

Rehabilitation following Acquired Brain Injury

A Headway Review of Guidelines and Evidence

What is Rehabilitation?

The Oxford English Dictionary definition of Rehabilitation is:

“1) to restore to health or normal life by training and therapy. 2) restore the standing or reputation of. 3) restore to a former condition.”

Rehabilitation is a term that is commonly used to describe training or treatment services which focus on difficulties following illness, injury, substance abuse or criminal behaviour. It is a generic term, covering a huge range of potential activities, conditions and circumstances.

The UN Convention for the Rights of People with Disabilities (Article 26; 2008) describes habilitation and rehabilitation in the context of basic human rights, requiring governments to take “effective and appropriate measures” to:

“enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.”

Article 26 emphasises early access and voluntary participation in rehabilitation; multidisciplinary assessment of needs; promotion of inclusion and participation in society, and provision of services close to clients’ communities, including rural areas. It also outlines that governments should promote continuing training of staff working in this area and availability, knowledge and use of assistive technology as related to rehabilitation.

Rehabilitation is a process closely linked with Acquired Brain Injury (ABI). Following brain injury, the need for rehabilitation often crosses several domains of activity, with different rehabilitation needs becoming more evident at different points in the recovery process.

In their report, “Rehabilitation following acquired brain injury: National Clinical Guidelines” (BSRM, 2003), the British Society of Rehabilitation Medicine, specifically referring to rehabilitation in the context of brain injury, defined it both in terms of the concept and of service. The concept of rehabilitation they define as a

“process of active change by which a person who has become disabled acquires the knowledge and skills needed for optimal physical, psychological and social functioning. “

They describe the rehabilitation service as:

“the use of all means to minimise the impact of disabling conditions and to assist disabled people to achieve their desired level of autonomy and participation in society. “

The BSRM report outlines the UK national clinical guidelines for best practice in all areas of rehabilitation following brain injury, from acute service provision through to discharge and community integration. Of note, they present a model of rehabilitation referred to as the ‘slinky’ model (Fig 1). The critical point of this model is that, although clients may need to access different services as they progress, their transition between services should be smoothed by communication and sharing of information between services, so that they progress in a seamless continuum of care through the different stages. They also acknowledge the fact that rehabilitation is not a linear

process, and clients will often need to visit and revisit points on the continuum as their recovery progresses and new challenges emerge.

Rehabilitation following acquired brain injury: national clinical guidelines

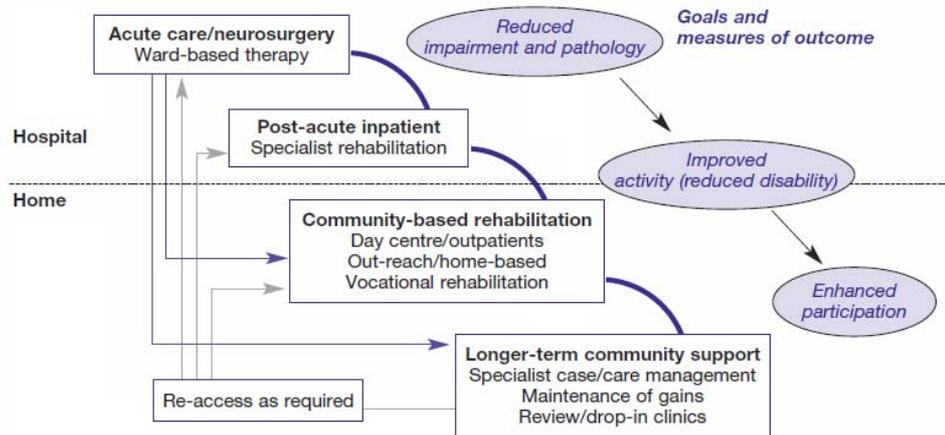


Figure 1 the "slinky" model of ABI Rehabilitation from the BSRM National Clinical Guidelines (BSRM, 2003)

