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STUDIES ON  
NEUROPSYCHOLOGY,  
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# *Neuropsychological Rehabilitation*

Theory and Practice

Edited by Barbara A. Wilson

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# NEUROPSYCHOLOGICAL REHABILITATION

STUDIES ON NEUROPSYCHOLOGY, DEVELOPMENT, AND COGNITION

*Series Editor:*

Linas Bieliauskas, Ph.D.  
University of Michigan, Ann Arbor, MI, USA

# NEUROPSYCHOLOGICAL REHABILITATION: THEORY AND PRACTICE

Edited by

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# From the Series Editor

In teaching students, I have always stressed that reporting of the results of assessment of cognitive deficit is only a first step. A Clinical Neuropsychologist must also address 'the bottom line,' which is to address the question 'Now that we know what is wrong, so what?'. It does not much good to answer a referral to evaluate speech difficulties in a young patient by informing the referring source that the patient has aphasia. Our series is intended to integrate scientific, theoretical, and applied aspects of neuropsychology and this is done superbly by Barbara A. Wilson in this volume.

Dr. Wilson has organized some of the best minds in the field of Neuropsychological Rehabilitation to answer the question 'So What?'. The development of the field is reviewed and rehabilitation approaches are described for a wide spectrum of neuropsychological disorders ranging from traditional areas of focus such as language and memory to current advances in helping patients with dementia or brain injury in childhood. The authors present not only state-of-the art techniques and approaches, but also the theoretical rationale for their development. As such, this contemporary text will be of significant value to understanding the practical implications of cognitive impairment and how to put forth the best effort at remediation or compensation. *Neuropsychological Rehabilitation: Theory and Practice* will be a welcome addition to the library of students who are developing their intervention skills, neuropsychologists in rehabilitation settings, and clinicians who seek to increase the usefulness of the recommendations in their assessment reports to meet 'the bottom line' needs of our patients.

*Linas A. Bieliauskas*  
Ann Arbor, January, 2003





# Foreword

My earliest exposure to patients with brain injury came as a result of a request to consult with a small community rehabilitation hospital in developing more effective rehabilitation programs. It seems the social work staff, in conducting routine surveys of former patients and their families a year post-discharge from inpatient rehabilitation, were surprised and very concerned about their contacts regarding individuals affected by traumatic brain injury. Reports of failed attempts to return to school and work, changes in behaviour and personality, and generally far less successful adjustment in this primarily young adult group had not been anticipated. After all, 'they had seemed to be doing so well when they left the hospital,' after a traditional rehabilitation focus on recovery of motor, self-care, and communication skills. This was in the early 1980s, and the long term, often devastating effects of brain injury in young adults resulting from trauma had just begun to be recognized. Armed with backgrounds in clinical neuropsychology, speech pathology, occupational therapy, and the neurosciences, many clinicians turned their attention to the rehabilitation of individuals with cognitive impairments. Surely the collected experience and wisdom of the traditional rehabilitation therapies, and the exciting new developments in understanding functional brain organization could be mined to reveal the fundamental nature of the problems and indicate the essence of what could and should be done.

In the two decades since, those of us working in rehabilitation have been humbled in our recognition of the impact of brain injury on our most basic cognitive capacities and functional abilities – to concentrate, to learn and remember, to think ahead, and to plan and organize one's behaviour to reach the simplest of everyday functional goals. Equally important and frequently disabling are the losses in self-confidence, and the ability to feel in control of one's actions and emotions. It became clear that effective interventions would require creativity, a deeper understanding of the impact of brain injury on everyday abilities, and an appreciation for the context in which individuals were living and working.

Barbara Wilson and her colleagues have consistently been at the forefront of this effort. Their contributions include the development of psychometric

measures that began to address everyday functioning, the systematic incorporation of basic findings from experimental and cognitive psychology into rehabilitation practices, and an emphasis on clinical efficacy. In an impressive collection of books, monographs, clinical research studies, and position papers, Barbara and many of the authors in this volume have disseminated information and stimulated discussion about the theories and models underlying brain injury rehabilitation, best clinical practices, and the use of emerging technologies.

This latest edited text includes current research findings and thinking of some of the best researchers and clinicians working in neuropsychological rehabilitation today. It highlights and exemplifies the major shifts in the field: the focus on everyday functioning, the involvement of clients and families in developing and implementing treatment plans and strategies, the incorporation of activities to address behavioural and emotional responses to cognitive impairment, and the critical importance of seeing clients not strictly as individuals, but as imbedded in a social context which has tremendous power for change. It also reflects the broadening of neuropsychological rehabilitation to include children and individuals with progressive neurological disorders. There is an emphasis on scientific rigor, but in the service of developing practical and effective rehabilitative approaches, tools and techniques.

Clinical experience shines through this volume written by clinical researchers who have developed and then tested their theories and approaches to treatment within the context and realities of real-life rehabilitation programs, families, and communities. In a field that has come under great scrutiny, and for which doubters abound, this volume, reflecting the work of researchers on three continents, provides a foundation for realistic, yet optimistic expectations that neuropsychological interventions can make a difference in people's lives that is meaningful, practical, and cost-effective. It will be a great practical resource and rewarding read for anyone involved in rehabilitation.

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# Chapter 1

## THE THEORY AND PRACTICE OF NEUROPSYCHOLOGICAL REHABILITATION: AN OVERVIEW

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### Introduction

Neuropsychological rehabilitation is concerned with the amelioration of cognitive social and emotional deficits caused by an insult to the brain. Like other kinds of rehabilitation, the main purposes of neuropsychological rehabilitation are to enable people with disabilities to achieve their optimum level of well being, to reduce the impact of their problems on everyday life and to help them return to their most appropriate environments.

Because of the complexities of the difficulties facing people with brain injury, neuropsychological rehabilitation must draw on a number of theoretical approaches. As Gianutsos said of cognitive rehabilitation (a part of neuropsychological rehabilitation) in 1989, it is a hybrid born of a mixed parentage including neuropsychology, occupational therapy, speech and language therapy and special education. Others draw from different fields. Wilson (1987) believed that three areas from within psychology are important namely neuropsychology to help us understand the working of the brain, cognitive psychology from which we obtain models of cognitive functioning

that help us explain and predict phenomena and behavioural psychology to provide us with treatment strategies that can be modified or adapted for people with brain injury. McMillan and Greenwood (1993) believed that rehabilitation should draw on clinical neuropsychology, behavioural analysis, cognitive retraining and group and individual psychotherapy. Diller (1987) believed that it was important to take into account several theoretical bases.

In a recent paper Wilson (2002) attempts to put together a comprehensive model of cognitive rehabilitation. Starting with the belief that no one model is sufficient to address the complex problems facing people with brain injury, the comprehensive model includes models of cognition, assessment, recovery, behaviour, emotion, compensation and learning. Many of these models are addressed in this volume.

## Theories of Neuropsychological Rehabilitation

### Some early theoretical influences on neuropsychological rehabilitation

One of the earliest attempts to provide paradigms or models of treatment for people with brain injury was provided by Powell (1981). He suggested there were six treatment paradigms:

1. The non-intervention strategy (letting nature take its course).
2. The prosthetic paradigm whereby patients are helped to make the most effective use of prostheses.
3. Practice or stimulation, which is probably the most widely used treatment technique, although there is little evidence to support the notion that, on its own, it is effective for many of the problems faced by people with brain injury (Miller, 1984).
4. The maximizing paradigm in which therapists tend to maximize the extent, speed, and level of learning by such procedures as positive reinforcement and feedback.
5. Brain function therapy, or directed stimulation which aims to focus or direct tasks at certain regions of the brain to increase its activity or re-establish functions in new areas.
6. Medical, biochemical, and surgical treatments which, although beyond the brief of this chapter can sometimes be combined with other therapeutic treatments (Durand, 1982).

Although these paradigms may describe the various situations in rehabilitation they seem to be more a list of headings than they are theoretical models. Closer to models in the sense of providing theories of treatment are the five models of neuropsychological interventions suggested by Gross and Schutz (1986). These are:

1. The environmental control model
2. The stimulus-response (S-R) conditioning model

3. The skill training model
4. The strategy substitution model
5. The cognitive cycle model

Gross and Schutz claim that these models are hierarchical so that patients who cannot learn are treated with environmental control techniques; patients who can learn but cannot generalize need S-R conditioning; patients who can learn and generalize but cannot self-monitor should be given skill training; those who can self-monitor will benefit from strategy substitution; and those who can manage all of the above and are able to set their own goals will be best suited for treatment that is incorporated within the cognitive cycle model.

Although such a hierarchical model has a neatness about it, a rigid adherence to its parameters could lead to some spurious conclusions. It is highly unlikely, for example, that absolute agreement would be found between therapists who were asked to make decisions about whether a particular patient could learn or generalize. These models imply that an inability to learn can be recognized with relative ease, yet we know that even comatose head-injured patients are capable of some degree of learning Boyle and Greer (1983); Shiel, Wilson, Horn, Watson and McLellan (1993). Furthermore, it is possible to teach generalization in many instances (Zarkowska, 1987). Despite these, and possibly other reservations, it can be argued that Gross and Schutz's models are useful in encouraging therapists to think about ways of tackling problems in rehabilitation.

An interesting analogy model, 'Sinfonia Hemispherica', was presented by Buffery and Burton in (1982). They compared the brain to a symphony orchestra and brain damage to the situation which might arise should several members of the orchestra develop food poisoning and die a few hours before a concert. From their analogy we can derive several possible approaches to cognitive rehabilitation (Wilson, 1989). First there are three factors affecting the overall performance of the orchestra.

1. The *size* of the lesion – the more violinists who have died the worse will be the performance.
2. The *position* of the lesion – some violinists, such as the leader, are more important than others.
3. *Shock* – although the remaining members of the orchestra are not ill themselves, initially they will be affected by the sudden demise of their colleagues.

Buffery and Burton suggest several ways the orchestra might cope with its predicament. First, the orchestra could recruit new members to replace those who have died. Second, the orchestra could change its repertoire so that missing members are not required to perform. Third, the leader of the orchestra could ask some other members to learn the violin. These members would not be learning from scratch because they would be able to read music and fol-

low the conductor. However, the subsequent decrease in the number of other instruments would lead to an overall decline in the orchestra's performance. Fourth, the leader could ask other instrumentalists to play the violin parts on their instruments. The resulting sound would not be perfect but would probably be reasonably acceptable.

How do these approaches translate into cognitive rehabilitation practice? Recruiting new members to replace those who have died is equivalent to restoring or repairing damaged tissue. Mechanisms of recovery will be addressed later in the chapter. Changing the repertoire is equivalent to changing the living situations and demands on people with brain injury in order to avoid problem areas and is similar to the environmental control model. Asking other members of the orchestra is equivalent to anatomical reorganization based on the idea that undamaged areas of the brain can take on the skills or functions of the damaged areas. Again, this topic will be considered below. Asking other instrumentalists to learn the violin parts is equivalent to functional adaptation or, in other words, if you cannot do something one way, find another way to do it.

Although the 'Sinfonica Hemispherica' model is a useful way of thinking about cognitive rehabilitation there are limitations to the model. In particular it does not take into account the situation which often occurs in brain injury, namely that isolated focal lesions rarely occur. Widespread diffuse damage is more likely after certain conditions such as traumatic head injury so the orchestra would not lose *all* the violinists, nor would it lose *only* violinists. Treatment in this case might involve teaching members of the orchestra to use their residual skills more efficiently, perhaps through extra rehearsal or slowing down the performance.

### **Rehabilitation derived from theories of cognitive functioning**

In 1984 Coltheart argued that rehabilitation programmes should be based on a theoretical analysis of the nature of the disorder to be treated. He expanded on this in 1991 arguing that in order to treat a deficit one had to fully understand its nature and to do this one needed to know how the function is normally achieved. Without this model, said Coltheart, it would be impossible to determine the appropriate treatment. Although it is necessary to understand the nature of the deficit, models of cognitive functioning do not in themselves inform us on the method of treatment. Knowing *what* to treat does not tell us *how* to treat. In the words of Caramazza (1989)

'There is nothing specifically about our theory of the structure of the spelling system (or the reading system, the naming system, the sentence comprehension system, and so forth) which serves to constrain our choice of therapeutic strategy. Merely 'knowing' ... the probably locus of a deficit ... does not, on its own, allow us to specify a therapeutic strategy. To do so requires not just a theory of the structure of the system, but also, and more important, a theory of therapeutic intervention

- a theory of the ways in which a damaged system may be modified as a consequence of particular forms of intervention' (p.392).

We can conclude from this that theories of cognitive functioning are necessary but not sufficient in cognitive rehabilitation.

