with a change in life circumstances. In the case of children⁶, rehabilitation needs to recognise and manage problems that may become evident at different developmental stages, and that are not always predictable. It should also consider the roles of the paediatrician, developmental therapist and specialist education services as part of the rehabilitation team.

⁵ Refer to Appendix 1 for an explanation of these three terms.

⁶ Refer to Section 13 (pages 26 to 27) for a more complete account of issues concerning children and adolescents.

Positive results are those that are measurable and meaningful to individuals with TBI and their families. They are most likely to be achieved through a process combining:

- assessment
- planning
- implementing the plan (appropriate service delivery)
- evaluation.

8 Assessment

Assessment underpins the development of a rehabilitation programme. It focuses on what should happen during rehabilitation, including treatment goals based on the individual's assessed areas of difficulty and strengths. This process includes:

- assessing the individual's social environment and supports, including family morbidity
- developmental needs (of children)
- predisposition towards mental illness⁷
- previous substance abuse⁸
- coping strategies.

Rehabilitation assessment's key features include⁹:

- recognising cultural factors and belief systems
- gathering baseline information against which change can be measured
- considering a history of previous TBI (it is now well recognised that the effects of even minor TBI are cumulative)
- considering any post- and pre-injury assessments where relevant
- assessing pre-morbid function¹⁰
- considering the severity indicators of the initial injury
- distinguishing between current impairments, disabilities and handicaps (refer to Appendix 1)
- information about all the usual consequences of TBI (refer to Appendix 2)
- including ways to maximise the chance of success
- multiple information sources (significant others, family/whanau, past medical files and work mates may need to be involved to complete the picture)
- ethically sound, valid and reliable methods. Assessment processes must not rely on a single method
- including the parent or caregiver as an active participant in the assessment process for children and adolescents.

⁷ Refer also to Section 14 on Psychiatric Consequences.

⁸ Refer also to Section 15 on Substance Abuse.

⁹ Refer to Moore, TJ (1995) p.29, for further points for rehabilitation service providers about the assessment of need.

¹⁰ Relates to all aspects of function before the identified TBI. These include previous illnesses, operations, TBIs, other injuries, personality and temperament, intellectual and cognitive function, interests, personal goals, aspirations and beliefs.

Note that the validity and usefulness of an assessment can be influenced by whether the assessment:

- takes place in an environment that is the individual's usual environment¹¹
- addresses real life tasks.

Other factors affect an assessment:

- diminished self-awareness, which may result in over-estimating performance when an individual with TBI self-reports
- communication disorder, which may be (a) deceptive and not readily apparent or (b) so severe it interferes with the assessment process
- the individual's social roles and pre-injury educational achievements
- the re-assessment timing (different parameters need to be assessed at different stages)
- the level of fatigue, which will not only be associated with a disturbance of all cognitive and other functions but will disrupt behaviour and may also lower the seizure threshold
- the associated effects of intercurrent illness and medications.

The Panel draws attention to three additional factors:

1. Brain imaging¹² is rarely a useful tool after the acute phase of management. It may be needed where there are indications of a late complication, but it gives little or no information about functional capacity or rehabilitation needs.
2. Individuals (including children) with spinal injury and multi trauma need to be adequately assessed for brain injury.
3. People admitted to hospital or accident and emergency clinics in an alcohol (or other drug) induced coma need to be adequately assessed for TBI. A diagnosis of TBI may be missed because of more obvious factors.

People admitted to hospital or accident and emergency clinics:

- in alcohol-induced coma
- with drug overdose
- with spinal injury or multi trauma
- with confusion or disorientation
- with reported or suspected loss of consciousness
- with whiplash

need to be adequately assessed for brain injury.

¹¹ *It is important that assessment take place in the usual environment, wherever possible, and this is particularly important when assessing children with TBI. It may be appropriate for the assessment to be carried out in several environments.*

¹² *Examples of brain imaging are CT (computerised tomography), MRI (magnetic resonance imaging) and SPECT (single photon emission computerised tomography).*

9 Planning

The main components of planning for rehabilitation after TBI are goal setting and service planning. The following two sections comment on implementation and evaluation, which must be considered when undertaking planning.

Planning must consider outcomes on at least two levels:

- 'global outcomes'
- 'specific intervention outcomes'.

A 'global outcome' is the predicted result in its most general form. It provides direction for the overall management of rehabilitation. Goals of global outcomes include 'living alone' or 'return to work'.

A 'specific intervention outcome' refers to the individual goals expected to be achieved through a specific plan covering a specific time period. These may be medical, functional, psychological, social, educational or vocational.

In line with other medical insurers (nationally and internationally) ACC is increasingly requiring service providers to submit rehabilitation plans in the form of functional¹³ or vocational outcomes.

Rehabilitation planning is a dynamic process that involves integrating the information obtained through assessment and, with the individual and their family/whanau, identifying realistic and valuable rehabilitation results, goals and objectives (ie, steps towards those goals).

Objectives must be:

- measurable
- achievable
- observable
- timed in relevant ways
- timebound.

Rehabilitation planning also includes considering how to achieve those objectives and the measures needed to assess progress. This should recognise the importance and validity of having access to various types of services and service delivery methods.

Note that interventions must be prioritised, as not all problems and rehabilitation goals are equal. Some may not require any specific attention at a given time if they are not going to affect the global outcome.

Many aspects of assessment feed into the planning, implementation and evaluation processes. The developmental level of children with TBI must also be part of the plan. Appropriate assessment is therefore vital to effective intervention.

Planning must be seen as a dynamic and continuous process rather than a one-off event.

¹³ Refer to footnote 3, page 15 for an explanation of 'functional'.

Effective TBI rehabilitation plans must at least:

- identify the level(s) of the apparent impairment (where possible), disability or handicap being targeted and measured
- be based on the actual and assessed abilities and needs of the individual
- address the specific needs of the family and other significant relationships in the person's life
- specify intended short-, medium- and long-term results and relevant measures where possible
- consider and make best use of available resources
- lead to realistic and achievable results, considering pre-morbid functioning
- focus on the functions that have meaning for the person and their family/whanau
- identify all available strategies and possible interventions
- identify those responsible for implementing, monitoring and evaluating the plan
- specify timeframes, including review dates
- show proactive ways to deal with predictable changes in circumstances

Those involved must be flexible and diligent in working to the plan, to identify and respond to any unexpected changes in circumstances.

10 Implementation

Comprehensive assessment and careful planning will direct the implementation.

- Needs (and therefore services) will be prioritised.
- Strategies will be changed or refined so that results are consistent with continually assessed needs and rehabilitation plans.

In short, implementation is the consistent and vigilant actioning of a well considered and dynamic plan.

Effective implementation includes:

- focusing on the individual and their family/whanau
- using a sound and carefully considered practice model, based on research where possible
- flexibility to respond to changing needs
- continually refining strategies/techniques based on monitoring
- continually co-ordinating all service components
- involving and educating all key support people wherever possible and appropriate
- using age-appropriate techniques and environments
- using an appropriate mix of therapy disciplines
- employing appropriately trained personnel
- taking a consistent approach
- making appropriate and timely use of compensatory strategies including environmental adaptations
- using interventions and styles that are non-aversive and ethically sound.

11 Evaluation

Evaluation is as important a part of the rehabilitation process as assessment and planning. It ensures that implementation is consistent with the plan and that, where necessary, plans are altered to meet changing needs or circumstances.