Principles of Rehabilitation Following Brain Injury

In a review of ABI, its consequences, and its rehabilitation, Vogenthaler (1987), identified five principles that unite the implementation of rehabilitation strategies across therapies (e.g. Medical, Social, Cognitive and Psychological);

1. They should begin as **early after the injury** as is feasible. Research has shown that doing so enhances eventual outcome.
2. Services should be provided in a **holistic** manner.
3. Services should be provided in an **interdisciplinary** manner.
4. Various therapies must focus on **both the micro deficits and the macro deficits** simultaneously. While it is important to remediate specific cognitive problems within a laboratory/treatment setting, it is equally important to focus on the client's own real-world circumstances, (e. g. daily living activities). Therefore, attempts to remediate a cognitive problem should occur on both 'fronts' simultaneously.

5. The design and implementation of the various therapeutic regimens should emanate from a comprehensive, systematic, interdisciplinary **evaluation process**.

These principles are echoed in several other documents addressing best practice in the area of rehabilitation following brain injury; they can be seen as the core considerations in planning rehabilitation strategies and will be referred to repeatedly later.

A Holistic Approach to Rehabilitation

At this point it is worth exploring the principle advocating a holistic approach to the rehabilitation process, and defining what that means for a community based service such as Headway. In the context of a service such as ours, a holistic approach requires us to look at the individual as whole, including cognitive, social, emotional and functional aspects of the clients' experience.

In 1990, Ben-Yishay said in relation to rehabilitation after ABI:

"[it] can best be achieved by a holistic and integrated programme. Such a programme must co-ordinate cognitive remedial interventions with efforts to improve functional skills and interpersonal functions, providing specialised methods of clinical management designed to ameliorate problems stemming from poor compliance, lack of malleability, lack of sufficient awareness and lack of acceptance of one's existential situation."

More recently the holistic approach was advocated by Barbara Wilson in 2002 and by the BSRM in 2003.

The results of a systematic review published by Cicerone and colleagues in 2011 suggest that comprehensive-holistic neuropsychological rehabilitation can improve community integration, functional independence, and productivity, even for patients who are many years post-injury. As a result the

Brain Injury Interdisciplinary - Special Interest Group (BI-SIG) recommend that post-acute, comprehensive-holistic neuropsychological rehabilitation should be provided to reduce cognitive and functional disability after moderate or severe TBI as a practice standard.

Furthermore, a systematic review of treatment approaches (ABA, CBT and comprehensive-holistic) for clients with behavioural and psychosocial disorders following acquired brain injury by Cattelani and colleagues (2010) indicated that a comprehensive-holistic approach should be considered a treatment standard. [See Cattelani et al. 2010 for description of this approach].

Inclusion of Family

Another important factor in rehabilitation following brain injury relates to the inclusion of the family or primary carer in rehabilitation planning. The BSRM's definitional framework stresses that ABI rarely happens to individuals in isolation and that the needs of the family members and carers should be addressed as part of the rehabilitation process. This is echoed by the Society of Cognitive Rehabilitation (2004), and expanded upon in the BSRM Standards for Rehabilitation Services Mapped on to the National Service Framework for Long-Term Conditions report (2009). There, it is recommended that family members are offered assessment as standard to establish their needs, and acknowledges that addressing the needs of the family unit increases sustainability of their role.

Cognitive Rehabilitation

A standard component of brain injury rehabilitation are interventions designed to promote the recovery of cognitive function and to reduce cognitive disability: 95% of rehabilitation facilities in the US servicing the needs of persons with brain injury provide some form of cognitive rehabilitation, including combinations of individual, group and community-based therapies

(Cicerone et al, 2000). Much of the work carried out by client-facing services within Headway involves cognitive rehabilitation.

The Brain Injury Interdisciplinary Special Interest Group (BI-SIG) of the American Congress of Rehabilitation Medicine defined cognitive rehabilitation as:

“a systematic, functionally-oriented service of therapeutic cognitive activities, based on an assessment and understanding of the person’s brain-behaviour deficits.”