### **Are there theoretical models of Cognitive Rehabilitation?**

Some people claim to be following a theoretical approach without actually doing so. An influential book by Sohlberg and Mateer (1989) appeared in 1989 in which we are told that cognitive rehabilitation should be grounded in theory. Robertson (1991), however, believes the authors do not follow their own advice. He writes, somewhat harshly... 'the theories of neuropsychological functioning which Sohlberg and Mateer present as underlying their treatment and assessment methods are frankly facile. They are not theoretical models but collections of headings to guide assessment and treatment' (p. 88). Robertson accepts that many of the approaches make intuitive sense but he objects to them being called 'theoretical models'. A later book by Sohlberg and Mateer (2001) does much to redress these criticisms.

Gianutsos (1991) argues that cognitive rehabilitation is the application of theories of cognitive sciences to traumatic brain injury rehabilitation. Apart from the fact that it is not only people with TBI who receive cognitive rehabilitation (people with stroke, encephalitis and hypoxic brain injury are frequently seen in rehabilitation programmes), Gianutsos' approach does not appear to be at all influenced by theories from cognitive science. She favours an approach that stresses exercise and repeated practice in which clients are engaged, for the most part, in computerized exercises (Gianutsos, 1981, 1991; Gianutsos, Cochran, & Blouin, 1985; Gianutsos & Matheson, 1987). There is little, if any, evidence in these papers of theories of cognitive neuroscience.

Models and theories of cognitive rehabilitation then are hard to come by (but see Wilson, 2002). This is not to say that people are uninfluenced by theories. The models of cognitive functioning particularly those from language and reading have been very influential in the assessment and understanding of disorders (see for example Berndt & Mitchum (1995) and Basso, Cappa & Gainotti (2000)). The point to be made here is that they are limited in the contribution they make to treatment. As stated before they tend to tell us what is wrong rather than what to do about it. In addition, people rarely have isolated deficits. They may have widespread cognitive problems together with emotional, social and behavioural problems. They will probably require help with everyday difficulties resulting from their impairments rather than help with a particular deficit caused by a failure in one part of the cognitive model. It is not only theories of language that have been helpful other theories from cognitive psychology have influenced rehabilitation and are frequently used, perhaps implicitly, in the assessment and management of neuropsychological impairments. The working memory



model, for example, (Baddeley & Hitch, 1974), allows us to understand why someone with a normal immediate memory has problems after a delay or distraction. The dual-route model of reading (Coltheart, 1985), has revolutionised reading assessments over the past 15 years. The Supervisory Attentional System of Norman and Shallice (Norman & Shallice, 1986) has influenced the rehabilitation of people with attention and executive deficits. The list is extensive but it is still the case that in order to address the many problems faced by people with brain injury, other theoretical approaches are essential (Wilson, 2002).

### **Other theories relevant to cognitive rehabilitation**

One of the major tasks of a clinical neuropsychologist is to undertake assessments. These are carried out in order to understand the cognitive strengths and weaknesses of our patients and clients. For this purpose standardised tests are often sufficient. They are not sufficient, however, when we want to know about the nature of everyday problems, how families cope and what treatment to offer. In these circumstances we may need to carry out a functional or behavioural assessment. Several theoretical approaches are likely to be involved in our assessments. These include psychometric models, assessments derived from models of cognitive functioning, ecologically valid assessments, localisation models and behavioural models concerned with the observation of real life problems.

Those engaged in rehabilitation will also need some understanding of theories of recovery as some of our patients/clients may be in the natural recovery period. People who survive a severe, traumatic brain injury may show recovery over a period of several years. Robertson and Murre (1999) discuss theories of recovery in some detail and Wilson (1998) considers the evidence for recovery of cognitive function after brain injury.

The management and remediation of the emotional consequences of brain injury and cognitive impairment has become increasingly important over the past decade or so. Prigatano (1999) argues that rehabilitation is unlikely to be successful if we do not deal with the emotional issues. Perhaps the most successful theoretical model for treating emotional disorders is Cognitive Behaviour Therapy (Beck, 1976; 1996). Although it is certainly one of the most important and best validated psychotherapeutic procedures (Salkovskis, 1996), less has been published about cognitive behaviour therapy with survivors of brain injury than with neurologically intact people. Williams et al. (2003), however, describe a combination of cognitive rehabilitation and cognitive behaviour therapy with two such survivors. Both had post traumatic stress disorder together with cognitive impairments. The combined treatment resulted in a reduction of their PTSD symptoms and improvement in both psychosocial and cognitive functioning (see Williams, this volume). Others, particularly Prigatano (1999) favour a milieu-orientated psychotherapeutic approach, developed from Ben-Yishay's milieu holistic approach (Ben-Yishay, 1996).

Compensating for cognitive deficits is one of the major strands of neuropsychological rehabilitation and has been for many years (Zangwill, 1947). It is akin to what Luria called Functional Adaptation (Luria, 1963). A theoretical framework for understanding compensatory behaviour was published by Bäckman and Dixon (1992) and further modified by Dixon and Bäckman (1999). Applying this framework to people with memory impairment following brain injury, Wilson and Watson (1996) found that much of the framework applied but that some modifications were required. Wilson (2000) discussed the framework in relation to a wider range of cognitive problems including language, reading and visuo-spatial deficits while Evans et al. (in press) consider factors that predict good use of compensatory strategies. The main predictors appear to be age, severity of impairment, specificity of deficit and premorbid use of compensations.

Theories and models of behaviour and learning are also necessary in understanding problems and designing neuropsychological rehabilitation programmes. Early behavioural models such as those of Kanfer and Saslow (1969) and more recent ones such as Wood (1990) enable us to incorporate the physical and neurological status of the individual together with behaviour, motivation and other factors. Wilson (1999) provides an example of how the Kanfer and Saslow (1969) model helped both in the understanding and treatment of the problems faced by a man who survived a traumatic head injury.

Learning theory, arguably one kind of behavioural theory, is of paramount importance in achieving change. Baddeley (1993) said 'A theory of rehabilitation without a model of learning is a vehicle without an engine' (p. 235). In recent years the principle of errorless learning (i.e. avoiding trial-and-error learning) has been highly influential in memory rehabilitation (Baddeley & Wilson, 1994; Wilson, Baddeley, Evans, & Shiel, 1994). Errorless learning is discussed in more detail in chapter 10 (this volume).

Although the theories and models described here are among the most important ones in neuropsychological rehabilitation, the list is not exhaustive. Wilson (2002) makes an attempt to put a number of theoretical models together to provide a comprehensive model of rehabilitation but even this model omits some aspects such as motor functioning and physical recovery.

### **Combining theory and practice**

In our clinical work theoretical models can only take us so far. We have to adapt to the individual's needs and circumstances. The work on errorless learning, for example, has established that trial-and-error learning is not a good principle to follow for people with significant memory impairments. In order to benefit from our mistakes, we need to be able to remember them otherwise we may strengthen the incorrect response. In practice, however, the way we apply the principle will vary depending on the goals set. Clare et al's

work with people with Alzheimer's Disease illustrates the point well (Clare, Wilson, Breen, & Hodges, 1999; 2000). One man wanted to remember the names of people at his social club, another woman needed to check a memory board so that she did not pester her husband with questions ad nauseam. Thus the way the principle was applied differed each time. If theories are going to be clinically useful then we need to use our clinical experience and common sense to apply the research findings. The contributors to this book illustrate some of the ways we can integrate theory and practice in neuropsychological rehabilitation.

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# Chapter 2

## STAGES IN THE HISTORY OF NEUROPSYCHOLOGICAL REHABILITATION

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### Introduction

Neuropsychological rehabilitation can be defined as the use of all available means to improve the independence and the quality of life of persons with neuropsychological impairments (Jefferson, 1942). This chapter briefly reviews the history of neuropsychological rehabilitation, emphasizing general trends and identifying a few major historical figures. Other publications with more detailed information about the history of neuropsychological rehabilitation are available (Boake, 1989, 1991, 1996; Ducarne de Ribaucourt, 1997; Howard & Hatfield, 1987; León-Carrión, 1997; Prigatano, 1999).

### Early Neuropsychological Rehabilitation

Neuropsychological rehabilitation is probably as old as neuropsychology itself. The French physician Paul Broca, in one of his papers describing cerebral localization of language, presented a rehabilitation program for an adult patient who was unable to read words aloud (Broca, 1865; Berker, Berker & Smith, 1986). Broca reported that the rehabilitation program began with a kind of

phonics approach in which the patient was sequentially taught to read letters, then syllables, and finally to combine syllables into words. Broca reported that the program succeeded to a limited extent, in that the patient learned to read letters and syllables, but 'failed completely' to read words of more than one syllable. The rehabilitation program then switched to a whole-word approach, in which Broca 'tried then to show him these words without breaking them up into syllables, and I succeeded in teaching him a good number of them' (Berker et al., 1986, p. 1070). Broca expressed surprise that when the patient read words aloud, 'he did not recognize them through their syllables or letters,' and that 'it was only their general form, their length, their appearance that registered' (p. 1070). To check whether the patient used a whole-word reading strategy, Broca presented the patient with misspelled words created by changing 'one or two letters within a word, by replacing them with letters of the same length, as *m* for *n*, *e* for *s*, *p* for *q*, *l* for *t*' (p. 1070). Broca reported that when reading these misspelled words, the patient 'did not even notice it' (p. 1070). Broca concluded that the patient 'was learning to read through a process that was essentially different from that he went through during his youth' and that he 'could recognize a word as one would a face or landscape, the details of which had never been analyzed' (p. 1070).

In attempting to restore the reading skills of his patient, Broca was not setting a precedent. Howard and Hatfield (1987), in their historical review of aphasia therapy, cite several publications from the 1600s and 1700s that describe persons with aphasia who were helped to relearn speech and language skills. Beginning in the 1800s, Edouard Séguin and other French physicians pioneered techniques to improve the cognitive skills of children with developmental cognitive disorders. Among the tools used in this form of cognitive retraining were wooden form boards with pieces cut out in the shapes of different geometric forms. First intended as training tasks, these form boards were later adapted to serve as performance tests of intelligence (Pichot, 1948). It is unknown how and when the first steps were taken in training cognitive skills of persons with acquired brain injury. As suggested by Broca's case study, it is likely that initial attempts at neuropsychological rehabilitation of persons with acquired brain injury were aimed at language disorders. Indeed, Howard and Hatfield (1987) discuss several case studies from the late 1800s and early 1900s that used various techniques to improve communication skills of patients with aphasia. While the number of aphasia therapy publications from this period was small by current standards, the content of these publications appears to emphasize language skills relative to other cognitive domains.

One of the prominent individuals from the early period of neuropsychological rehabilitation is the American psychologist Shepherd Franz. Among Franz's many contributions are his use of psychological methodology to study the efficacy of aphasia therapy and his studies of motor learning in hemiparesis. It is possible that Franz's interest in neuropsychological rehabilitation was linked to his belief that localization of cognition in the brain was exaggerated

by contemporary neurologists. In 1905 Franz reported a rehabilitation program for a patient with aphasia secondary to stroke. Following a habit-learning approach, the patient was drilled on multiple trials of naming colors and numbers, and rehearsing a prayer and poem. This type of bottom-up relearning program was typical of early attempts at aphasia therapy, termed 'speech gymnastics' by Howard and Hatfield (1987). Franz noted that the patient's gradual course of improvement was more in keeping with acquisition of a new habit than with relearning of an old habit (e.g., ice skating). Franz speculated that 'new brain paths are opened in the reeducation process' and that 'it is probable that the right side of the cerebrum takes part' in this process (Franz, 1905, p. 597). In 1917 Franz reported a study of motor relearning in monkeys with hemiparesis produced by surgical lesions (Ogden & Franz, 1917). The monkeys, who underwent a kind of rehabilitation program involving restraint of their intact forelimb, improved their motor performance in their affected forelimb. These monkey studies later helped to inspire current research into forced-use and constraint-induced therapy for hemiparesis.

### First World War

Major developments in neuropsychological rehabilitation took place during the First World War, when dedicated brain injury rehabilitation centers were created for the first time. Probably the greatest development of these centers was in Germany and Austria, where a group of centers was created for medical care and rehabilitation of soldiers with brain wounds (Poser, Kohler & Schönle, 1996) (see Table 1). The Frankfurt center included a residential program or hospital, a psychological evaluation unit, and a special workshop for patients to practice and be evaluated in vocational skills. Today we are more familiar with the activities at the Cologne and Frankfurt centers because of the writings of the centers' directors, Kurt Goldstein and Walther Poppelreuter (Poppelreuter, 1917/1990).

Goldstein's writings include specific recommendations about therapy for impairments of speech, reading, and writing (Goldstein, 1919, 1942; Goldstein & Reichmann, 1920). The therapy techniques generally followed the strategy of using preserved skills to substitute for lost skills. For example, a

Table 1. Brain Injury Centers in German and Austria during World War I.