The evaluation process must be aligned with assessment and planning at two levels:

- the individual level
- the programme level.

Evaluation at the individual level does not need sophisticated measurement tools or processes, but there has to be commitment to ensure that it happens.

Key questions for the individual level evaluation:

- Were the outcome targets met for this person?
- If not, why not? (The reasons may help other clients.)
- If so, why? What worked?

Evaluation at the programme level depends on a number of factors, including funder requirements, provider goals and service structure.

Key questions for the programme level evaluation:

- Are the overall results of the programme consistent with the expectations of:
 - the service's consumers (individuals/families/carers)
 - the providers
 - the funders?
- Was the programme carried out as specified?
- How do the results of this programme compare with those of similar programmes (or similar clients in a different type of programme) both locally and overseas?
- Do the results justify the costs (for consumers, providers, funders)?
- Can we improve our service to better meet the needs of consumers and funders? How?
- Can we improve the efficiency with which we provide the service without compromising results?
- What is the service's case-mix?
- What are the benefits or limitations of the programme for enhancing interdependence?¹⁴

- 14** *Some programmes may evaluate poorly because people with severe TBI generally have a poorer rehabilitation outcome than other individuals whatever the treatment, so that the outcomes of a programme with a relatively large percentage of people with severe TBI are likely to be generally poorer than those for a programme dealing mainly with individuals with mild or moderate TBI, independent of programme content or quality.*

Some additional questions:

- How does the service measure resource use? This will vary with the type of service, eg, length of stay, hours of contact time, numbers of visits in the community.
- How does the service measure consumer and funder satisfaction?
- How does the service measure programme implementation?
- How does the service control outcome measures for factors that affect outcome, eg, pre-morbid status, drug abuse, other medical/surgical or psychiatric conditions, family/whanau circumstances? As a minimum this information needs to be collected (see Section 8, Assessment), although it is acknowledged that gathering such information is usually difficult.

3.0

Part Three: Key issues

TBI happens within the wider context of an individual's life. Providers need to carefully consider issues related to family, age and age-related activity, psychiatric consequences and substance abuse.

12 Effects on the family

Families play a critical role in the achievements of individuals with TBI, so it is important that they are aware of the risk of many negative effects, and where they can get support if they need it. A high proportion of families become key carers and many experience long-term burden and strain in the absence of appropriate and adequate support.

Effective rehabilitation also requires addressing the issues of grief, guilt, blame and a changed parenting or spouse role. There are many possible sources of stress that may affect the family's or whanau's ability to involve themselves in the rehabilitation process. They include:

- low income
- split families
- both parents in the paid workforce
- distance from rehabilitation services
- coping strategies
- available support structures.

The following actions are recommended:

- assess the affect of TBI on the family/whanau, including siblings
- support families
- be aware of the effects of psychological distress, including Post Traumatic Stress Disorder (PTSD), depression and substance abuse on the individual and family members.

The large amount of descriptive and controlled research on the effect of TBI on the family (Brooks, 1991) has produced a remarkably consistent picture.

In the absence of appropriate support, the effects are largely negative (Smith and Godfrey, 1995). Inappropriate support results from a reaction to the adverse cognitive and personality changes experienced by the injured individual, and to their inability to fulfil their pre-injury social roles (Carr, 1993; Lezak, 1978).

This reaction typically involves burden on the part of relatives, which worsens with time (Livingston, Brooks and Bonds, 1985; Oddy, Humphrey and Uttley, 1978; Peters et al, 1990) and is still evident a decade or more after injury (Thomsen, 1984).

Support for families should address the wider family's needs as they attempt to cope with the challenges of head injury (Conoley and Sheridan, 1996). It has been found that siblings of brain-injured children are themselves at greater risk of developing behavioural problems (Bragg, Klockars and Berninger, 1992).

13 Return to school and work

Some challenging aspects to school or work re-entry are:

- the person with TBI is brought face to face with their limitations. Sensitivity is needed by staff, rehabilitation personnel and peers
- lack of teacher/employer understanding the implications of TBI, especially the subtle effects, eg, discrepancies between the individual's ability to *describe* a series of actions and actually *perform* them
- difficulties with:
 - forming concepts
 - organising and screening sensory information
 - attention, memory and new learning
 - flexible thinking
- any prior behavioural problems almost always remain after TBI
- significantly increased risk of seizure
- fatigue and frequent yawning
- headaches
- disinhibition
- inability to respond appropriately to social feedback.

Planning for re-entry will include considering:

- reduced work load
- rescheduled work load (doing the most taxing tasks early in the day, when energy is usually at its peak)
- access to a 'quiet' room
- regular and as-required rest breaks
- circle of informed friends/student buddies
- adaptations, eg, writer/note-taker, exams out of noisy environment, extra time
- organisational strategies, eg, diary.

Other issues to consider are:

- providing training, monitoring and appropriate use of teacher aides/job coach
- the school's/workplace's flexibility to accommodate alternative/adapted programmes, eg, correspondence education, longer rest breaks
- the availability of a range of rehabilitation options, including residential programmes.

(a) Early childhood and children of school age

Although the child's injury may have been 'mild', providers and families should stimulate language and learning through play to avoid losing valuable developmental time.

Additional recommendations for TBI rehabilitation in early childhood:

- a family/whanau focus to planning and evaluation
- recognition that interventions are most effective when carried out by those with whom the child has ongoing significant relationships (eg, family)
- enrolment in appropriate early childhood education setting, and providing support, including:
 - educating teaching staff
 - appropriately skilled, educated and monitored early intervention personnel
 - an Individualised Developmental Plan that emphasises the inclusion of the individual in activities of their peers, while accommodating individual needs
- preparation, liaison and education with the school before entry
- assessments must be age and developmentally appropriate
- a child with TBI should always be considered in the context of their family unit (including siblings).

The differences between an injury to a developing brain and that to an adult brain have only recently been recognised. It was previously thought that children's brains had the developmental capacity to compensate for damage. It is more accurate to say that brain damage interferes with the normal developmental process.

It is now acknowledged that even so-called 'mild' injuries to the immature brain may not show up as difficulties until many years later. For example, damage to the frontal lobes may not be apparent until the individual is faced with the increasingly complex demands of higher-order functions.

Motor functions are often the first to improve. There is often greater functionality than expected, but this may be misleading as an indicator of overall recovery. In general, social communication improves rapidly, but complex language skills, such as finding words, understanding complex instructions and sequencing may continue to be problematic (Ylvisaker, 1985). For example, recovering higher-order cognitive skills, memory and attention may be slower, and may happen to a lesser degree, than motor functions.

Children with TBI may reach a result within the normal range when tested soon after injury. However, if tests are done at regular intervals post-injury, children with TBI as a group will not perform as well as control subjects, and begin to fall behind their peers (Ylvisaker, 1985). This change in acquiring developmental skills has significant implications for children, their families and teachers.

All family/whanau members are affected by the TBI. The young person, like anyone with TBI, may look no different after the injury, so it is particularly hard for families to accept the range and severity of disabilities that may emerge. They may not even associate the difficulties with the earlier injury.

Particular problems arise when children's injuries result from abuse. The injury typically occurs at a very early stage when the brain is rapidly developing. In these cases the family may not be a safe place for the child or an appropriate rehabilitation environment.

TBI rehabilitation must consider the inter-relatedness of home, school and the wider community.

Return to school after TBI requires careful management and planning, and should be gradual and monitored.