Services aim to achieve functional changes by (1) reinforcing, strengthening, or re-establishing previously learned patterns of behaviour, or (2) establishing new patterns of cognitive activity or compensatory mechanisms for impaired neurological systems” (Harley, et al., 1992, p.63).

Tsaousides and colleagues (2009; p179) summarise the evidence for cognitive rehabilitation into the following key concepts:

- Cognitive rehabilitation is a treatment for cognitive impairments related to brain injury that is supported by well-designed research.
- A neuropsychological assessment is required in order to assess cognitive function and develop an appropriate treatment plan.
- Cognitive rehabilitation consists of diverse interventions that must be tailored to the individual patient.
- Cognitive rehabilitation can be effective regardless of the length of time since the injury and the injury severity level.
- Cognitive rehabilitation leads to improvements in cognitive and psychosocial functioning.

A difficulty faced when designing and applying cognitive rehabilitation strategies for individuals with ABI evolves from the heterogeneous nature of

the brain injured population. This also poses several major challenges for clinical research that confound traditional randomized controlled trial designs [RCTs], as no two groups of brain-injured clients are equivalent.

As outlined by the National Institutes of Health (NIH) consensus Statement on Rehabilitation of Persons with Traumatic Brain Injury, rehabilitation services should be:

“matched to the needs, strengths, and capacities of each person with TBI and modified as those needs change over time” (NIH Consensus Statement, 1998, p.23).

This requirement emphasises the need for person-centred interventions for cognitive rehabilitation.

Cicerone and colleagues have conducted systematic reviews of the literature on cognitive rehabilitation in 2000, 2005 and 2011, which supported the effectiveness of cognitive rehabilitation interventions for individuals with TBI and stroke. Cicerone et al. (2000, 2005, 2011) used these reviews to develop evidence-based practice standards, guidelines, and options for practitioners working with brain-injured clients in the domains of attention, memory, and executive function. Rohling and colleagues (2009) conducted a meta-analysis of the data reviewed in Cicerone and colleagues' 2000 and 2005 papers, which provided quantitative support for most of the findings and recommendations. It also identified four factors that moderate treatment efficacy; treatment domain (e.g. memory, attention, language), aetiology (e.g. TBI, stroke), recovery level (6-months, 1 year post-injury), and mean age of participants. In other words, variability in these areas influence the rehabilitation outcome in different ways (cf. Rohling et al., 2009).

However, several broadly accepted guidelines exist, some of which have previously been referred to earlier in this document. Here follows a list

delineating relevant general guidelines comprising recommendations from the BSRM report (2003), the National Academy of Neuropsychology Brief Position Paper on Cognitive Rehabilitation (2002), The Society for Cognitive Rehabilitation's Recommendation for Best Practice in Cognitive Rehabilitation Therapy: Acquired Brain Injury, The Department of Health and Children/HSE National Policy for the provision of Integrated Neuro-Rehabilitation Services, and Cicerone (2000; and updated reviews in 2005 and 2011) Evidence-based Cognitive Rehabilitation: Recommendations for Clinical Practice.

Summary of Guidelines for Cognitive Rehabilitation following ABI

Who should be involved?

- Inclusion of the individual as a part of the team – the person with the injury should be included in the planning of interventions whenever possible. A study by Webb (1994) showed that clients who were active participants in goal setting and monitoring of progress showed superior goal attainment and maintenance.
- The importance of empowering the client to become active participants in their own care is a core value of the Person Centred Care approach (cf. presentation by Wegener, 2011).
- Family involvement- not only should the needs of the family member or carers be taken into consideration, but they should be included in the planning and execution of rehabilitation strategies whenever possible.
- Appropriately trained staff – staff should be appropriately trained to understand, develop and administer protocols.
- Where possible input should be multi-disciplinary, particularly for moderate to severe brain injuries. (cf. Cochrane review, Turner-Stokes et al. 2011).