Country	City	Director
Germany	Cologne	Walther Poppelreuter
	Frankfurt	Kurt Goldstein
Austria	Munich	Max Isserlin
	Graz	H. Hartmann
	Vienna	Emil Froeschels



strategy used with patients who could not make certain speech sounds was to elicit a similar movement (e.g., blowing out tobacco smoke) and then to shape this movement into the desired speech sound. Since Goldstein did not state the source of these substitution or compensation strategies, it is possible that he deserves credit for creating or elaborating this approach. In discussing prediction of a patient's potential to return to work, Goldstein stressed the need for clinical assessments to be combined with direct observation in special vocational workshops.

The history of neuropsychological evaluation during and after World War I is less well documented. After the war, there was a clear falling off of publications about neuropsychological rehabilitation in the medical literature, probably due to the decreased incidence of traumatic brain injury in the postwar years. The neurosurgeon Harvey Cushing (1919) complained that in the USA, many veterans with brain wounds had been evaluated for disability determination, awarded a pension that was inadequate for their degree of disability, and then discharged home without further rehabilitation. Franz (1917) proposed the creation of a national institute to develop more effective interventions for veterans with nervous system injuries. Unfortunately the plan was not funded and the potential of this proposal was never realized.

## Second World War

The continuity of neuropsychological rehabilitation was restored by Alexander Luria, a Russian psychologist who had earned the medical degree in order to facilitate his neuropsychological research with medical patients. When the Soviet Union entered the Second World War, Luria was assigned to a special hospital for brain-wounded veterans (Luria, 1979). Luria's synthesis of his findings with veterans with selective neuropsychological deficits due to penetrating brain wounds served as the basis for his theory of functional systems, which provided a rationale for neuropsychological rehabilitation. Therapy strategies based on this model reached beyond aphasia therapy to include interventions for disorders of motor planning, visual perception, and executive functions (Christensen & Castano, 1996). Fortunately, some of Luria's most important works were translated into other European languages. In English, the books *Restoration of function after brain injury* (Luria, 1948/1963) and *Traumatic aphasia* (Luria, 1947/1970) present Luria's work with brain-wounded veterans of the Second World War.

Developments in neuropsychological rehabilitation in other countries during and immediately after the Second World War continued the focus on aphasia. In the UK, a group of brain injury treatment centers was created, each providing both medical and rehabilitation services. The centers in Oxford and Edinburgh were sources of important discoveries in clinical neuropsychology. At the Oxford center, the neurologist W. R. Russell demonstrated the value of post-traumatic amnesia duration in predicting functional outcome from trau-

matic brain injury (Russell, 1971). In Edinburgh, Edna Butfield and the psychologist Oliver Zangwill carried out an uncontrolled study of outcome from aphasia therapy, using therapy techniques largely adapted from Goldstein. The authors noted that, while the results showed that patients' speech 'was judged to be much improved after re-education,' the lack of a control group limited the conclusions that could be reached because 'we possess no definite standards whereby to assess spontaneous recovery of cerebral function as opposed to the effects of re-education' (p. 75). In an attempt to control for spontaneous recovery, Butfield and Zangwill carried out a separate analysis of the outcomes of patients who had started therapy at least 6 months after the onset of illness, 'when relatively little further spontaneous improvement was to be expected'.

Zangwill made a number of theoretical and clinical proposals that are still relevant to neuropsychological rehabilitation. He proposed that neuropsychological rehabilitation could follow either of two strategies, one of 'direct retraining' and the other of 'substitution' (Zangwill, 1947). He speculated that direct retraining might be more effective with impairments, such as those of speech articulation and arithmetic, that could be addressed through drill exercises. In discussing the use of psychological testing in brain injury rehabilitation, Zangwill (1945) stressed the need for comparing psychological test results with performance in vocational workshops, in order to reach a more valid prediction of vocational outcome.

Possibly in imitation of the UK model, a group of brain injury centers was established in the USA to provide specialist medical and rehabilitation services to brain-wounded veterans (Spurling & Woodhall, 1958). In the center at Dewitt General Hospital in California, Joseph Wepman (1951) carried out an uncontrolled study of outcome from aphasia therapy. It is interesting to note that some of the psychological tests (e.g., Wechsler intelligence scales) administered to veterans in this study remain in use today, a half-century later (Boake, 2002).

In contrast to the decline in activity in neuropsychological rehabilitation after the First World War, the period after the Second World War witnessed the large-scale creation of rehabilitation programs in different countries. The profession of speech-language pathology dramatically expanded in order to meet the need for aphasia therapy in new rehabilitation facilities (e.g., Veterans Administration hospitals in the USA). The professions of occupational therapy, physical therapy, psychology, and vocational rehabilitation counseling also underwent rapid development in order to meet the needs of veterans with disabilities.

## Postwar Developments

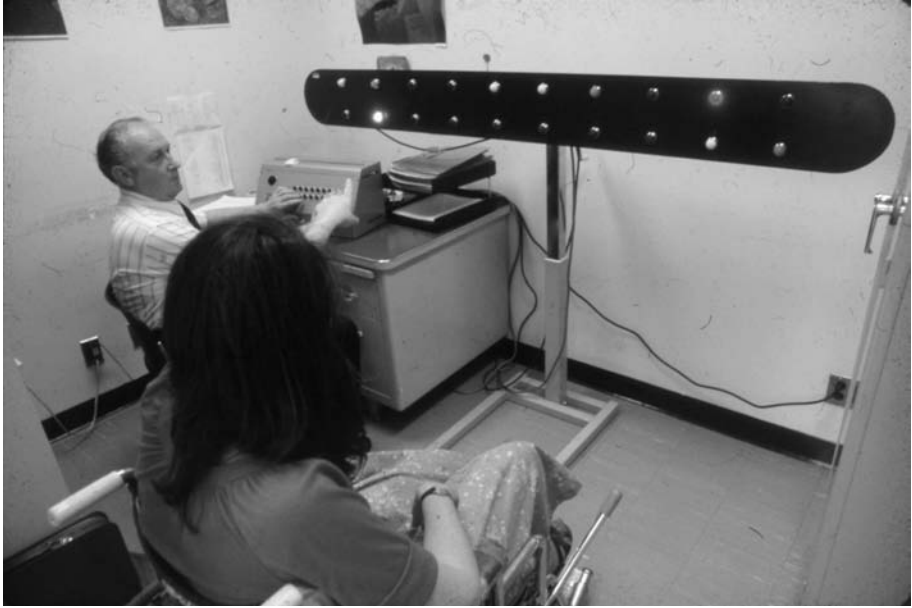
The beginning of the current period of neuropsychological rehabilitation was rooted in the postwar growth of neuropsychological research and in the

increasing incidence of traumatic brain injury from motor vehicle accidents (Jennett & Teasdale, 1981). Discoveries in neuropsychological research helped to identify the specific impairments responsible for perceptual and memory disorders, implying that remediation of these underlying deficits could improve performance in a wide range of activities.

A seminal event in the history of neuropsychological rehabilitation was the rehabilitation program developed by neuropsychologists at New York University (NYU) Medical Center for patients with left visual neglect due to stroke. Research analyzing the difficulties experienced by these patients pointed to an underlying deficit in visual scanning, such that the patients made relatively fewer attempts to scan toward their left side (Diller, Ben-Yishay, Gerstman, Goodkin, Gordon, & Weinberg, 1974). Based on this research, a rehabilitation program was created to train patients to scan toward their left side. The rehabilitation program began with relatively simple scanning tasks in which patients were provided with multiple verbal and visual cues to respond correctly. With progress, patients were provided with fewer cues and presented with more difficult tasks (e.g., paragraph reading). The NYU neuropsychologist Leonard Diller and colleagues carried out a small controlled trial evaluating the visual-motor performances of patients who received scanning training on cancellation and visual search tasks (Diller et al., 1974) (see Fig. 1). Later studies by the NYU group extended the scope of training to include visual construction and body awareness (Gordon et al., 1985; Weinberg, Diller, Gordon, Gerstman, Lieberman, Lakin, Hodges, & Ezrachi, 1977, 1979). The therapy model of scanning training has inspired a large number of research studies in neuropsychological rehabilitation and appears to have influenced clinical practices of neurorehabilitation therapists (Bergero, Azouvi, Deloche, Samuel, Louis-Dreyfus, Kaschel, & Willmes, 1997; Kerkhoff, 2000; Pizzamiglio, Antonucci, Judica, Montenero, Razzano, & Zoccolotti, 1992; Robertson & Halligan, 1998; Wagenaar, Van Wieringen, Netelenbos, Meijer, & Kuik, 1992; Wiart, Saint Côme, Debelleix, Petit, Joseph, Mazaux, & Barat, 1997).

Signs of increased interest in rehabilitation of persons with traumatic brain injury became evident in the late 1960s and early 1970s, in the form of meetings devoted to this topic (Höök, 1972; Walker, Caveness, & Critchley, 1969). Accompanying this interest was a shift in the focus of research on neuropsychological consequences of traumatic brain injury, away from the functional versus organic dichotomy toward establishing an objective basis for cognitive and behavioral problems.

The development of specialized brain injury rehabilitation programs in Israel after the Yom Kippur War in 1973 is yet another example of how war-time casualties have stimulated progress in neuropsychological rehabilitation. The NYU neuropsychologist Yehuda Ben-Yishay developed a day treatment program in Tel-Aviv, where small groups of veterans with brain wounds participated in a program comprising cognitive exercises, psychotherapy, and therapeutic community activities for a duration of several months (Ben-



**Fig. 1.** Dr. Joseph Weinberg (left) operating a visual scanning apparatus (or ‘scanner’) at Rusk Institute of Rehabilitation Medicine, New York University Medical Center. The scanner was used during the 1970s and 1980s in a neuropsychological rehabilitation program for patients with visual neglect (Gordon, Hibbard, Egelko, Diller, Shaver, Lieberman, Shaver, & Ragnarsson, 1985). The scanner consisted of a stimulus board with two rows of colored light bulbs, controlled from a console operated by the therapist. Patients were trained to visually scan the stimulus board from left to right, in order to detect which lights were illuminated. In the first stage of training, patients detected single lights in the unaffected visual field. Scanning tasks were gradually increased in difficulty until the patient detected multiple lights on both sides of the stimulus board. (Photo reproduced by permission of Dr. Weinberg).

Yishay, Ben-Nachum, Cohen, Gross, Hofien, Rattok, & Diller, 1978). A major focus of therapy activities was to increase the patients’ awareness of injury-related impairments and acceptance of realistic outcomes, particularly vocational goals (Ben-Yishay, 1996). The day treatment program model was recreated at NYU in a form adapted to young adults with closed head injuries, generally the result of civilian motor vehicle accidents. The basic model of his program has been emulated in many countries (Christensen, Pinner, Møller-Pederson, Teasdale, & Trexler, 1992; Prigatano, Fordyce, Zeiner, Roueche, Pepping, & Wood, 1986; Scherzer, 1986).

During the 1970s and 1980s several new models of neuropsychological rehabilitation programs were created. In a transitional learning center or residential rehabilitation program, patients reside at the center while receiving interventions for behavior and self-care that would be more difficult to

address in a day treatment setting (Boake, 1990). The newest type of rehabilitation program attempts to directly improve the patient's adjustment to a particular residence, community, and job, while providing few or no services in a center. For example, a supported employment program attempts to place a patient into a job and then provide services (e.g., job-specific memory aids) at the actual job site (Wehman, West, Kregel, Sherron, & Kreutzer, 1995).

Alongside the holistic and vocational programs there developed a number of interventions directed at specific cognitive deficits, many of which involved the use of computer programs to administer repetitive drill exercises. Among the earliest computer programs were those developed by Rosamond Gianutsos for remediation of memory and visual impairments. For example, Gianutsos (1981) reported a case study of a rehabilitation program for a professor with amnesia caused by encephalitis. The rehabilitation program aimed to directly improve his memory for new spoken information by using mass practice in memorizing word lists. Similar treatment programs, also based on computer software, were developed for retraining of deficits in language and visual perception. During the 1980s a debate occurred between advocates of direct retraining of cognitive deficits and those who maintained that, because direct retraining was impossible, therapies should address concrete goals such as performing a specific job (Mateer & Sohlberg, 1988).

A recent development in neuropsychological rehabilitation is the concern with providing hard data about the efficacy of neuropsychological rehabilitation. In the USA, where clinicians have encountered increasing difficulty obtaining insurance funding, reviews of treatment efficacy studies have reached conflicting conclusions about the efficacy of neuropsychological rehabilitation (Chesnut, Carney, Maynard, Mann, Patterson, & Helfand, 1999; Cicerone, Dahlberg, Kalmar, Langenbahn, Malec, Bergquist, Felicetti, Giacino, Harley, Harrington, Herzog, Kneipp, Laatsch, & Morse, 2000; Consensus Conference on Rehabilitation of Persons with Traumatic Brain Injury, 1999). However, one conclusion shared by most reviewers is that methodological flaws in existing research on neuropsychological rehabilitation limit the specific treatment recommendations that can be made in terms of intensity, duration, and cost-effectiveness (Chesnut et al., 1999). Therefore, the future of neuropsychological rehabilitation may be shaped not only by research showing that patients' outcomes need to be improved, but also by research showing that interventions are effective in doing so.