It is essential to educate teaching staff and peers about the effects of TBI and develop strategies to help the student cope in the educational setting *before* they return to school. Close liaison between the acute rehabilitation setting and staff, family and school-based support staff is vital to ensuring a smooth and managed transition for the student.

The overall aim is to help students achieve the best possible learning and inclusion in their school and the wider community.

Features of the school context well suited to the student's rehabilitation include:

- regular, structured programmes
- systematic building on previous skills
- inclusion in purposeful activities with peers
- social interaction with peers.

These factors may limit the effectiveness of TBI rehabilitation for children and adolescents:

- pre-existing conditions, such as learning difficulty, developmental delay, medical conditions and treatments leading to a markedly increased risk
- previous TBI
- dysfunctional family
- risk-taking behaviours, such as reckless driving, that may mask suicide attempts
- drug, alcohol and solvent abuse
- ADHD (attention deficit and hyperactivity disorder)
- parenting style (a very 'open' style may condone a higher risk level than a more structured approach)
- limited coping strategies
- poor maternal health.

(b) Adolescents

In addition to the above considerations for school-aged students, the following may affect adolescents' successful inclusion and rehabilitation:

- the balance between desire for independence and safety concerns
- sexuality
- heightened difficulties with relationships/social interactions
- exacerbation of typical adolescent problems, eg, mood swings, anger management
- a higher risk of suicide attempts
- difficulty in achieving adolescent developmental milestones through restricted participation in usual life experiences access to respite for their families
- managing the transition to work.

(c) Adults

This section provides some comments and recommendations on adults who are students and/or in employment at the time of their TBI.

Return to study

Returning to an educational institute after a TBI presents similar challenges for an adult to those faced by the brain-injured child returning to school. Some key elements of a successful return to education are:

- identifying an appropriate course. This often deviates from what was planned or previously engaged in. Studies must lead to realistic employment outcomes
- educating tertiary educators so that the student receives special considerations during the semester and at exam times
- helping develop specific compensatory strategies to minimise the effects of lowered energy levels and deficits in attention/ concentration, memory, information processing and the ability to complete tasks
- providing technological assistance and training. Examples include dictaphones, electronic dictionaries, computer hardware and software
- access to disability/learning support and student health facilities, together with appropriately trained staff in each of these areas.

Few tertiary students with a moderate or severe TBI are able to resume full-time courses of academic study in the first 12 to 24 months after an injury.

Appropriately selected courses may improve rehabilitation by focusing on functional abilities and opportunities to develop foundation skills such as planning, organisation, understanding the written word and expressing thoughts and understanding in writing. These, together with a focus on social skill development, may increase the chances of the person with TBI being employed at a later stage.

Return to work

Finding work may be very difficult for individuals with TBI. Cognitive and psychosocial deficits may result in poor performance in a job interview. They may be unable to respond to questions quickly or appropriately (Gronwall et al, 1993). Impaired social skills may create a negative impression on potential employers, and an individual's own lack of self awareness may prevent them from assessing the ways they present to others (Winthrop, 1996).

The goal for every individual with a vocational rehabilitation programme is effective job placement at the highest possible level.

Changes in the individual's abilities (decreased information processing speeds, communication disorder, slowed reaction times, fatigue, impaired judgement and balance and co-ordination disturbances) may affect their ability to perform work tasks and to perform them safely. They may cause the individual to be less efficient and less able to cope with change and less likely to be able to resume responsibility.

The following factors should be considered for individuals with TBI about to undergo vocational rehabilitation:

- pre-injury skills and abilities
- the work and family environment and whether it is supportive enough
- the expectations of the individuals and their families
- the need for vocational rehabilitation
- the individual's motivation to participate in a vocational rehabilitation programme
- the awareness and level of acceptance of the individual and their family that they may need to be re-deployed or placed in an alternative organisation and/or occupation
- the impact of fatigue and reduced activity tolerance
- the complexity of impairment involving physical, cognitive, psychological and social functioning¹⁵
- the relatively long-term recovery from TBI.

In a study in the United States, individuals with TBI required an average 18 weeks of time-limited job coaching services to achieve job stabilisation, with a mean time of 13.6 hours per week. The same study also found enormous variability in the amount and type of services required to promote long-term employment success for individuals with TBI (Wehman, Kregel, et al, 1994).

Raising awareness of and getting commitment to supported employment among employers is a key starting point in vocational rehabilitation, as the individual may need supported employment for their remaining working life.

Once the occupation or range of occupations for which the individual is best suited has been identified, the level of support can be established.

On- and off-site supports include:

- informed supervision (ie, on-site presence of a supervisor who knows how the consequences of TBI affect the worker's ability to do their job duties successfully)
- transport (to and from the workplace with a suitable vehicle, and within the workplace)
- job coaching
- counselling (eg, on-the-job behavioural counselling)
- job engineering
- job restructuring
- alternative work schedules (eg, gradual re-entry, flexible time, permanent part time)
- employer education
- job modification
- co-worker acceptance.

(Tooman, Revell and Melia, 1987)

15 *These include memory and the ability to learn, plan and carry out tasks using compensatory strategies if necessary, receive and respond to feedback, adapt behaviour to the context, problem solve, reason, judge and seek assistance appropriately.*

A study involving individuals with TBI completing a job placement form after having been employed for 30 days, and with follow-up every six months from the start date of the work re-entry programme, showed an overall retention rate of 71% (Abrams and Haffey, 1991). This rate was twice that for individuals receiving no vocational rehabilitation.

The likely benefit of vocational rehabilitation is strongest when combined with supported employment involving a job coach, an interdisciplinary team and appropriate on- and off-site support (Hall and Cope, 1995).

Purposeful activity

Returning to paid employment or study after TBI may not be an option for all individuals in the short or long term. It is therefore vital to consider all activities that the individual and their families identify as important and meaningful in their lives.

'Purposeful activities' will be unique to each individual. They should be identified as part of the assessment and incorporated where appropriate in the overall rehabilitation plan. They may include (but are not limited to) ongoing education, recreation, leisure and other tasks the individual undertakes during their life.

If it is necessary to help the individual develop a new range of activities, this should be done in close collaboration with them and their family to ensure the activities have meaning and a sense of purpose for the individual.

Driving

A individual's ability to resume driving will depend on the extent of their initial injuries and the degree of recovery. A person sustaining a severe brain injury with substantive cognitive, physical and sensory impairment is unlikely to resume driving.

Assessing fitness to resume driving after TBI is not easy. The consequences likely to affect an individual's ability to drive include:

- cognitive impairments such as reduced attention levels, fatigue and reduced speed of information processing
- physical and sensory changes such as hemiparesis, impaired balance and co-ordination and partial or complete loss of vision.

The individual needs to be very carefully assessed if they are considering resuming driving.

14 Psychiatric consequences

Psychiatric disorder is common after TBI, and the individual may have mood and personality changes as well as TBI consequences.

The symptoms may look similar, eg, fatigue may mimic irritability of mood disorder, but the impairment is different. Consequently the standard treatments for psychiatric diagnosis may be ineffective – for example, the individual may be hypersensitive to medication. It is important that the diagnosis is made by a person who understands both TBI and psychiatry.

Emotional deficits are difficult to identify and quantify, yet are integral to interpersonal communication and social re-integration.

Refer to page 43 and Appendix 6 for a more detailed list of psychiatric consequences of TBI.