Communication

- Communication - between the members of the team, and with other involved professionals and agencies is vital to the appropriate, timely and effective application of a rehabilitative intervention.
- Open and honest explanation of the system - a client should never be told that their functioning is going to be restored, rather advised that the aim is to maximise or optimise these skills, while learning new ways of doing things to minimise the problems. All parties involved should share a common understanding of the process.
- All individuals with ABI should receive education appropriate to their abilities and needs. Generally the brain injured person should be fully apprised of his or her cognitive problems, the fact that he or she has had a brain injury and the likely prognosis for the individual cognitively, at the earliest stage possible.
- A growing body of evidence suggests that information and advice is usually more appropriate for mild brain injuries than intensive rehabilitation (Turner-Stokes et al., 2011)

Goals and Goal Setting

- Open and honest explanation of the system, client should never be told that their functioning is going to be restored, rather advised that the aim is to maximise or optimise these skills, while learning new ways of doing things to minimise the problems.
- Goals should be discussed and agreed with the client and where possible the caregiver, they should be provided in writing and they should be Specific, Measurable, Attainable, Realistic and Timely/Time bonded (SMART)
- Regular re-assessment of the protocol

- Goals should be tailored to enhance the individual's ability to function as independently as possible in the least restrictive setting. The end result of CRT must be to improve quality of life and real life skills.
- Functional goals should be selected in close consultation with the person with brain injury. They should be goals that are valuable and important to the person rather than to the therapist.

Therapy

- All rehabilitative interventions should be informed by appropriate assessment of deficit. Where possible a neuropsychological assessment should be provided in order to gain as much information as possible about the target cognitive difficulty.
- Restitution and Compensation - There has been much debate about whether rehabilitation should be aimed at overcoming a neurological problem or instead at compensating for the loss. However, this should not be viewed as an either/or scenario. It is more appropriate to match the approach to the client. According to Wilson (2002):

"Sometimes we try to restore lost functioning, or we may wish to encourage anatomical reorganisation, help people use their residual skills more efficiently, find an alternative means to final goal (functional adaptation), use environmental modifications by bypass problems or use a combination of these methods."

- Therapy should be systematic, structured and repetitive according to the needs of the client.
- Intervention protocols should be regularly reviewed and re-assessed.
- All cognitive rehabilitation strategies should focus on improving real life functioning.
- Intervention should incorporate opportunities to practice in real life settings in order to develop generalisation and transfer of learning. Compensatory

approaches improve functioning in everyday life, working best when the teaching of adaptive cognitive strategies is emphasised and offered within a naturalised context (Cicerone, 2007).

- Interventions should incorporate work on awareness and psychosocial skills (coping, anxiety, mood, self-esteem, self-concept etc), essentially within a holistic framework.

These points offer an overview of general guidelines that should inform any cognitive rehabilitation intervention. More specific guidelines and protocols exist for each specific domain of cognitive functioning. A meta-analysis of the data included in Cicerone and colleague's (2000, 2005) systematic reviews suggested that some cognitive domains (e.g. visuospatial, language, attention) are more amenable to restorative rehabilitation than others (e.g. memory) (Rohling et al. 2009), but in general there appears to be strong benefits of compensatory rehabilitation across most domains (see references for review documents relating to evidence-based domain specific strategies; in particular Rohling et al. 2009, Cicerone et al. 2000, 2005, 2011, and see BSRM Neurological Rehabilitation 2010 for a chart summarising Cochrane reviews of rehabilitation approaches for various aspects of functioning post brain-injury).

There remains a need for more evidence-based work to further define and tailor cost-effective cognitive rehabilitation interventions (Ricker, 1998), and specifically more research into the real-world efficacy of various treatment approaches (Cicerone, 2007). "Future research should move beyond the simple question of whether cognitive rehabilitation is effective, and examine the therapy factors and patient characteristics that optimize the clinical outcomes of cognitive rehabilitation" (Cicerone et al. 2005, p. 1681 and reiterated in Rohling et al. 2009).