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# Chapter 3

## REHABILITATION FOR DISORDERS OF ATTENTION

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### Summary

The scientific study of attention is a relatively new and rapidly developing field. Insights from this work are already influencing clinical practice in terms of improved assessment and rehabilitation of people with brain injuries. After briefly introducing some conceptual issues, a major section of this chapter concerns one of the most striking and surprisingly common acquired disorders of attention, unilateral spatial neglect. Six very different approaches to ameliorating this condition are considered, including recent results using prism lens adaptation. In the second section, the chapter focuses on difficulties in non-spatial attention faced by adults who have suffered a brain injury. Disorders of attention are associated with slowed recovery and reduced outcome. It is clear that in addition to any direct impediment to everyday activities, problems at this level can compromise the useful expression/recovery of other capacities. Although theory, assessment and rehabilitation in this important clinical area are at an early stage, the reviewed evidence provides some optimistic pointers for future development.

### Introduction

Looking around, there are probably numerous objects that you could choose to examine, pick-up, prod or just think about. If you close your eyes, you can

become aware of a startling number of background sounds – the wind outside, the whirring of the ventilation system, the distant swearing of children. If you move your focus to the sensations on your skin – you may be able to feel your watchstrap or become conscious of the pressure of your shoes against your feet. Finally try to think about the last time you were on a boat – Why were you there? Who else was present? In each case, objects, sensations or thoughts that lay largely outside awareness a moment ago can be promoted to dominate current experience by a mere expression of will. In general, we would view this capacity to selectively focus and to suppress competing information as a useful thing – allowing us to prioritise our processing and to get a job done. At other times, we can become aware that this selection is not simply a matter of choice. If we are desperately trying to listen to the sports results on the TV, for example, while maintaining a polite conversation about a friend's recent gardening triumphs, maintaining an even distribution of attention between the two competing inputs is extremely difficult.

William James (1890) wrote of attention:

‘Everyone knows what attention is. It is the taking possession by the mind, in clear and vivid form, of one out of what seem several simultaneous possible objects or trains of thought. Focalisation, concentration of consciousness are of its essence. It implies withdrawal from some things in order to deal effectively with others.’

Crucial aspects of this definition remain central to contemporary views, in particular the notions of *selection* from between potential targets, that attending to one thing is likely to be at the expense of another (*capacity limitation*) and the close relationship between attention and conscious experience.

In the 1940s and 50s, attention came to some prominence as a topic amenable to empirical as well as introspective investigation. Psychologists would, for example, ask experimental participants to try to divide their attention between two streams of information presented using headphones to different ears (Broadbent, 1958). In other studies, deterioration in performance over long periods of performing the same, dull monitoring task was taken as the variable of interest (Mackworth, 1948). This early work has been hugely influential. The explosion in scientific investigation over recent decades has been so great that it is now, by common consent, almost impossible to provide an exclusive definition of the term ‘attention’.

The application of these experimental techniques to people with brain injuries, and, increasingly, to healthy individuals in brain scanning studies, has led to a developing understanding of how our brains might perform ‘attention’. Reviewing this area in the 1990s Posner and Petersen (1990) proposed a provisional set of principles. The first was that the brain has networks or systems that are somewhat specialised in attention – that is, they are separable from basic perceptual and motor processes. Clinically, this means that it is possible to acquire a deficit that is predominantly or exclusively attentional in

nature. Secondly, in experimental studies, researchers had generally referred to the 'type' of attention required in terms of the particular task demands (e.g. 'focused attention', 'spatial attention', 'sustained attention' and so forth). Posner and Petersen argued that these functional distinctions might be mirrored, to a degree, in the brain, with different areas performing rather specific attentional processes. In particular they highlighted potential separation between '*orienting*' or '*spatial attention*' – the capacity to prioritise information from one region of space; '*focused*' or '*selective attention*' – the capacity to prioritise relevant information and suppress irrelevant information regardless of its location in space; and '*alertness*', '*vigilance*' or '*sustained attention*' – the capacity to maintain a general 'ready-to-respond' receptive state. Clinically, this again means that, depending on the location of damage, very different profiles of attentional impairment may be apparent (for other taxonomies see Mirsky, Anthony, Duncan, Ahearn, & Kellam, 1991; Van Zomeren & Brouwer, 1992).

Problems in attention and concentration are among the most commonly reported consequences of traumatic brain injury (e.g. Oddy, Coughlan, Tyerman, & Jenkins, 1985; Brooks & McKinlay, 1987). Impairments in attention, particularly spatial attention, have also been documented in over 50% of patients who have suffered a stroke in the immediate post-lesion stage (e.g. Ogden, 1985; Stone, Halligan, & Greenwood, 1993; Leclerk & Zimmermann, 2002). As our understanding of attention improves, its importance in recovery from brain injury is increasingly apparent. This applies both to attention as a useful skill in its own right and to its potential role in mediating recovery in ostensibly very separate systems, such as motor function (Ben-Yishay, Diller, Gerstman, & Haas, 1968; Denes, Semenza, Stoppa, & Lis, 1982; Fullerton, McSherry, & Stout, 1986; Sea, Henderson, & Cermack, 1993; Blanc-Garin, 1994; Robertson, Ridgeway, Greenfield, & Parr, 1997c; Cherney, Halper, Kwasnica, Harvey, & Zhang, 2001; de Seze et al., 2001; Paolucci, Antonucci, Grasso, & Pizzamiglio, 2001a; Paolucci et al., 2001b). Interventions that can lead to improvements in attentional function – or which ameliorate the effect of impairments – are therefore important clinical aims.

This chapter considers various attempts to work with patients in 'rehabilitating' these disorders. It is important, however, to issue a few words of caution at this stage:

Firstly, rehabilitation is used in inverted commas because the term should really refer to improvements in a patient's capacity to achieve important functional goals in everyday life. As we shall see, this has only been assessed in a few of the studies presented. Many of the concepts of attention that we use clinically have been imported from the 'normal' experimental literature. This offers some advantages in terms of conceptual clarity but the extent to which these relate to the difficulties that patients actually report often remains an open question. Although it is difficult to believe that we have functions that are only tapped by neuropsychological measures and untouched by real life,

whether any change actually contributes to complex everyday activities should be evaluated rather than assumed. Measuring such changes amid the ‘noise’ of real life is, of course, a far from easy business. Many of the studies discussed here should therefore be considered as optimistic pointers to what may be possible, rather than rehabilitation per se.

Secondly, the study and assessment of attention are at a very early stage. Attention cannot be observed directly and must be inferred from the performance on tasks that require many other abilities – features that make it both a somewhat approximate exercise and one that is vulnerable to swings in the theoretical pendulum. The attention taxonomies proposed are provisional and subject to continual revision. It may well be that in a few years we will have a quite different view of the problems presented by patients and, if rehabilitation has been very closely linked to, and evaluated by, particular paradigmatic approaches, will need to rethink our interventions.

The final point, which almost goes without saying, is that rehabilitation is optimally conducted in a manner that takes into account the individual goals and circumstances of a patient, and which operates at a number of levels, including psychosocial support for the patient and his or her family. Many studies quite rightly attempt to control out such factors as ‘nuisance variables’ in order to examine specific effects (e.g. more general supportive rehabilitation will be offered to both the experimental and the control group). This emphasis can sometimes be misinterpreted and clearly the techniques described here are best explored as part of a broader, holistic rehabilitation framework.

## Spatial Attention

### Unilateral spatial neglect

Unilateral spatial neglect is probably the most striking manifestation of an *attentional* disorder. It refers to a difficulty in detecting, acting on or even imagining information from one side of space, that cannot be fully accounted for by basic perceptual loss. Patients with neglect may, for example, fail to detect food on the left side of their plate, fail to notice someone approaching from the left, miss words from the left side of a page, forget to wash or dress the left side of their body, and collide with objects when moving around. In principal, neglect can be assessed on any task that has a spatial component, as the key issue is the *difference* between performance on one side and another. In addition to observing difficulties in everyday activities, widely used standardised measures include cancellation tasks (in which patients are asked to find and cross out stimuli distributed over a sheet), line bisection (in which patients are asked to find and mark the centre of a line), and varieties of drawing and copying tasks. It is important to note at this stage, however, that spatial neglect is a rather heterogeneous condition or syndrome, with many dissociations being noted between manifestations in different patients. This means that, whilst performance on any task that shows a lateralised attentional bias may

be considered definitive of neglect, it does not necessarily follow that neglect will be apparent on all other measures. Similarly, the absence of neglect on a task can not be used to completely rule out bias in other activities – or indeed to convincingly demonstrate recovery or rehabilitation.

Although neglect can occur in a variety of neurological conditions, its most frequent cause is cerebro-vascular disease, where it has been observed in up to 82% of patients with right hemisphere stroke and 65% of left hemisphere patient in the immediate post-stroke stage (Ogden, 1985; Stone et al., 1992; Stone et al., 1991; Stone et al., 1993). This almost even distribution in risk following damage to either side of the brain is followed by a strikingly asymmetrical pattern of recovery. Although the majority of patients with left or right sided damage show quite rapid spontaneous improvement in this aspect of their condition, almost all patients with chronic forms of neglect will have right hemisphere lesions and neglect the left side of space (Ogden, 1985; Stone et al., 1992; Stone et al., 1991).

In terms of the location of lesions that can lead to neglect, the disorder has classically been associated with damage to the parietal cortex (Brain, 1941; Vallar & Perani, 1986). Subsequent studies have shown, however, that neglect can be observed following damage to a variety of cortical regions (including temporal and frontal) and subcortical structures (Mesulam, 1981; Damasio, Damasio, & Chui, 1980; Bradshaw & Mattingley, 1995; Chung et al., 2000; Hier, Davis, Richardson, & Mohr, 1977; Kumral, Evyapan, & Bal-kir, 1999; Velasco, Velasco, Ogarrio, & Olvera, 1986; Samuelsson, Jensen, Ekholm, Naver, & Blomstrand, 1997; Karnath, Ferber, & Himmelbach, 2001). These observations suggest that aspects of the disorder can emerge following damage to a widely distributed network responsible for attention and action within space.

The *attentional* nature of the disorder is perhaps best characterised through comparison with unilateral visual field deficits, basic perceptual losses that often co-occur with neglect and which can be difficult to distinguish from the condition. Like neglect, *hemianopia* (loss of information from the majority of one visual field – and, hence, side of space) or *quadraniopia* (loss of information from one quadrant of the field) are primarily caused by cerebro-vascular disease (Hier, Mondlock, & Caplan, 1983; Zihl, 2000).

Important distinguishing features include the fact that that visual field disorders are retinotopically based, meaning that information reaching a particular *area of retinal cells* will simply not get through.<sup>1</sup> In contrast, neglect generally affects awareness of information because of *where it is in space*

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<sup>1</sup> The situation can be slightly more complicated, depending on the precise locus of the damage. Processing in the visual system is conducted in a parallel and hierarchical fashion and it is possible to lose specific elements of information (e.g. colour, form, motion) from particular regions of the visual field. See, for example Zihl, (2000) for more detailed discussion of visual field disorders and their rehabilitation.

rather than where it falls on the retina. The neglected space may be defined relative to the head, the body midline (Karnath, Schenkel, & Fischer, 1991) or (in the case of tactile stimuli) by the location of the limbs (Mattingley & Bradshaw, 1994). Neglect can also operate along spatial co-ordinates that have little to do with the relative location of one's body. This is sometimes apparent in multiple object drawing tasks in which patients may successfully copy the right side of *each* of the presented objects, even those that lie to the left of details of another object that they omit. In a striking demonstration of such 'object-based' neglect, Driver and Halligan (1991) used drawings of skyscraper-like buildings that had a clear principle axis. They found that, as they rotated the building (causing it, for example, to lean to the right) the patient's neglect 'rotated' with it – they continued to ignore the 'left-side' of the building, despite it now being on the right side of 'space'.

Neglect, unlike visual field cuts, can be modulated by attentional cues (Posner & Walker, 1984; Riddoch & Humphreys, 1983; Halligan & Marshall, 1994b), simultaneously affect different modalities (vision, hearing, touch), and show interactions between modalities (for example, the presence of a right sided visual stimulus can modulate patients' ability to detect a touch to their left; Mattingley, Driver, Beschin, & Robertson, 1997). Bisiach and Luzzatti (1978) demonstrated that neglect could affect mental imagery as well as current perceptual input – famously showing that Milanese patients' ability to recall the buildings in the Piazza del Duomo was significantly modulated by where they imagined themselves standing – again a feature that would not be observed with basic visual loss.