15 Substance abuse¹⁶

International studies have suggested that up to two-thirds of individuals who are involved in TBI rehabilitation programmes have substance abuse difficulties. There is a strong suggestion that substance abuse problems are significant within the high-risk profile of males over 30 who:

- have low educational achievement
- are of lower socio-economic status
- were intoxicated at the time of injury (Corrigan, 1996).

An essential part of any assessment process is a comprehensive history of alcohol and substance abuse, leading to goal setting that minimises future abuse.

Substance abuse/disorder may be the most common co-morbid problem associated with TBI, and when present must also be the focus of treatment. Substance abuse (either non-prescribed drugs or alcohol) affects all areas of human function.

In New Zealand, the common drugs of abuse are alcohol and marijuana.

If alcohol/drugs are involved in the TBI, it is likely they were a problem before the injury.

Acute management issues that should be considered include:

- behaviours after intoxication are often similar to those after a TBI, so TBI is commonly not diagnosed
- withdrawal syndromes are also a cause of agitation
- agitation is more common in those with substance abuse problems, beyond the withdrawal period
- drug-drug interactions should always be considered.

¹⁶ *A guideline for managing substance abuse by primary health professionals (including but not limited to general practitioners) is currently being developed by the National Health Committee.*

Other features of substance abuse include:

- those intoxicated before TBI have lower cognitive status later
- TBI is associated with a reduced tolerance to alcohol and marijuana
- subsequent deterioration from a post-injury baseline may be, and frequently is, the result of substance abuse
- the inter-relationship between TBI, alcohol use/abuse and criminality/arrest.

Substance abuse leads to an associated negative effect on any rehabilitation process. It is traditionally an extremely difficult area in which to change attitudes and behaviour.

16 Consent

Rights

The rights of the individual with a disability are supported by a number of instruments, including:

- the Education Act (1989)
- the Education Amendment Act (1991)
- the Health and Disabilities Services Act (1993)
- the Human Rights Act (1993)
- the Mental Health (Compulsory Assessment and Treatment) Act (1992)
- the New Zealand Bill of Rights Act (1990)
- the Privacy Act (1993)
- the United Nations Convention on the Rights of the Child
- the United Nations Standard Rules on the Equalisation of Opportunities for People with Disabilities (4 March 1994).

Rehabilitating individuals with TBI will reflect the following essential human rights:

- social valorisation – the right to respect as a unique and useful contributor within society, and to be accorded dignity and respect for disability experience
- the right to be part of the community of choice, including the right to be educated alongside peers in ways appropriate for age, culture, gender and individual needs
- the right to respect for individual family cultural identity. This includes religious and ethnic cultures and deaf and other disability cultures. There is a risk of a lack of cultural safety for Maori, which means potential harm to an individual and their whanau when there is insufficient recognition of their values and belief systems (Kahu Pounamu, 1996)
- the right to information and support in the individual's primary means of communication, ie: speech in the language of the family; sign language or sign system; augmentative or facilitative communication system
- the right of access to any information collected in relation to the individual and family/whanau
- the right to responsive and consistent services provided in the least intrusive way possible, preserving the individual and family dignity and privacy
- the right to an accurate identification of individual needs that is not influenced by the availability of services or resources.

Service providers are responsible for ensuring respect for the philosophies, values and cultures of all individuals with TBI, their families and whanau. This includes effective, respectful communication with all concerned, which may require a range of supports such as language translation or augmentative communication systems, including signing and assistive technology.

Right to refuse treatment

After all plans and interventions have been effectively discussed, the individual with a TBI may still not wish to participate in the recommended rehabilitation. It is their right to refuse an intervention, or to select specific programmes. Such refusal will not prejudice other interventions being offered.

In some circumstances, the individual will be required to undergo treatment under the Accident Rehabilitation and Compensation Insurance Act 1992. However, such requirements must be reasonable.

Informed consent

The Health and Disability Commissioner's 'Code of Health and Disability Services Consumers' Rights', in particular Rights 6 and 7¹⁷, sets out the rights of the reasonable and competent consumer to be fully informed in order to make an informed choice and give informed consent.

Children can generally be considered to have the same rights as adults and the same obligations apply on creating optimal conditions for them to give informed consent. There are also issues relating to a child's competencies and vulnerabilities (Morrow and Richards, 1996).

17 Refer to Appendix 4

4.0

Part Four: References

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Appendix 1

Understanding impairment, disability and handicap

These concepts are crucial to understanding the breadth of rehabilitation and how different perspectives on 'where the problem is' can have a significant effect on the way a client is treated by medical staff, other health professionals, family and others. One of the reasons rehabilitation has been a 'poor cousin' of medicine is that its focus has been away from the traditional areas of pathology, diseases and 'cures' and *towards* the needs of the client and their interaction with their own environment. Expressing this different focus has always been rather difficult, allowing medical professionals and funding bodies to ignore it.

The World Health Organization (WHO) has developed a model that expresses the different aspects of 'health' from the individual's point of view: the International Classification of Impairments, Disabilities and Handicaps (ICIDH).

The model uses four categories to describe disturbances in health. A lot has been written that suggests this might be too simplistic, but it is a good place to start.

Impairment

This is a *loss or abnormality of psychological, physiological or anatomical structure or function*. Impairments are disturbances at the level of the organ that includes defects, loss of limb, organ or other body structure as well as defects or loss of mental function. Examples are a 50% loss of high frequency from industrial noise exposure, weakness in one leg after a stroke, reduced movement in the wrist from arthritis.

Disability

This is any *restriction or lack* (resulting from an impairment) *of ability to perform an activity* in the manner or within the range considered normal for a human being. Disabilities are disturbances in function or activity at the level of the person, caused by an impairment. Examples of functional limitations include difficulty reading, speaking, moving, climbing stairs, grasping and reaching. Examples of basic activity restrictions include dressing, bathing/washing, feeding oneself, toileting, transferring to a bed or chair.

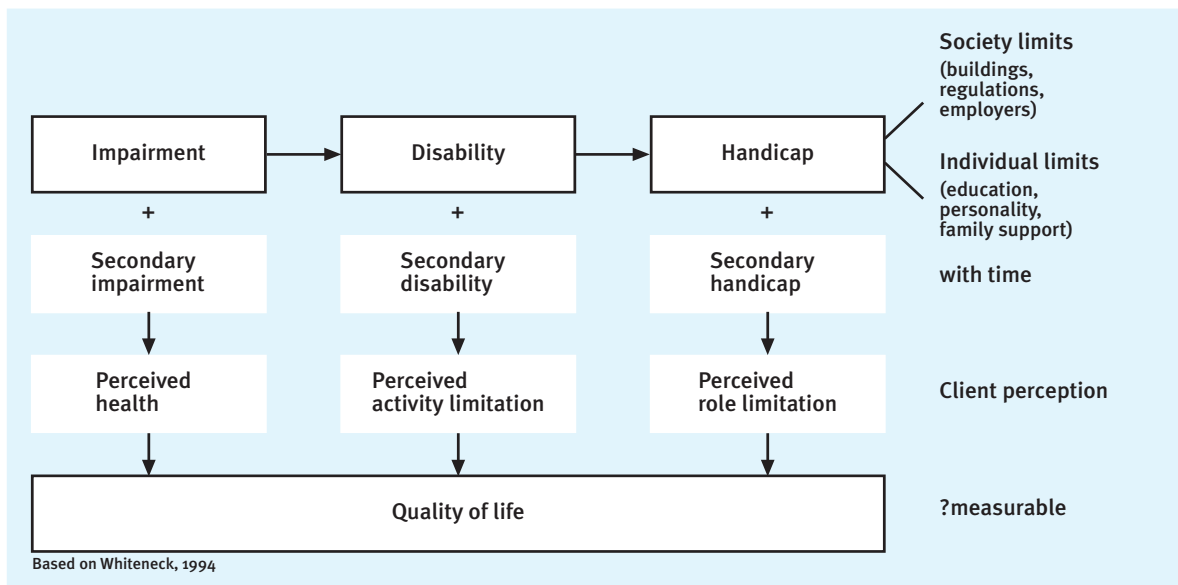
Handicap

This is more difficult to explain. It is usually described as a **disadvantage** for a given individual, resulting from an impairment or a disability that limits or prevents the fulfilment of a role that is normal for that individual.