In relation to a community-based rehabilitation service such as Headway, emerging evidence indicates that community-based rehabilitation is at least

as good as inpatient rehabilitation (Cicerone, 2007), and systematic reviews of research on community-based approaches in brain injury rehabilitation in high-income countries indicate that such approaches are at least as effective or more effective than traditional [inpatient] approaches, and have greater psychosocial outcomes and a higher degree of acceptance by people with disabilities and their families (Barnes et al. 2001; Chard, 2006; Evans et al. 2008; Doig et al. 2010).

Community (Re)Integration

Community integration (CI) is often cited as the ultimate aim of rehabilitation, however many people following ABI do not reach previous levels of integration or resume previously held roles. In the longer term 26-45% of people with severe Traumatic Brain Injury (TBI) are poorly integrated into their communities despite having accessed rehabilitation services (Doig et al., 2001). Generally community integration priorities include the opportunity to obtain a residence, maintain a social support network and engage in productive activity. Sloan and colleagues (2004) expand on this stating the following as the aims of such a service:

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

These aims reflect the standards of rehabilitation as recommended by the UN Convention for the Rights of People with Disabilities (Article 26; 2008).

However, limited evidence exists to guide implementation of the above aims, or to direct clinical practice in this area. A recent paper described a successful case study of a new model “Community Approach to Participation” (CAP, 2003; Sloan et al., 2004) developed in Australia for people with TBI and which they describe as an “individualised and collaborative model of community based practice”, which appears to echo Headway’s emphases on person-centeredness and communication. The authors recommend that the Community Integration service provide “a high level initial intervention followed by a period of consolidation during which supports can be scaled back” (Sloan et al., 2004; p16). A systematic review of the evidence for CI by Reistetter & Beatriz (2005) found strong evidence for use of two outcome measures of CI, and for using severity of injury measures to predict CI. They also found moderate evidence that social integration is related to life satisfaction.

In terms of Headway’s CI service, the emphasis is on social integration, upskilling, education and meaningful routine, rather than on job attainment and salary, as these latter aspects are contingent on the economy and availability of jobs.

Vocational Rehabilitation

WHO Guidelines emphasise the importance of recognizing that people with disabilities are important contributors to society and that allocating resources to their rehabilitation is an investment. In addition, the WHO urges the promotion and protection of the rights and dignity of persons with disabilities to ensure their full inclusion in society, particularly by encouraging training and protecting employment (World Health Organisation, 2010).

There is strong evidence for cost-benefits of return to paid employment after injury, in that the salaries from paid employment exceed the cost of

intervention (Murphy et al., 2006) with overall gain to the tax-payer (Wehman et al., 2003).

In terms of practice guidelines, a recent review of the evidence supporting different approaches to vocational rehabilitation (programme based rehab model, supported employment model, case-coordinated model & qualitative studies) reported little clear evidence to indicate the best practice approach to Vocational Rehabilitation for people with TBI (Fadyl & McPherson, 2009). The authors stated that further research will need to evaluate efficacy of intervention models for different types of traumatic brain injury, develop standardised measures and interventions and evaluate long-term effects of vocational rehabilitation on employment. Another recent systematic review of different aspects of brain injury rehabilitation reported that evidence for vocational rehabilitation was limited, but suggests benefits to the individual and to society. There was evidence from one study included that the supported employment model improves employment outcomes (Cullen et al., 2007).

The BSRM Standards for Rehabilitation Services Mapped on to NSF for Long-Term Conditions (2009) has a section on standards and guidelines for best practice in vocational rehabilitation for any person with a long-term neurological condition. In summary, as standard, all adults of working age should have their vocational needs addressed and have access to a local or specialist vocational rehabilitation service as part of their programme of rehabilitation or through appropriate sign-posting or referrals. There is also reference made to those who cannot return to work or training, that they are advised regarding financial implications and building in other purposeful activities.

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