As discussed, the great majority of neglect patients show rather rapid recovery from their spatial bias – and this process disproportionately favours patients with left hemisphere damage. The reasons for the association between chronic neglect and right hemisphere damage remain somewhat open. Weintraub and Mesulam (1987), for example, have argued that the left hemisphere is responsible for the allocation of attention to the right half of space while the right hemisphere is capable of driving attention to the left or the right. Consequently, damage to the right hemisphere leads to domination of a rightward bias from the intact left hemisphere, while an intact right hemisphere is able to compensate for damage to the left. Given recent evidence for a primary role of the temporal cortex in mediating neglect, it has been suggested that the specialisation for language within this region on the left may account for this asymmetry and differences with the animal literature (Karnath et al., 2001). Another model suggests that each hemisphere may be somewhat specialised for particular forms of processing, with the right hemisphere being better adapted to take in the whole scene and the left hemisphere better adapted to focus on local details. Again, the consequence would be that damage to the right hemisphere would lead patients to focus on specific details within right space. In contrast, damage to the left hemisphere may impair detailed processing but leave a gross representation of the spatial characteristics of a scene intact (Halligan & Marshall, 1994a).

An alternative view, emphasises the role of damage to non-spatial right hemisphere capacities that may form the setting conditions that allow neglect to *persist* (see Heilman & Valenstein, 1979; Heilman, Schwartz, & Watson, 1978; Posner, 1993; Robertson et al., 1997b; Samuelsson, Hjelmquist, Jensen, Ekholm, & Blomstrand, 1988; Robertson & Manly, 1999). In line with this view, a recent study has shown that neglect can re-emerge in apparently recovered patients as they performed a spatial test, if they were given a second attentionally demanding task to perform at the same time (Barolomeo, 2000; see also Robertson & Frasca, 1992). Similarly, Lazar et al. (2002) have shown that administering a sedative (midazolam) to 'recovered' neglect patients could also unmask residual spatial biases – again suggesting that the availability of non-spatial limited capacity attentional resources may be important in mediating recovery.

These findings have a number of implications for how rehabilitation should be conducted with people who show a protracted form of unilateral neglect, and how the results should be assessed. The first is that rehabilitation techniques that rely on patients being aware of their deficit and using conscious (attentionally demanding) strategies to overcome it are unlikely to be effective for anything more than a brief period (see Halligan & Marshall, 1994b). The more successful techniques (see below) should be those that effectively *oblige* (rather than *encourage*) patients to become more aware of left space. The second is that – in assessing recovery and rehabilitation – if we rely exclusively on tests that are conducted in a quiet atmosphere and which implicitly focus the patient's attention on a single task, we may miss residual deficits that will be apparent in the complex, demanding and noisy setting of many everyday activities.

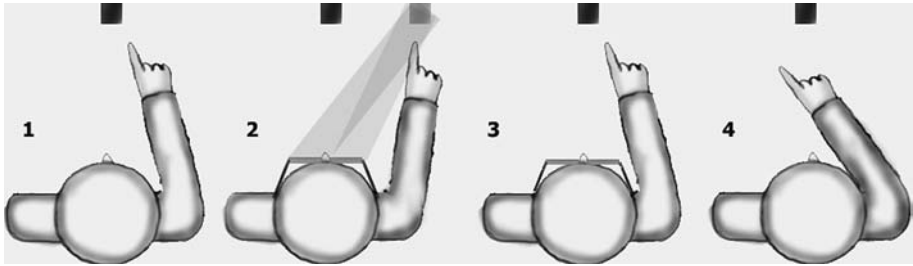
## Rehabilitation for unilateral neglect

### *Prism lens adaptation*

Prism lens adaptation based therapy for unilateral neglect is a relatively recent development. If the promise of these initial studies is realised, this easily administered technique is set to become a key element in programmes addressing the disorder.

Most readers are probably familiar with the distorting effects of prism lenses. If such lenses are worn as spectacles, the visual world can be shifted to the left or right, up and down, or even completely inverted. If, when first wearing such glasses, we are asked to reach out to touch an object, we will almost certainly be inaccurate – quite reasonably reaching to where we see the object rather than where it actually is. Quite rapidly, however, our motor system takes account of the shift and accuracy is restored. Although such changes could be strategic, ('I must point to the left of where I think the object is'), the effect of removing the spectacles suggests that a much more automatic correction is occurring. When the lenses are removed, pointing now tends to be inaccurate in the opposite direction – that is, the correction





**Fig. 1.** Normal prism adaptation effect. 1) Before wearing the prism lenses, pointing to the object is accurate. 2) Wearing lenses that distort space to the right initially leads to inaccurate reaching towards the apparent location. 3) Experience of errors leads to correction. 4) Removal of the lenses leads to a distortion in the opposite direction.

for the presence of the lenses is still in place. This ‘rebound’ is called the *negative after-effect* (see Fig. 1). If healthy individuals are prevented from seeing their reaches during the negative after-effect period (and therefore quickly re-adapting), the distortion may last from minutes to hours (Redding & Wallace, 1997).

On the face of it, prisms could have a use as a prosthetic aid in visual neglect – shifting objects located on the neglected left side to the right and into awareness. Remarkably, however, the greater therapeutic effect appears to emerge not when the prisms are worn permanently, but when they are briefly used to create the negative after-effect.

Rossetti and colleagues (1998) asked a group of patients with right hemisphere lesions and left neglect to wear prism spectacles that caused a 10-degree rightward distortion. The training involved less than five minutes of pointing towards targets. During this phase, the reaching hand (and, hence, the error) was visible to the patients. When the spectacles were removed there was the expected negative after-effect. The patients’ ‘straight ahead’ reaches now deviated to the left relative to the pre-prism exposure baseline. Although Rossetti et al. report that the negative after-effect was much reduced in patients showing neglect when wearing prism lenses that caused a leftward deviation, the most striking result concerned the effect of this brief exposure to rightward distorting prisms on subsequent spatial tests. Significant improvements were apparent in the patients’ line bisection, line cancellation, drawing and reading performance. These benefits were maintained for at least two hours after the prisms had been removed.

In healthy people, the negative after-effect of wearing prism lenses tends to be restricted to the ‘prism-trained’ hand, and, as discussed, is quite quickly corrected if they are allowed to see their reaches during the post-prism phase. The results of research with patients who show neglect suggests that something rather different and more powerful is occurring. Rossetti et al. (1998) showed that the benefits were apparent on a *reading* test – a task that clearly does not

require reaches from the trained hand (a result recently confirmed by Farnè, Rossetti, Tonolio, & Ladavas, 2002). Subsequent research has also shown improvements in general postural control (Tilikete et al., 2001), wheelchair navigation (Rossetti et al., 1999), and even mental imagery (Rode, Rossetti, & Boisson, 1999). In accounting for these apparently pervasive and lasting benefits, Rossetti et al. (1998) have suggested that the mismatch between the seen and actual location of objects acts – in some manner – to ‘re-calibrate’ the pathological system in a more adaptive way. Mattingley (in press), citing work from Duhamel, Colby, and Goldberg (1992) and Heide and Kompf (1997), draws attention to the potential role of this strong ‘error signal’ in updating information from extra-retinal sources in the posterior parietal cortex.

In the largest clinical study on prism lens adaptation so far reported, Frassinetti, Angeli, Meneghello, Avanzi, and Ladavas (2002) examined the effects of a two week programme of prism exposure (20 minutes per day, 5 days per week). As with the original Rossetti et al. study, patients were instructed to point to (90) visual targets presented centrally or to the left and right, while wearing prisms that created a 10-degree rightward shift. Compared with a control group (who, although in a different hospital, were otherwise well matched on age, time-since injury and neglect severity) the prism-exposed group showed significant improvements across a range of tasks. These included both the Conventional and Behavioural subtests of Behavioural Inattention Test (Wilson, Cockburn, & Halligan, 1987), a reading measure (Ladavas, Shallice, & Zanella, 1997) and tasks requiring patients to name objects located around a room and to reach for objects on a table. As would be predicted from the earlier studies, these improvements were of much greater longevity than the negative after-effect itself, and were still present or even strengthened 5 weeks after the end of the training period.

### *Eye-patching*

The superior colliculi in each hemisphere have a role in controlling eye-movements and shifts of attention into contralateral space. They also exist in somewhat of a dynamic relationship, activity in the right hemisphere serving to suppress activity in the left, and vice versa. As the colliculi primarily receive input from the contralateral eye (rather than visual field), Butter and Kirsch (1992) predicted that preventing stimulation to the unimpaired left colliculus by patching the right eye, may allow residual function in the right hemisphere to be better expressed.

In a study that attempted to strengthen this effect by presenting flickering light stimulation to the left eye (and therefore right colliculus), this prediction appeared to be well supported. Approximately 70% of the patients showed significantly reduced bias on a line bisection test performed while the patch was in place (although a number of other measures were unaffected).

Subsequent evaluations have, however, produced more varied results. Serfaty, Soroker, Glicksohn, Sepkuti and Myslobodsky (1995) found that, while approximately half of their sample showed benefits from right-eye

patching, an almost equal number showed no benefit, and two patients were actually worse. Walker, Young and Lincoln (1996) found improvement in three patients, poorer performance in four patients and no change in two. In a case study, Barrett, Crucian, Beversdorf and Heilman (2001) reported that, whilst right eye patching produced a poorer performance, patching the *left* eye was associated with a significant reduction in neglect. It is clearly premature to rule out what might be a powerful and easily applied technique simply because it does not work for everybody. As discussed, neglect is a very heterogeneous condition. As with all the other rehabilitation interventions described here, much more work is required in examining which patients – or which forms of neglect – are most likely to benefit.

Beis, Andre, Baumgarten and Challier (1999) considered the effect of blocking input from one spatial hemifield, rather than one eye. This technique may be effective because of a behavioural training effect, effectively forcing patients to make leftward scans (or at least not let their gaze deviate to the right) if they are to 'see' at all. Reducing cortical visual stimulation to the left hemisphere may also provoke an effect similar to that outlined above, namely through allowing residual function in the damaged right hemisphere to be better expressed.

Twenty-two patients with neglect were randomly allocated to one of three groups. The first received no treatment. The second, as with Butter et al.'s study, were asked to wear glasses with patches over the entire right lens. The third group wore glasses that, due to the masking of the right side of each lens, obscured the right visual hemifield. Patients in each of the treatment conditions were asked to wear the adapted glasses for approximately twelve hours a day over a three-month period.

When re-tested at the end of the treatment (without the glasses), the hemifield group showed significantly increased spontaneous eye-movements into left space relative to the untreated control group. They also showed significant gains on a measure of functional independence in everyday activities, although the higher level of performance of the control group at the outset (leading to possible ceiling effects) means that this result should be interpreted cautiously. In contrast, the right eye patched group showed no significant benefits.

While further evaluation is warranted, including on the usefulness and safety of the treatment in the context of a dense left hemianopia, this technique is certainly easy to implement and, importantly, does not require patients to remember a strategy or consciously adjust their behaviour. If the gains in everyday activities prove reliable, the fact that the patients were exposed to the treatment as they went about their normal routine for well over 1000 hours may also be valuable in understanding this generalisation.

### *Visual scanning training*

Attempts to increase leftward visual scans through progressive training and reinforcement have been explored since at least the 1960s. Lawson (1962), for example, describes a systematic attempt to reduce the number of left-

sided word omissions made by a patient when reading a book. The procedure involved repeated reinforcement for finding the left margin of the page before beginning to read each line – in essence creating an ‘object’ on the left which re-contextualises the beginning of the text line as being on the ‘right’. The intervention was indeed effective in reducing the frequency of left sided word omissions. The difficulty highlighted by Lawson and subsequent researchers was that such improvements could often be highly specific to the trained context – in this case not even generalising to a different edition of the same book.

Weinberg et al. (1977) and Diller and Weinberg (1977) developed a different and more abstract technique for training leftward scanning. In their procedure, patients would be asked to look at an array of lights and to track the ‘movement’ of the light as adjacent bulbs were sequentially illuminated. The technique was to begin with movement predominantly within right space and then progressively increase the frequency of scanning into left space. As with the reading training, patients performance on the task tends to improve but, again, generalisation to other activities has unfortunately proved rather elusive (see Webster et al., 1984; Wagenaar, Wieringen, Netelenboss, Meijer, & Kuik, 1992; Ross, 1992; Robertson, Gray, & McKenzie, 1988). This lack of generalisation does not mean that such techniques have no value in rehabilitation but does suggest that training is best conducted on activities that patients want or need to perform. Webster et al. (2001), for example, have shown that systematic training related to navigating an electric wheel-chair can produce tangible real-life advantages for patients.