Handicaps describe restrictive circumstances or disadvantages in social and economic roles. Examples of limitations include physical independence, main occupation (includes home, school and work), mobility, social integration and economic self-sufficiency. Examples of handicaps include unemployment, social isolation, being bedridden or home-bound, unable to use public transport. In this context, unemployment is not a handicap in itself, unless the unemployment is a consequence of an impairment or disability.

Disablement and therefore rehabilitation may be lifelong

Consider the scheme in the figure below. Not only may the considerations of impairment, disability and handicap be influenced by different disease and personal factors, but also the effect of time. Examples of secondary impairments are contractures developing at an elbow in someone with a severe stroke or head injury. A secondary disability related to this may be worsening ability to dress or wash owing to the contracture. Secondary handicaps can arise for a variety of reasons; the loss of a local bus service may severely disadvantage an individual with limited mobility and insufficient financial resources to afford taxis.



Updated ICDH imminent

In 1993, in response to increasing criticism, the ICDH Collaborating Centres around the world began reviewing the 1980 ICDH. A second draft has recently been made available for comment with a formal release of the new ICDH due in 1999.

The new draft maintains three dimensions but alters the terminology. ‘Impairment’ remains unchanged but the term ‘disability’ has been replaced by the neutral term ‘activity’, and ‘handicap’ has been replaced by ‘participation’.

Hence:

- activity is the nature and extent of functioning at the level of the person. Activities may be limited in nature, duration and quality
- participation is the nature and extent of a person's involvement in life situations in relation to impairments, activities, health conditions and contextual factors.

The current draft is available for viewing on the Internet at <http://www.who.ch/programmes/mnh/mnh/ems/icidad.htm>

Appendix 2

Consequences that may influence recovery

Cognitive

- Attention disturbed
 - Fixing
 - Sustaining
 - Divided
 - Alternating
 - Volume of attention (ie, amount that can be held at one time)
- Confabulation – unconsciously filling memory gaps with false information
- Apathetic syndrome – disturbance in:
 - Motivation
 - Initiation
 - Drive
- Egocentricity
- Slowed information processing
- Reaching cognitive overload more readily
- Communication disturbance
 - Inappropriate comments
 - Being argumentative
- Language disturbance
 - Word finding
 - Ordering of speech sounds, syllables, words
 - Processing of auditory or visual input
- Memory impairment
- Metacognitive disturbance – eg:
 - Reduced self reflection and therefore self awareness
 - Inability to use one's experience to learn
- Sequencing disturbance
- Planning/goal setting/anticipation difficulty
- Difficulty shifting mental set
- Social awareness disturbance
- Social judgement disturbance

Behavioural

- Frustration tolerance reduced
- Impulse control reduced

- Libido altered (usually reduced)
- Disinhibition
- Aggression
- Social avoidance

Emotional

- Anxiety disorders
 - Post-traumatic stress disorder
 - Generalised anxiety disorder
 - Obsessive compulsive disorder
 - Panic attacks
 - Social phobia
- Depression
 - Adjustment disorder
 - Major depressive disorder
- Disturbance in control of amplitude (amount) of mood
- Inappropriate mood
- Catastrophic reactions
- Anger

Psychosis

- Paranoid disorder
- Schizophreniform disorder
- Hallucinations

Somatic

- Balance disturbance
- Fatiguability
- Hearing
- Tinnitus
- Photophobia (intolerance of light)
- Phonophobia (intolerance of noise)
- Primitive reflexes
- Disturbed sleep/wake cycle
- Swallowing disturbance
- Temperature tolerance disturbed (especially heat)
- Visual disturbance
 - Depth judgement
 - Field disturbance
- Vertigo
- Speech disturbance
 - Slurring
 - Sound sequence problems
- Voice disorder
 - Difficulty whispering
 - Difficulty controlling volume
- Movement planning disturbance
- Impaired sensory processing (ie, perceiving, but not making sense fully of the perception)

Appendix 3

Glossary

Family ‘support’

Support here refers to a wide range of strategies designed to minimise the level of stress experienced by families (see Smith and Godfrey, 1995, for a description of strategies). They aim to enhance family members’ perceptions of their ability to cope with problems they face, to encourage family members’ use of informal and formal sources of social support, and to teach and/or foster the use of effective coping skills (see Godfrey, Knight and Partridge 1996, for a description of this model).

Interdisciplinary team approach

This refers to an approach towards a common goal by professionals from different disciplines. However, team members not only require the skills of their discipline but must also be able to contribute to a group effort on behalf of the client.

The team’s programme is synergistic, producing more than each discipline could provide individually. The interdisciplinary team concept provides a means for client diagnosis, goal setting, problem solving and treatment in a co-ordinated, non-fragmented, cost-effective way by specialists representing several disciplines that will produce a positive rehabilitation result that would not be possible without this structure.

Multidisciplinary approach

This refers to specially oriented efforts that represent the sum of each discipline, providing its own unique activity. The efforts are discipline oriented – to operate in a multidisciplinary setting one needs to know the skill of one’s own discipline.

Pathology

This is the ‘disease process’ affecting organs in the body, for example, the demyelinating plaques in multiple sclerosis or the nerve entrapment with a herniated (‘slipped’) disc. You usually need a sample of the tissue (biopsy) or special imaging to ‘see’ the pathology.

Appendix 4

The Code of Health and Disability Services Consumers' Rights

(ref Health and Disability Commissioner, 1996)

Right 6

Right to be fully informed

- (1) Every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, would expect to receive, including –
 - (a) An explanation of his or her condition; and
 - (b) An explanation of the options available, including an assessment of the expected risks, side effects, benefits and costs of each option; and
 - (c) Advice of the estimated time within which the services will be provided; and
 - (d) Notification of any proposed participation in teaching or research including whether the research requires and has received ethical approval; and
 - (e) Any other information required by legal, professional, ethical and other professional standards; and
 - (f) The results of tests; and
 - (g) The results of procedures.
- (2) Before making a choice or giving consent, every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, needs to make an informed choice or give informed consent.
- (3) Every consumer has the right to honest and accurate answers to questions relating to services, including questions about –
 - (a) The identity and qualifications of the provider; and
 - (b) The recommendation of the provider; and
 - (c) How to obtain an opinion from another provider; and
 - (d) The results of research.
- (4) Every consumer has the right to receive, on request, a written summary of information provided.