Given that neglect exerts an influence over so many activities of daily living, the goal of a more general rehabilitation technique that may produce benefits across different contexts and on untrained tasks remains important. In this respect, more recent incarnations of leftward scanning training give grounds for optimism. Pizzamiglio et al. (1992) describe a programme in which patients were offered approximately 40 hours of highly systematic training. Using a variety of tasks, patients were initially given highly salient cues and encouragement for even moderate visual scans into left space. As performance improved these were progressively faded. The results suggested that, in addition to enhancing performance on the trained tasks, the programme was associated with improvements on untrained tests and, crucially, on structured everyday activities. The results were subsequently replicated in a fully randomised trial (Antonucci et al., 1995). The reasons for the success of the generalisation in comparison to previous scanning training studies remain unclear, although the authors suggest that the extended duration of the programme may have been an important factor.

#### *Optokinetic Stimulation, Caloric Vestibular Stimulation, and Neck Muscle Vibration*

A number of techniques that induce a distortion in the perception of space have been used to correct the bias of neglect. These are; *optokinetic stimula-*

*tion* (where a background pattern of moving dots induce involuntary eye-movements and a subjective shift in midline; Pizzamiglio, Frasca, Guariglia, Incoccia, & Antonucci, 1990); *caloric vestibular stimulation* (where a difference in temperature between the ears induced by hot or cold water induces a distortion via the vestibular system; Rubens, 1985; Cappa, Sterzi, Vallar, & Bisiach, 1987); and *posterior neck muscle vibration* (which is thought to create the illusion that the head is somewhat turned; Karnath, 1994; Karnath, Christ, & Hartje, 1993). Although these effects have been theoretically illuminating, the relatively brief duration of the improvements, in combination with the practicalities of administration, have led to pessimism about their role in rehabilitation. However, it may be that, in giving patients experience of 'the left' without requiring voluntary exertion of effort, such interventions may have value as part of broader rehabilitation programmes.

### *Limb Activation*

Joanette and Brouchon (1984) and Joanette, Brouchon, Gauthier and Samson (1986) observed that a patient showed significantly less neglect when using her left hand to point to targets than she did when using her right. Halligan and Marshall (1989) observed similar effects of hand use in the performance of cancellation and line bisection tests. This could be explained in a number of ways. Firstly, the patient's hand and arm may form a visual cue and either serve to attract attention to the left, or to re-contextualise the left of the task as being to the 'right' of something else. Secondly, the difficulty or novelty of using the left hand may induce a generally more alert state (the positive effects of such general alerting are discussed in the next section). Thirdly, making movements with the left hand may produce a general 'activating' effect on the impaired right hemisphere, assisting it in competing with the intact left hemisphere. Finally, Rizzolatti and Camarda (1987) have argued that spatial attention is intimately connected with the intention to perform motor actions. It is therefore possible that the location of the movement rather directly serves to enhance perceptual/attentional representations of that region.

In a series of single case and group studies, Robertson and colleagues examined some of these possibilities (Robertson & North, 1992; Robertson & North, 1993; Robertson & North, 1994; Robertson, North, & Geggie, 1992; Robertson, Tegnér, Goodrich, & Wilson, 1994). The results can be summarised as follows:

1. Movement of the left hand to the left of the body midline reduced perceptual neglect, whether or not that movement was visible to the patient.
2. Movement of the *right* hand to the *left* of midline did not produce a significant reduction in neglect compared with a no movement condition.
3. Movement of the left hand alone, but to the *right* side of the body midline did not produce a significant reduction in spatial neglect.
4. Simultaneous movement of both hands (whether both to the left of the body midline, both to the right of midline, or with each hand in its congruent location) abolished the benefits of the left hand moving in isolation. In

one study, spatial performance during bilateral movements was actually worse than in the no movement condition.

5. With different patients, the left 'limb activation' effect has been shown to work in the context of cancellation tasks performed in 'near space' (within reaching distance on the table top) and 'far space' (2.44 meters away; Robertson & North, 1993 – see Halligan & Marshall, 1991 for discussion on dissociations for neglect in near and far space), for reading tasks (Robertson & North, 1992; Robertson & North, 1993; Robertson & North, 1994), for a purely tactile exploratory task (Robertson et al., 1992), for walking trajectories (Robertson et al., 1994), and for covert shifts of attention (that is moving the focus of attention in space without accompanying eye or head movements; Mattingley, Robertson, & Driver, 1998).
6. In an initial study, Robertson and North (1993) found that passive movements of the left hand (i.e. when the experimenter moved the patient's fingers) did not produce a reduction in neglect – although in this case the right hand was simultaneously moving in order to perform the cancellation task. Subsequently, however, Frassinetti, Rossi and Ladavas (2001) have shown that passive abduction and adduction of the left arm can produce benefits.

The results strongly suggest that the benefits of moving the left hand cannot be adequately explained by a visual cueing argument. The possibility that the effect is mediated by generalised arousal caused by the novelty or difficulty of moving the left hand is also difficult to sustain, given the abolition of benefits in bi-manual movement conditions. The fact that neither movement of the left hand in right space, nor movement of the right hand in left space were sufficient to produce the effect suggests a) that it is neither a simple effect of the location of action facilitating attention to that region nor b) a simple effect of left hand movement 'activating' the right hemisphere. The hemispheric activation hypothesis may, however, be tenable if it is argued that a combination of the movement and the region of space in which that movement occurs is necessary to produce a strong enough effect.<sup>2</sup>

Whatever the precise mechanisms, the results suggest that encouraging use of the left limb to the left side of the body may be of value in rehabilitation. This has now been explored in a number of studies. One of the difficulties is that many neglect patients under-use their left limbs, despite residual function. To counter this, Robertson et al. (1992) developed an automatic cueing

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<sup>2</sup> Interestingly, although interactions between movement and spatial attention have not been found in healthy adults (Bonfiglioli, Duncan, Rorden, & Kennett, in press), they appear to be present in young children. Dobler et al. (2001a) found that asking six and seven year old children to make (hidden) hand movements immediately prior to judging pre-bisected lines exerted a significant influence over their subsequent perception. The direction of the influence was consistent with that seen in adult neglect.

device. The 'neglect alert device' consisted of a button, variable timer and a buzzer. Patients were asked to hold the button in their left hand and remember to press it as frequently as possible while performing other tasks. If the patients did not press the button for a particular interval (usually around 8 seconds) the buzzer would be activated, reminding the patients to continue these actions. In the first series of case studies, Robertson et al. (1992) demonstrated the effectiveness of the device in improving reading and cancellation task performance. The effects were persistent in at least one patient for at least three weeks following the end of formal training. Persistent effects have been found in subsequent studies using more ecological measures (Robertson, Hogg, & McMillan, 1998a; Wilson, Manly, Coyle, & Robertson, 2000). In accounting for this persistence, it has been suggested that a positive feedback loop may be established whereby greater awareness of left space leads in turn to increased spontaneous use of the left hand.

Although some apparently severe left-sided motor problems may have an attentional component, it remains true that many patients with neglect also suffer from dense hemiplegia or find left-sided movements painful or impossible. Such patients seem, therefore, unlikely candidates to benefit from limb activation effects. Recently, however, we have examined whether observing someone else's movements may produce benefits.

The term 'mirror neurons' has been coined to refer to populations of brain cells that are active both during the execution of movement and the observation of someone else making the same movement (Di Pellegrino, Fadiga, Fogassi, Gallese, & Rizzolatti, 1992; Gallese, Fadiga, Fogassi, & Rizzolatti, 1996; Rizzolatti, Fadiga, Gallese, & Fogassi, 1996a). Such cells have been argued to play a role in motor learning by imitation and in understanding another's actions (a 'motor idea'; Fadiga, Fogassi, Gallese, & Rizzolatti, 2000; Iacoboni et al., 1999). In human functional imaging studies, that have almost invariably considered the effects of watching another making movements with the *right* hand, such populations have been detected in left inferior frontal gyrus (BA 45; Rizzolatti et al., 1996b; Grafton, Arbib, Fadiga, & Rizzolatti, 1996), left rostral parietal cortex (BA 40) and left supplementary motor area (Grafton et al., 1996). In a study examining observed movements of the mouth, right hand and right foot, the pattern of activations suggested a rather specific topographical distribution of these effects (Buccino et al., 2001). The question we (Manly, Woldt, George, & Warburton, in preparation) considered, therefore, was whether patients with neglect and left hemiplegia could benefit from a 'limb activation' effect simply through observing somebody else make movements with their left hand?

Given that patients must have numerous opportunities to observe other people moving, it may seem unlikely that additional observation of movements would have any effect. However, in many situations it might be rather unhelpful to have our motor system activated by any movements that happen to be going on around us (imagine the effect of being at the disco, for example) and attention may, therefore, be an important mediator for this

process. It is certainly the case that existing studies of mirror neurons have implicitly focused the participant's attention on another's actions. As people with unilateral neglect will tend to have rather poor attention in general, a rather specific focus on another's activity may be necessary to see any potential effect.

We tested six patients with right hemisphere lesions and left unilateral neglect on a simple naming task. Four of the patients were unable to make intentional movements with their left hand or arm. In the test, the patients first watched a video clip of an actor making repeated grasping gestures with his left or right hand. As the clips continued in a box at the centre of a computer monitor, a spatially distributed array of twelve objects (pictures, letters etc) appeared around it. By asking the patients to name the objects, we were able to get an estimate of their perception of the spatial extent of the screen without requiring them to make any hand movements themselves. Presented in a random order, the three conditions showed the actor making movements with his left hand, his right hand or remaining still for an equal period of time. Compared with the stationary condition, both hand movements were associated with significantly improved naming performance. Observing the actor's left hand moving was, however, associated with significantly better performance than observing identical movements of the right hand. It should be noted that the actor's moving left hand appears towards the right side of the screen. Consequently this effect is unlikely to emerge as the result of a purely visual cueing effect. We are currently investigating how specific this effect is to biological movement by using an additional control in which a dot moves in the same location and frequency as the hand.

#### *Increasing general arousal – behavioural and pharmacological effects*

Many neuropsychological deficits are neither absolute (in the sense that a patient can show some residual capacity) nor entirely stable (in the sense that performance will vary from one time or context to another). Whilst these fluctuations may reflect random variation or 'noise' within the system, if it is possible to identify factors that are consistently associated with improved levels of performance, these may have value in rehabilitation. Neglect illustrates these characteristics extremely well. It is rare to work with a patient who has absolutely no ability to become aware of information to the left and, within individuals, the extent and severity of neglect can be extremely variable. As discussed, one factor that reliably modulates neglect in some patients is activity of the left limbs. Another appears to be patients' state of general alertness or 'readiness-to-respond'.

In addition to chronic spatial neglect, damage to the right hemisphere has long been known to produce disproportionate deficits in a cluster of abilities variously termed alerting, arousal, vigilance or sustained attention (De Renzi & Faglioni, 1965; Boller, Howes, & Patten, 1970; Heilman et al., 1978; Howes & Boller, 1975; Heilman & Van Den Abell, 1979; Wilkins, Shallice,



& McCarthy, 1987; Rueckert & Grafman, 1996). This neuropsychological association has now received support from the normal functional imaging literature (Pardo, Fox, & Raichle, 1991; Cohen & Semple, 1988; Cohen, Semple, Gross, King, & Nordahl, 1992; Lewin et al., 1996; Sturm et al., 1999). It would be expected, therefore, that many patients with neglect would also show these deficits.

In fact, evidence suggests that this association may be more specific. Robertson et al. (1997b) asked a large group of patients to perform a rather boring task in which they were asked to keep count of the number of tones heard within a particular interval. Although this task had previously been shown to be sensitive to right hemisphere lesions (Wilkins et al., 1987), Robertson et al. observed no difference in performance between neurological patients with left hemisphere damage, and patients with right hemisphere damage *who did not show neglect*. The group of patients with right hemisphere damage who *did* show neglect were, however, extremely poor at performing this simple, non-spatial, sustained attention test. Samuelsson et al. (1988), using a different reaction time paradigm, reached similar conclusions – namely that within groups with right hemisphere lesions, chronic neglect was disproportionately associated with non-spatial attention deficits.

Robertson, Mattingley, Rorden and Driver (1998b) investigated whether there may be a direct modulatory relationship between general alertness and spatial inattention to the left. A group of patients showing neglect were asked to perform the computerised spatial task of judging which of two lateralised stimuli had appeared first (so called ‘prior entry’ task; Stelmach & Herdman, 1991). Under normal circumstances, the patients’ pathological bias predisposes them to see the right sided stimuli as appearing first (Rorden, Mattingley, Karnath, & Driver, 1996). In Robertson et al.’s study, however, when a loud tone was presented immediately before a trial, the patients’ neglect was either significantly ameliorated, abolished or, in some cases even reversed. As the tone had no predictive value for whether the left or right target would appear first, the result was interpreted as a direct effect of transitory changes in alertness on spatial awareness. These results have recently been replicated in a case of a child with neglect of developmental origin (Dobler et al., 2001b).