Right 7**Right to make an informed choice and give informed consent**

- (1) Services may be provided to a consumer only if that consumer makes an informed choice and gives informed consent, except where any enactment, or the common law, or any other provision of this Code provides otherwise.
- (2) Every consumer must be presumed competent to make an informed choice and give informed consent, unless there are reasonable grounds for believing that the consumer is not competent.
- (3) Where a consumer has diminished competence, that consumer retains the right to make informed choices and give informed consent, to the extent appropriate to his or her level of competence.
- (4) Where a consumer is not competent to make an informed choice and give informed consent, and no person entitled to consent on behalf of the consumer is available, the provider may provide services where –
 - (a) It is in the best interests of the consumer; and
 - (b) Reasonable steps have been taken to ascertain the views of the consumer; and
 - (c) Either, –
 - (i) If the consumer's views have been ascertained, and having regard to those views, the provider believes, on reasonable grounds, that the provision of the services is consistent with the informed choice the consumer would make if he or she were competent; or
 - (ii) If the consumer's views have not been ascertained, the provider takes into account the views of other suitable persons who are interested in the welfare of the consumer and available to advise the provider.
- (5) Every consumer may use an advance directive in accordance with the common law.
- (6) Where informed consent to a health care procedure is required, it must be in writing if –
 - (a) The consumer is to participate in any research; or
 - (b) The procedure is experimental; or
 - (c) The consumer will be under general anaesthetic; or
 - (d) There is a significant risk of adverse effects on the consumer.
- (7) every consumer has the right to refuse services and to withdraw consent to services.
- (8) every consumer has the right to express a preference as to who will provide services and have that preference met where practicable...

Appendix 5

Summaries of three review articles

Basic evidence grading system

There are several evidence-based rating systems that assess the efficacy of interventions in developing clinical guidelines. We include the evidence grading system that has been used in other NHC-sponsored guidelines (Sainsbury, Collins et al, 1977). Most of the recommendations in these guidelines are consensus opinion based on the combined experience of the guidelines development group. This is not unusual and, as has been previously noted, “strict adherence to an evidence-based approach would exclude most of modern medical practice...” (Woolf, 1992).

Table 1. Basic evidence grading strategy

Grade 1	Randomised controlled trials
Grade 2	Non-randomised controlled trials
Grade 3	Non-randomised historical cohort studies and other studies with non-experimental designs (eg, population-based studies, case-control studies)
Grade 4	Case series
Grade 5	Expert opinion

Methodology

Two recent review articles have assessed TBI rehabilitation effectiveness (Cope, 1995; Malec and Basford, 1996). To assess the evidence for cost-effectiveness, a 1997 review article was appraised (McGregor and Pentland, 1997). These reviews were assessed using a standard tool adapted from several sources (Mulrow, 1987; Oxman, 1994; Hunt and McKibbin, 1997; Greenhalgh, 1997).

A Medline literature search was conducted for the period January 1993 to July 1997 to update these reviews. The search aimed to identify studies that had examined the effectiveness of comprehensive rehabilitation for individuals with TBI. The following databases were also examined:

- EMBASE 1991 - July 1997
- Psychlit 1984 - June 1997
- UNCOVER July 1988 – August 1997

The reference sections of other identified review articles were scanned for additional studies of rehabilitation after TBI. Members of the advisory Panel also identified key references for review.

The subject headings and keywords used in the searches were:

1. TBI
2. head injury
3. brain injury
4. rehabilitation.

Table 2. Summary of review articles on the effectiveness and cost-effectiveness of TBI rehabilitation

Author, year of publication, country and review aims	Review conclusions	Comments
<p>Cope, 1995, USA. To assess whether the overall contribution of the sum of therapeutic rehabilitation interventions, compared with standard care, makes a worthwhile difference in the result.</p>	<p>The weight of current evidence supports rehabilitation for TBI patients and suggests it is cost effective.</p>	<p>Traditional narrative-style review provides a comprehensive summary of previous studies of the effectiveness of TBI rehabilitation. However, it has several limitations:</p> <ul style="list-style-type: none"> • it is not systematic • there is no grading of the strength of the evidence in the original studies • it rarely mentions the statistical significance of the results of individual studies • as there is limited discussion on the methodological problems with the individual studies, it is difficult to assess whether studies are comparable.
<p>Malec and Basford, 1996, USA. To describe the state of the art in post-acute brain injury rehabilitation (PABIR).</p>	<p>PABIR has a number of benefits for many individuals with brain injury. The current level of evidence supporting the efficacy of rehabilitation programmes is at Grade 3. Most studies report an improvement in behaviour and everyday activities after rehabilitation (not quantified). Increased 'independent living' – but idiosyncratically defined by different investigators.</p>	<p>Narrative rather than systematic – difficult to assess owing to publication bias. Outcome data on vocational status are integrated and the overall result is tested for statistical significance. No measures of statistical significance were detailed for individual studies.</p>

	<p>Higher rate of return to independent work, training or home-making (56% vs. 43%: $p < 0.001$).</p> <p>Lower level of unemployment (29% vs. 47%: $p < 0.001$)</p> <p>In most cases, early rehabilitation was more effective than delayed intervention.</p> <p>No consistent relationship has been demonstrated between treatment outcome and either length of stay or cost.</p> <p>Systemic studies of the efficacy of cognitive-behavioural psychotherapy in TBI patients are lacking.</p>	
<p>McGregor and Pentland, 1997, UK.</p> <p>To consider the evidence for the economic efficiency of TBI rehabilitation programmes.</p>	<p>Many of the studies purporting to provide evidence of cost-effectiveness neither included appropriate data nor followed standard methodological guidelines.</p> <p>While individual studies demonstrate some economic benefit from TBI rehabilitation, there is a paucity of reliable and methodologically sound evidence on its cost effectiveness.</p>	<p>This paper appraises economic analysis of TBI rehabilitation in a structured manner using predetermined criteria based on accepted methodology.</p> <p>This review provides a timely reminder that future research in this area needs to have a sound methodological base, given the comparatively high cost of rehabilitation services and the increasing awareness of economic efficiency in health care services.</p>

Methodological issues in studying the effectiveness of TBI rehabilitation and further research needs

Haffey and Lewis (1989) identified three principal threats to the internal validity of studies measuring the effect of rehabilitation interventions:

- spontaneous recovery
- pre-injury characteristics
- the nature and site of the brain injury.

Studies that include an appropriate control group can minimise the bias arising from these three problems. However, randomly assigning patients to treatment or no treatment is not acceptable to patients, their families, professionals and payers (High, Boake and Lehmkuhl,

1995). In addition, control group selection in other types of study, eg, cohort studies, has a number of difficulties that tend to affect the choice of study design and the study conduct.

In particular, there is a myriad of pre-injury factors (age, education, occupation, personality, emotional adjustment, substance abuse) and post-injury factors (other injuries sustained, co-morbidity, pain, family support, compensation, stress, expectancy, substance abuse) that interact with cognitive function and will affect recovery after TBI (Kibby and Long, 1996). It is difficult to assess or measure many of these factors and therefore to control, by matching or when analysing results, for their effect as potential confounders.

Other problems will affect study validity:

- The high prevalence of some of these factors (such as alcohol and drug misuse) in brain-injured individuals makes follow-up difficult.
- Deciding the appropriate outcome measures can be difficult. For example, in measuring cognitive recovery, researchers must consider the precise testing schedule, the functions to be measured, separating practice from recovery, and appropriate control or comparison groups (Brooks, Deelman et al, 1984). Outcome measures most commonly fall into the three categories of functional and psychosocial adjustment, living status and vocational status (Malec and Basford, 1996).