Although this form of external alerting does not easily lend itself to long-term rehabilitation, particularly as the novelty of the tone may be important, other means of inducing more generally alert states have been explored. Robertson, Tegnér, Tham, Lo and Nimmo-Smith (1995) trained patients in a self-instructional procedure. In the training, the patients were asked to perform rather boring (although not particularly spatial) activities such as sorting cards or coins. Occasionally – and with the patients’ prior consent – the therapist would create a loud, *inherently* alerting noise by slapping the table-top. When this occurred, the patients were instructed to say a phrase such as ‘Pay Attention!’, the idea being to associate this self-instruction with the sensation of increased alertness. As the training

progressed, the patients were first instructed take over the generation of the alerting stimulus by wrapping on the table as they said 'Pay Attention!'. After being encouraged to use the verbal cue out-load while imagining the alerting stimulus, they were finally asked to simply imagine the stimulus and the instruction and to indicate to the therapist when they were doing this. Although compliance with this training is difficult to assess, the procedure nevertheless produced significant improvements in the non-spatial tone counting measure described above. Importantly, significant reductions in spatial neglect were observed coincident with this shift, despite the absence of any spatially specific training or instruction.

Given the apparently beneficial effects of increased arousal/alertness on spatial attention, and indeed the negative effects of sedative medication (Lazar et al., 2002), an alternative approach to behavioural training may be to use pharmacological stimulants. Fleet, Valenstein, Watson and Heilman (1987) administered bromocriptine to two patients. This was associated with improvements in some, but not all, neglect measures – improvements that reversed when the medication was withdrawn. Hurford, Stringer and Jann (1998) compared the effects of methylphenidate ('Ritalin') with bromocriptine. They report that, although methylphenidate produced benefits compared with the no-treatment condition, bromocriptine produced the stronger results. These preliminary studies suggest that medication may indeed have a role within rehabilitation for neglect, although larger fully controlled trials are required.

### *Summary of rehabilitation for neglect*

It is clear that a number of very different approaches have produced significant reductions in unilateral spatial neglect. As well as helping patients, several of these techniques have also been useful in clarifying the underlying nature of the disorder, and raised important theoretical questions for further study. In terms of the clinical application of these techniques, there remain some important questions, including:

- Neglect is a heterogeneous condition and none of the techniques described here have been effective for *all* patients. Is it useful to treat neglect as homogeneous entity in terms of rehabilitation? Are there particular patterns of response associated with different manifestations of neglect, or different lesion locations, that can allow us to better target interventions?
- Are the effects of different interventions additive in some cases?
- To date, the effects of rehabilitation have generally been assessed on standardised tests given up to one month post-intervention. In addition to investigating the maintenance of these improvements over the longer term, results showing that neglect can 're-emerge' in apparently recovered patients under demanding conditions (Bartolomeo, 2000) – or when drowsy (Lazar et al., 2002) – means that generalisation to complex everyday activities requires careful evaluation.

- Given the links between neglect and non-spatial disorders, is reducing the spatial bias sufficient *in itself* to promote significantly improved outcomes? In other words, although spatial neglect may be the most salient symptom for some patients, is it their biggest problem?

## The Rehabilitation of Non-Spatial Attention

### Targeting functional goals

As discussed, deficits in non-spatial attention are among the most commonly reported problems following traumatic brain injury and stroke (e.g. Oddy et al., 1985; Brooks & McKinlay, 1987; Van Zomerén & Burg, 1985; Leclerk & Zimmermann, 2002; Conkey, 1938; Van Zomerén, 1981; Van Zomerén & Burg, 1985; Van Zomerén & Deelman, 1978; Ponsford & Kinsella, 1992; Robertson, Ward, Ridgeway, & Nimmo-Smith, 1996; Leclerk & Azouvi, 2002; Robertson, Manly, Andrade, Baddeley, & Yiend, 1997a; Rousseaux, Fimm, & Cantaglio, 2002). In comparison with unilateral neglect, specific rehabilitation for this cluster of disorders is at a very early stage. Although there is not the space here to do justice to the weighty topic of assessment,<sup>3</sup> it is worth re-emphasising some of the difficulties faced by clinicians in this respect. In assessing and treating unilateral neglect we are dealing with a problem that is strikingly different to the behaviour of healthy individuals and one that is relatively simple to operationally define (i.e. the left is worse than the right). While there are questions about generalisation of improvements, it is clearly the case that many measures used in neglect (e.g. finding and crossing out lines on a page) bear a reasonable resemblance to everyday difficulties faced by patients (e.g. finding and reaching for food on a plate). In contrast, non-spatial attention deficits are generally quantitatively rather than qualitatively different from normal capacity limitation. Given that they are likely to pervade most activities, they are difficult to assess in a manner that controls out other causes of poor performance (e.g. memory deficits, motor problems and so forth). The measures that allow some conceptual specificity are often so abstract and focused that it calls into question the extent to which they reflect everyday difficulties and whether, if they are the sole index of change, generalisation to complex activities has taken place.

One way out of this difficulty is to effectively ignore attention as a mediating variable and instead focus on functional goals. Wilson and Robertson (1992), for example, worked with a man who had suffered a head injury and who reported difficulty in 'keeping his mind' on what he was reading. They first established a baseline in which the patient used a counter to record when he felt his attention wandering from his book. At the outset of the treatment

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<sup>3</sup> Readers are directed towards books by Parasuraman (1998) and Leclerk and Zimmermann (2002) for an in-depth discussion of attention concepts and measurement. Useful sections on the clinical assessment of attention appear in Lezak (1995) and Crawford, Parker and McKinlay (1992).

phase, he began by reading for a very short period during which, according to the baseline data, a lapse was unlikely to occur. If this was the case, the duration of reading at the next session was increased by 10%. Over 160 sessions, the patient showed steady improvement and eventually reached his goal of reading without 'slips' for 5 minutes.

As many of the man's cognitive abilities (e.g. memory, general intelligence) were relatively intact – and he could read adequately for brief periods – it is reasonable to assume that there was strong attentional component to his difficulty. As reading duration was the sole outcome measure, however, whether or not the training improved his attention in a more general sense remains an open question in this case.

Alderman, Fry and Youngson (1995) highlight another case in which attention was thought to underlie the maintenance of difficulties in everyday life – in this example, very severe behavioural problems. SK was a young woman who suffered diffuse damage and focal lesions to the temporal lobes as the result of herpes simplex encephalitis. Three months after the injury, her behaviour at the rehabilitation centre was causing disruption to her own and others' programmes. In particular she was said to produce extremely loud comments about her own actions, the actions of others and their disabilities, and to do so in a near continuous manner. Initial behavioural treatment (in which SK was asked to give up a reward token each time the behaviour occurred) produced significant reductions in frequency but generalisation to a different context was disappointing. Hypothesising that SK may be rather unaware of her actions and therefore not ideally placed to reduce them, Alderman et al. then set out to train awareness. When walking with her therapist, SK was given a counter and asked to record each time she noticed herself making a verbal utterance. Comparison of her ratings with those of her therapist confirmed a vast disparity, with SK underestimating the frequency of her behaviour by approximately 90%. After a period during which she was prompted by the therapist to record instances as they occurred, SK was then given rewards conditional upon increasing the accuracy of her own monitoring. Only when this accuracy had improved to above 70% was any further attempt made to reduce the *frequency* of the behaviour – which was now successful. Again, it is unclear whether these improvements in self-monitoring and attention were specific to the verbal behaviour. The most important result, in terms of the likelihood of SK's returning to community living, however, was that the behaviour was reduced.

### **Training attention using abstract tasks**

Personal computers provide a now relatively cheap and highly standardised method for attention training. Although such exercises in the field of memory have tended to produce improvements that are specific to the trained material rather than to the learning process in general (e.g. Glisky, Schacter, & Tulving, 1986a; Glisky, Schacter, & Tulving, 1986b) this may not be the case for other capacities.

In a randomised controlled study, Gray, Robertson, Pentland and Anderson (1992) offered 15 hours of computerised training to people with attentional problems resulting from a brain injury. The exercises included: a reaction time task with feedback on speed, a task requiring the identification of two identical digit strings from a briefly presented array of 4, a digit-symbol translation task, and a colour-word Stroop task. On completion of the training, the patients showed significant improvements on two untrained measures (the WAIS-R Picture Completion subtest and the Paced Auditory Serial Addition Task PASAT) relative to the control group who had received similar periods of recreational computing. When reassessed six months later, these improvements had been well maintained and indeed now extended to a wider range of measures. Generalisation to functional activities of everyday life was not examined in this study.

In light of the proposed functional separation between different forms of attention (sustained attention, selective attention and so forth), and suggestions in the literature that attention training effects might be rather specific, Sturm, Willmes, Orgass and Hartje (1997) set out to specifically test this hypothesis in a rehabilitation study. Thirty-eight patients with quantified attention deficits (mainly resulting from stroke) took part in the trial using the AIXTENT<sup>4</sup> computerised package. The package consisted of distinct modules, each designed to train a specific attention function. In one of the sustained attention module tasks, for example, patients watch several aircraft slowly flying across radar screen. Their task is to look out for abrupt changes in any of the aircraft's velocity or the transitory appearance of new objects on the screen, signalling detection by pressing a button. In contrast, the selective attention training tasks include a 'photo safari', a much more briskly paced activity in which the patients are asked to 'take photos' of some, but not all, objects that pop-up from a scenic background. The other training modules were for alertness and divided attention. The difficulty of the all the tasks was automatically and incrementally increased in response to adequate performance.

To evaluate the success and the specificity of the training, Sturm and colleagues administered the modules to each patient in a randomly selected *order*. They hypothesised that, if the training was indeed specific, improvements in sustained attention function should be greater following sustained attention training than, for example, selective attention training. Evaluation was made using repeated administrations of the computerised Test of Attentional Performance ('TAP'; Zimmermann, North, & Fimm, 1993) – a battery that allows separable assessment of different attentional components.

The hypothesis was broadly supported. Detection rates for targets in the untrained TAP vigilance task was significantly improved, for example, only after sustained attention training and not following training in selective or divided attention. Similarly, reaction times in the selective attention test

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<sup>4</sup> An English Language version of this package is under development.

were improved following selective attention training, but not after training of sustained attention. As might be expected, some crossover effects were also observed (divided attention performance being significantly enhanced following training in selective attention, for example). The results have now been substantially replicated in a multi-centre study in which each patient was exposed to only one of the training modules (Sturm et al., 2002a).

### **Supporting residual function**

*Variability* is a central, if not definitive, feature of ‘attention’ deficits. The fact that performance on a task may, at one time, be adequate and, at another, quite deficient suggests that many of the basic components required for performance (e.g. vision, reading skill, motor responses) are present but for some reason are unreliably orchestrated to produce the desired results. As we saw with some interventions for neglect, if it is possible to identify factors that are consistently associated with better levels of performance, these may have value in rehabilitation.

Many of these ‘interventions’ will be of a type we all use in everyday life. These may include making sure the TV and radio are turned off before attempting an important activity or in planning regular breaks *before* concentration begins to flag. Given that patients may have limited insight into their deficits, or have trouble in spontaneously adjusting their behaviour to take account of deficits, it should not be assumed that these will be applied without assistance.

The extent to which poor performance on neuropsychological tests may be related to poor motivation or reluctance to expend ‘mental effort’ is often a tricky question, particularly on attention measures that are designed to be tedious and unrewarding. Of course, low motivation, or indifference to outcome, can itself be a consequence of brain injury (Stuss & Benson, 1983; Stuss & Benson, 1986), as well as resulting from patients becoming dispirited by repeated experience of failure, or from pre-morbid factors. It is certainly the case that ‘motivating’ instructions have been associated with improved performance relative to baseline on attentional measures (Blackburn, 1958; Shankweiler, 1959; Sturm et al., 2002b) and therefore by extension, may be effective in increasing attentional performance across a range of everyday tasks.