Other authors have critically evaluated studies of the effectiveness of TBI rehabilitation and can be referred to for a more detailed analysis (Corrigan, Bogner, et al, 1997; High, Boake and Lehmkuhl, 1995). Notwithstanding these obvious difficulties, there is still a widely acknowledged need for further controlled research into the effectiveness of different rehabilitative interventions and settings. Cope and Malec, among others, identify the need for prospective matched studies of TBI rehabilitation and research comparing different designs for rehabilitation services.

Summaries of three review articles

Paper: McGregor K, Pentland B. Head injury rehabilitation in the UK: an economic perspective. Soc Sci Med 1997;45(2):295-303.*

Was the specific purpose of the review clearly stated?	
A precisely formulated and focused question? (may be focused in terms of the population studied, the intervention given, the outcomes considered)	The aim of the paper is to consider the evidence for the economic efficiency of TBI rehabilitation programmes by critically reviewing literature on the economic aspects of TBI rehabilitation
Were sources and methods of the citation search identified?	
Search processes and time periods?	Electronic and hand search for articles looking at economic aspects of rehabilitation programmes for TBI, 1978 to present (probably 1996)
Databases?	'Medical and social science literature': not detailed
Follow-up from reference lists?	Not stated
Personal contact with experts?	No

Search for unpublished as well as published studies?	No
Search for non-English language studies?	No
Is it likely that important, relevant studies were missed?	Unpublished studies possibly missed. At least one relevant paper included in the Cope review is missing. ¹⁹ This could have been found by scanning the reference lists of relevant publications
Were explicit guidelines provided that determined the material included in and excluded from the review?	
Detailed exclusion and inclusion criteria for selection of the included data?	Not stated
Was a methodological validity assessment of material in the review performed?	
Systematic standardised methodologic assessment?	Yes. All studies assessed according to guidelines outlined in the paper.
Obtain missing information from investigators?	No
Appraisal of research designs, implementation and analyses?	Yes
Was the information systematically integrated with explication of data limitations and inconsistencies?	
Are the study assessments reproducible?	Yes – the assessment criteria are discussed in detail and based on widely used methodological guidelines for undertaking economic evaluations.
Are the study results sufficiently similar to permit pooling or comparison?	
Are the results similar from study to study?	Yes
Reasons for variations in results discussed?	N/a
Was the information integrated and weighted or pooled metrically?	No
Qualitative integration of findings by mentioning data limitations/ inconsistencies?	Yes
Quantitative meta-analysis?	N/a
(Possible) sensitivity analysis?	N/a

* This article is a review of economic analyses of TBI rehabilitation so some sections of the standard appraisal tool will not apply.

¹⁹ Ashley MJ, Krych DK, Lehr RP. Cost/benefit analysis for post-acute rehabilitation of the traumatically brain-injured patient. *Journal of Insurance Medicine* 1990;22:156-61.

Was a summary of pertinent findings provided?	
What is the overall result of the review?	<p>Many of the studies purporting to provide evidence of cost-effectiveness neither included appropriate data not followed standard methodological guidelines.</p> <p>While individual studies demonstrate some economic benefit from TBI rehabilitation, there is a paucity of reliable and methodologically sound evidence on the cost-effectiveness of TBI rehabilitation</p>
What are they and quantify?	Not quantifiable
How precise are they, ie, Confidence intervals?	N/a
Succinct and logically ordered summary of the data?	Yes – textual and tabular
Were all the important outcomes considered?	Yes
Recommendations that are linked to the strength of the evidence?	Yes
Cautious interpretation of subgroup analyses?	N/a
How will the results help in caring for patients/purchasing and providing services/making resource allocation decisions?	Emphasises the need for purchasers and providers of TBI rehabilitation to undertake economic analysis of their programmes.
Were specific directives for new research initiatives proposed?	Yes: the use of incremental analysis, differential timing and sensitivity analysis in future economic analyses of TBI rehabilitation.
	<p>Cost-benefit analysis most useful for vocational rehabilitation schemes.</p> <p>Cost-effectiveness analysis is probably the most appropriate appraisal for acute and post-acute TBI rehabilitation using both a functional assessment measure and a generic 'quality-of-life' instrument.</p>
Comments	<p>This paper appraises economic analysis of TBI rehabilitation in a structured manner using predetermined criteria based on accepted methodology.</p> <p>Given the comparatively high cost of rehabilitation services and the increasing awareness of economic efficiency of health care services, this review provides a timely reminder that future research in this area needs to have a sound methodological base.</p>
Are the benefits worth the harms and the costs?	N/a

Paper: Cope DN. The effectiveness of traumatic brain injury rehabilitation: a review. *Brain Injury* 1995;9(7):649-70.

Was the specific purpose of the review clearly stated?	
A precisely formulated and focused question? (may be focused in terms of the population studied, the intervention given, the outcomes considered)	No specific purpose stated. 'Topic of article' was: "The effectiveness of rehabilitation for traumatic brain injury and how it can be evaluated". Specific question may be, although it is not explicitly stated: "Does the overall contribution of the sum of the therapeutic rehabilitation interventions, compared to standard care, make a worthwhile difference in the outcome?" (Page 655).
Were sources and methods of the citation search identified?	
Search processes and time periods?	Not stated
Databases?	Not stated
Follow-up from reference lists?	Not stated
Personal contact with experts?	Not stated
Search for unpublished as well as published studies?	Not stated
Search for non-English language studies?	Not stated
Is it likely that important, relevant studies were missed?	Important relevant studies unlikely to have been missed given author's knowledge of the field but, in the absence of a detailed search strategy, it is not possible to rule this out.
Were explicit guidelines provided that determined the material included in and excluded from the review?	
Detailed exclusion and inclusion criteria for selection of the included data?	Studies included were those with significant elements of experimental group design and validity, with outcome measures that principally address the question of function at the handicap level and/or economically appraise the effect.
Was a methodological validity assessment of material in the review performed?	
Systematic standardised methodologic assessment?	Not stated
Obtain missing information from investigators?	No
Appraisal of research designs, implementation and analyses?	Not stated. (A paper by different authors critically appraises the methodological problems of the individual studies included in Cope's review. ²⁰)

²⁰ High WM, Jr; Boake C, Lehmkuhl LD. Critical analysis of studies evaluating the effectiveness of rehabilitation after traumatic brain injury. *J Head Trauma Rehabil* 1995;10(1):14-26.

Was the information systematically integrated with explication of data limitations and inconsistencies?	
Are the study assessments reproducible?	Study assessments not reproducible as assessment criteria not stated.
Are the study results sufficiently similar to permit pooling or comparison?	
Are the results similar from study to study?	Cannot assess if the results similar from study.
Reasons for variations in results discussed?	No
Was the information integrated and weighted or pooled metrically?	No
Qualitative integration of findings by mentioning data limitations/ inconsistencies?	Some discussion of limitations of individual studies.
Quantitative meta-analysis?	No
(Possible) sensitivity analysis?	N/a
Was a summary of pertinent findings provided?	
What is the overall result of the review?	There is increasingly strong evidence from a number of studies that comprehensive rehabilitation makes a substantial difference in outcome of handicap for traumatic brain injury patients. The emerging data strongly support the notion that even though intensive rehabilitation is very expensive, it may ultimately decrease the cost of care of TBI patients.
What are they and quantify?	Specific findings are not detailed and quantified any further.
How precise are they ie, Confidence intervals?	No
Succinct and logically ordered summary of the data?	Tabular summarisation of data but important information missing from this. Narrative summary of data is lengthy.
Were all the important outcomes considered?	All important outcomes probably considered.
Recommendations that are linked to the strength of the evidence?	Recommendations probably go beyond the strength of the evidence presented here.
Cautious interpretation of subgroup analyses?	N/a
How will the results help in caring for patients/purchasing and providing services/making resource allocation decisions?	Evidence for the effectiveness of traumatic brain injury rehabilitation is encouraging as it supports the provision of such rehabilitation services.

Were specific directives for new research initiatives proposed?	Yes – a prospective matched study and research comparing different designs for the delivery of rehabilitation services.
Comments	<p>Traditional, narrative-style review that provides a comprehensive summary of the state of knowledge on the effectiveness of traumatic brain injury rehabilitation. However, it has several limitations:</p> <ul style="list-style-type: none"> • Lacks a definitive search strategy, explicit inclusion criteria and a formal method of synthesising the data. Thus, the review cannot be classified as ‘systematic’ and there is a possibility of publication bias. • No grading of the strength of the evidence that the original studies provide. • The statistical significance of the results of individual studies is occasionally stated but not quantified. The numbers in many of the individual studies are small and are unlikely to have lead to statistically significant results. Without reporting the results of statistical testing, it is not possible to infer the significance of the results of the individual studies eg, one of the included ‘seminal’ studies showed a large (50%) reduction in acute and inpatient rehabilitation bed days, but there was no mention of the statistical significance of this important result. • Limited discussion of the methodological problems with the individual studies. The study stated in the preceding bullet point has been appraised elsewhere and a number of factors identified that may have affected the validity of the results.²¹ • Summary tables are included but they are not very comprehensive, making it difficult to assess how comparable the studies are.
Are the benefits worth the harms and the costs?	Cannot conclude from this study.

²¹ High WM, Jr, Boake C, Lehmkuhl LD. Critical analysis of studies evaluating the effectiveness of rehabilitation after traumatic brain injury. *J Head Trauma Rehabil* 1995;10(1):14-26.

Paper: Malec JF, Basford JS. Postacute brain injury rehabilitation. Arch Phys Med Rehabil 1996;77:198-207.

Was the specific purpose of the review clearly stated?	
A precisely formulated and focused question? (may be focused in terms of the population studied, the intervention given, the outcomes considered)	To describe the state of the art in postacute brain injury rehabilitation (PABIR), including an appraisal of the effectiveness of behavioural, cognitive, pharmacologic and vocational rehabilitative interventions.
Were sources and methods of the citation search identified?	
Search processes and time periods?	<i>Index Medicus</i> and <i>Psychological Abstracts</i> up to 1994 with follow-up from and post-1994 articles as they became available.
Databases?	Above
Follow-up from reference lists?	Yes
Personal contact with experts?	Not stated
Search for unpublished as well as published studies?	Not stated
Search for non-English language studies?	Not stated
Is it likely that important, relevant studies were missed?	Important, relevant studies may have been missed, although authors are leading academics in the field and should have been aware of all important studies.
Were explicit guidelines provided that determined the material included in and excluded from the review?	
Detailed exclusion and inclusion criteria for selection of the included data?	Not stated
Was a methodological validity assessment of material in the review performed?	
Systematic standardised methodologic assessment?	No systematic standardised methodologic assessment and missing information not obtained from investigators.
Obtain missing information from investigators?	No
Appraisal of research designs, implementation and analyses?	Research designs and implementation discussed but analysis of individual studies not mentioned.
Was the information systematically integrated with explication of data limitations and inconsistencies?	
Are the study assessments reproducible?	The study assessments are not reproducible and appear to be based on authors' personal interpretation.
Are the study results sufficiently similar to permit pooling or comparison?	
Are the results similar from study to study?	Results not always similar from study to study. For some of the interventions, there are conflicting results regarding efficacy.

Reasons for variations in results discussed?	Yes
Was the information integrated and weighted or pooled metrically?	Data on vocational outcomes after rehabilitation were integrated and compared to vocational outcome in groups of TBI individuals who received no, unspecified, or inpatient-only rehabilitation.
Qualitative integration of findings by mentioning data limitations/ inconsistencies?	Some
Quantitative meta-analysis?	No
(Possible) sensitivity analysis?	N/a
Was a summary of pertinent findings provided?	
What is the overall result of the review?	PABIR has a number of benefits for many individuals with brain injury. The current level of evidence supporting the efficacy of rehabilitation programmes is at Grade 3.
	1. Most studies report an improvement in behaviour and everyday activities following rehabilitation (not quantified).
	2. Increased independent living – but investigators tend to define the variable idiosyncratically.
	3. Higher rate of return to independent work, training or home-making (56% vs. 43%: p<0.001).
	4. Lower level of unemployment (29% vs. 47%: p<0.001)
	5. In most cases, early rehabilitation more effective than delayed intervention.
	6. No consistent relationship has been demonstrated between treatment outcome and either length of stay or cost.
	7. Systemic studies of the efficacy of cognitive-behavioural psychotherapy in traumatic brain injury patients are lacking.
What are they and quantify?	Above
How precise are they ie, Confidence intervals?	Not stated
Succinct and logically ordered summary of the data?	Yes
Were all the important outcomes considered?	Yes
Recommendations that are linked to the strength of the evidence?	Overall recommendations linked to the strength of the evidence.
Cautious interpretation of subgroup analyses?	N/a

<p>How will the results help in caring for patients/purchasing and providing services/making resource allocation decisions?</p>	<p>The review provides level 3 evidence for the efficacy and benefits of PABIR.</p>
<p>Were specific directives for new research initiatives proposed?</p>	<p>Yes. Available research is sufficiently encouraging to recommend more carefully controlled randomised studies. Better controlled studies of specific rehabilitation procedures with specified patient groups are needed including large multi-centre studies.</p>
<p>Comments</p>	<p>This review is more narrative than a systematic analysis of the evidence to date. The search strategy is detailed but there is no mention of inclusion or exclusion criteria for the reviewed articles and no strict methodological assessment of the studies. The authors did not search for unpublished study results so possible publication bias.</p> <p>The review focuses most intently on vocational outcomes. While there is no discussion of the statistical significance of the results of the individual studies, outcome data on vocational status were integrated and the overall result is tested for statistical significance.</p>
<p>Are the benefits worth the harms and the costs?</p>	<p>Costs and harms not quantified.</p>

Appendix 6

Psychiatric research findings

Research findings are not always consistent, with considerable variation in the quality of research.

The best estimates for major psychiatric diagnoses in association with TBI are:

- major depression, 25% (Jorge et al, 1993a - but up to 77% Varney et al, 1987)
- bipolar affective disorder/secondary mania - no clear defined rates, but increasingly reported
- psychoses - schizophreniform or paranoid – 5% to 8% (Hillborn, 1960; Achte et al, 1967/69; Ota, 1969)
- obsessive compulsive disorder, 3% (Epstein and Ursano, 1994)
- Post-Traumatic Stress Disorder, up to one third (Epstein, 1991)
- phobic disorder (social phobia common, although no defined rates)
- generalised anxiety disorder, commonly co-morbid with major depression (Jorge et al, 1993b)
- panic attacks and aggression (common)
- adjustment reactions (almost universal).

The range of neuropsychiatric syndromes includes:

- reduced impulse control
- attentional disturbance
- apathetic syndromes (impaired motivation, initiation, drive)
- memory dysfunction
- disturbances of emotional behaviour and experience.

Experience suggests that the above have not been well recognised by clinicians and consequently have not been appropriately managed.