We (Manly, Hawkins, Evans, Woldt, & Robertson, 2002) have recently explored the (perhaps obvious) possibility that patients may be better able to usefully attend if they are reminded to do so. In order to mimic some of the complexities and competing demands of real-life tasks, we adapted Shallice and Burgess’ (1991) Six Elements task. In this measure (the ‘Hotel Test’) the patients were provided with materials for 5 activities plausibly associated with running a hotel (sorting conference labels into alphabetical order, checking bills, proof-reading a tourist leaflet and sorting the coins from the charity collection). They were told that over the 15 minutes of the test they should try and sample each of the jobs but were warned that each task in isolation

would take longer than the available 15 minutes to complete. As with the Six Elements, therefore, the test emphasised the patients' ability to keep track of this main goal and to flexibly shift between tasks when appropriate. Also in line with the earlier finding, 10 TBI patients performed significantly more poorly than IQ matched controls, the key error being to get caught up in one of the component tasks to the detriment of monitoring the overall goal. When however, the patients were exposed to randomly timed auditory 'beeps' – and having been instructed to use these as a reminder to 'think about what they were doing', their performance was not only significantly improved but was also no longer distinguishable from that of the control group. The results suggest that, at least in this group, the key reason for poor performance was a failure to maintain sufficient attention on the main goal rather than, for example, forgetting what that goal was. It also suggests that, if the *use* of residual capacities is supported by cueing, performance in quite complex functional activities may be improved.

### **Summary of rehabilitation for non-spatial attention**

Although the rehabilitation of non-spatial attention is at an early stage (not least because theoretical development and assessment in this area are at an early stage) there are, nevertheless, optimistic signs. There is good evidence that functional difficulties in everyday life that seem to be partially determined by attention problems can be successfully retrained – although the extent to which this is possible will no doubt vary with the task.<sup>5</sup> There is also good evidence from a number of studies that repeated and progressive training, even on abstract computer tasks, can generalise to untrained measures. A clear direction for future work is to establish whether the functional goal based training approach produces more general improvements in attention function, and whether the abstract training produces benefits that generalise to functional real-life goals.

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<sup>5</sup> There is of course abundant evidence that, with sufficient practice, many tasks that are initially attentionally demanding can come to be performed in a relatively 'automatic' fashion (Shiffrin & Schneider, 1977; Schneider, Dumais, & Shiffrin, 1984) – a feature that should not be overlooked in the rehabilitation of specific activities.

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# Chapter 4

## REHABILITATION OF EXECUTIVE DEFICITS

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### Introduction

Deficits in executive functioning cause devastating social handicap after brain injury and therefore represent a major challenge for rehabilitation. The term ‘executive functions’ refers to a set of skills or processes required for effective problem-solving, planning and organisation, self-monitoring, initiation, error correction and behavioural regulation. Almost all theories of executive functioning have arisen from attempts to understand the role of the frontal lobes in cognition. Luria (1966) conceptualised the frontal lobes as being involved in problem solving, a process which includes the three phases of strategy selection, application of operations and evaluation of outcomes. Duncan (1986) described the role of the frontal lobes in terms of ‘goal maintenance’. He argued that the frontal lobes are involved in identifying ‘goals’ or behavioural objectives and managing actions that will lead to the achievement of those goals. Duncan suggested that frontal lobe damage causes ‘goal neglect’, whereby the individual with a brain injury is able to identify what he or she needs to achieve and may be able to derive a plan, but during the course of the operation of the plan, the main goals may become neglected and actions no longer lead to achieving the goal. Whilst not completely random, behaviour is no longer goal-directed.

Baddeley and Wilson (1988) drew on the work of Rylander (1939) who described how individuals who suffer damage to the frontal lobes have impairments in attention (being easily distracted), have difficulties grasping



the whole of a complicated state of affairs (an abstraction problem), and whilst they may be able to work along routine lines, they have difficulties in new situations. Baddeley (1986) coined the term *dysexecutive syndrome* as a replacement for the anatomically constrained term 'frontal lobe syndrome'. He suggested that one of the functions of the frontal lobes is that of the 'central executive' component of working memory.

Baddeley (1986) equated the concept of the central executive with that of the 'Supervisory Attention System' (S.A.S), described by Norman and Shallice (see Shallice, 1988). They discussed the control of action in terms of two levels of control; an automatic schema driven level (involving a non-conscious automatic control process referred to as contention scheduling) and the more conscious level referred to in terms of the S.A.S. This supervisory system was seen as responsible for, 'producing a response to novelty that is planned rather than one that is routine or impulsive' (Shallice, 1988, p. 345). More specifically the S.A.S. was described as being required in situations that involve; (1) planning or decision making; (2) error correction or troubleshooting; (3) responses that are not well learned or where they contain novel sequences of actions; (4) dangerous or technically difficult decisions; (5) situations that require the overcoming of a strong habitual response or resisting temptation.

Shallice and Burgess (1996) argued that the S.A.S. can be fractionated into a set of basic sub-components, or sub-processes and present evidence (based on neuropsychological dissociations and functional brain imaging), for the fractionation. They argue that responding appropriately to novelty requires three processes – (1) a process which results in the creation of a temporary new schema (since routine behaviour is governed by existing schema, novel behaviour will require the creation of a new schema), (2) a special purpose working memory that is required for the implementation of the temporary new schema and (3) a system that monitors, evaluates and accepts or rejects actions depending upon their success in solving the novel problem.

One source of evidence that the S.A.S. can be fractionated is that the sub-processes of S.A.S. dissociate. Patients with brain injury may have difficulty with one or more of the processes, whilst others remain intact. For example some patients appear to be aware that a problem exists, but may fail to identify more than one potential solution or make an adequate plan. Consequently the patient may respond to a problem with impulsive actions. Impulsivity is a relatively common consequence of brain injury, particularly where the frontal lobes have been involved. The individual appears to 'act without thinking', doing the first thing that comes to mind, failing to think of alternative solutions to a problem and failing to anticipate the consequences of the chosen action. In contrast, some patients are able to generate a plan, but plans are never translated into action. In each case the end result will be essentially the same in that the problem is not dealt with adequately, but for different reasons. Those reasons become important when considering the rehabilitation of these problems.

## **The Consequences of Executive Problems after Brain Injury**

The consequences of frontal lobe damage were most dramatically illustrated in the most famous of all ‘dysexecutive’ patients, Phineas Gage (Macmillan, 2000). He lost part of his frontal lobes as a consequence of a tamping iron being accidentally blasted through his skull. Probably the most remarkable thing about Phineas Gage was that he survived at all. However, he developed a tendency to be disinhibited and had an inability to follow through with intended plans. He failed to keep his job and became socially inept. Similarly patient EVR described by Eslinger and Damasio (1985) who had a large orbito-frontal meningioma removed, was described as having an IQ of over 130 and the ability to perform well on a wide variety of cognitive tasks, even post-injury. Yet as a consequence of his injury, his life became disastrously disorganised. He had previously been a successful professional and a respected member of the community, but he ended up losing his job, going bankrupt, being divorced, subsequently marrying a prostitute and divorcing again. He was described as having immense difficulties in making simple decisions, such as where to go out to dinner or what toothpaste to buy. The three patients described by Shallice and Burgess (1991) were all similar to EVR in that they appeared to have a combination of adequate general intellectual ability, impaired executive ability and disastrously organised lives. Patient RP (Evans, Emslie, & Wilson, 1998) similarly showed adequate general intellectual and memory functioning but impaired attention and executive skills. As a consequence, RP was unable to translate intention into action, to plan ahead, and sustain attention whilst carrying out tasks. She was unable to work or effectively manage the household and required constant support and supervision from her husband who had to give up his job to care for her. Crepeau and Scherzer (1993) provide further evidence of the social handicap caused by dysexecutive syndrome. They describe the results of a meta-analytic study that showed that the presence of impairments in executive functioning was a key factor predicting whether or not individuals will return to work.

## **Rehabilitation of Executive Impairments**

A key issue in rehabilitation is whether interventions should be aimed at treating the underlying impairment (i.e. restoring the lost function) or seek to provide clients with strategies that enable them to compensate for the impairment. As discussed below, the evidence that executive problems can be restored is not wholly convincing, whilst there is more evidence that mental strategies, or external aids can produce real benefits.

### **Re-training or restoring impaired executive functioning**

Evidence that executive dysfunction can be returned to normal is slim, if not non-existent. Placebo controlled single-case studies of the drug Idazoxan

(Sahakian, Coull, & Hodges, 1994) in patients diagnosed with frontal lobe dementia are promising. However, it is not clear that frontal lobe dementia is a good model for non-progressive, single event brain damage. Nevertheless, this work clearly needs expanding so that the potential benefit of pharmacological interventions is adequately assessed. Further work must also address the extent to which improvement of performance on specific tests of planning, such as those used in studies to date, generalises to everyday problem solving.

Retraining approaches to rehabilitation make the assumption that practicing a particular cognitive function through tasks and exercises will enable that function to return, in a more or less normal fashion. Von Cramon, Matthes-von Cramon and Mai (1991) and von Cramon and Matthes-von Cramon (1992) describe a group based training programme described as 'problem-solving therapy', which is seen as a retraining approach. Von Cramon and colleagues note that the broad aim of problem-solving therapy is to provide patients 'with techniques enabling them to reduce the complexity of a multi stage problem by breaking it down into more manageable portions. A slowed down, controlled and step wise processing of a given problem, should replace the unsystematic and often rash approach these patients spontaneously prefer' (1991, p. 46). The therapy approach adopts a problem-solving framework which draws on the work of d'Zurilla and Goldfried (1971). The specific aims of the therapy are to enhance the patients' ability to perform each of the separate stages of problem-solving, through practice on tasks that are designed to exercise the skills required for each of the separate stages. These stages include (a) identifying and analysing problems; (b) separating information relevant to a problem solution from unimportant and irrelevant data; (c) recognising the relationship between different relevant items of information and if appropriate combining them; (d) producing ideas/solutions; (e) using different mental representations (e.g. verbal, visual, abstract patterns such as flow charts) in order to solve a problem; and (f) monitoring solution implementation and evaluate solutions.

Exercises for working on the ability to separate information relevant to a problem from unimportant or irrelevant data include practice at formulating 'wanted' small ads and telegrams, where the need for only including relevant information is at a premium. Practice at generating ideas is gained from tasks such as completing unfinished stories, for and against discussions of current affairs and practice brainstorming sessions. Patients are encouraged to monitor solution implementation via the use of work books, and group activities where a patient is asked to be a co-therapist during a game (e.g. Mastermind), drawing other players' attention to mistakes, irregularities and unnecessary moves. Therapy runs for a period of about six weeks with an average of 25 sessions. Each group involves four to six clients who initially work independently, but as soon as possible two clients work together on an assignment, with the division of labour being clearly explained. Finally, task orientated groups are established in which each individual in the group takes on the

responsibility for finding the solution to the part of a project, (e.g. organising a visit to a museum in the city centre).

Von Cramon et al. (1991) compared a group of patients who received problem-solving therapy ( $n = 20$ ), with a group of patients who received a control 'Memory Therapy' Group ( $n = 17$ ). The control group allowed for the possibility that clients might benefit from general advice and group activity, rather than specifically from the tasks aimed at exercising executive skills. They showed that patients who underwent problem-solving therapy showed some improvement in tests of general intelligence and problem solving (Tower of Hanoi) compared with controls. Von Cramon and colleagues demonstrated some generalisation of problem-solving skills to untrained test tasks but there was no evidence of generalisation to everyday situations. Evidence for the latter is hard to obtain because of measurement difficulties but it is clearly important that some evidence is obtained of generalisation to situations outside of formal test sessions. Von Cramon and colleagues also noted that a small number of patients actually deteriorated on tests. They hypothesised that this was due to an increased awareness of the complexity of problems on the part of the patient, leading to confusion about how to respond. By contrast, such patients had a pre-treatment propensity towards premature or ill-considered actions, some of which would have been correct by chance.

### **Internal strategies**

A number of interventions aimed at helping clients with attention and executive difficulties might be considered as 'internal' strategies. Typically this means that the individual is using a mental routine or self-instructional technique of some sort.

Cicerone and Wood (1987) provide a good example of the use of the self-instructional technique in a 20 year old man with a severe head injury. He was described as functioning relatively independently, but impulsively interrupted conversations and generally appeared not to think before he did something. They used the Tower of London Test as a training task, asking the client to state each move he was about to make while attempting to solve the problem and then to state the move while he performed it. In stage two the patient was asked to repeat the first stage except to whisper rather than speak aloud. Finally in the third stage he was asked to 'talk to himself', (i.e. to think through what he was doing). This approach was successful in improving performance on the trained task, but more importantly, there was generalisation to two other untrained tasks. In addition, with some generalisation training, there were improvements in general social behaviour, rated by independent raters. The main change brought about by this simple self-instructional technique was that it helped the patient to slow his approach to the task in hand and, in effect, develop a habit of thinking through his actions rather than responding impulsively.

Von Cramon and Matthes-von Cramon (1995) provide an example of an internalised check list routinely applied to compensate for executive defi-

cits. They describe GL, a 33-year-old Physician who had a traumatic brain injury at the age of 24, resulting in bilateral frontal lobe damage. Despite the injury, GL passed his medical exams post injury (though after several failures). He was described as having 'drifted' through several jobs in neurosurgery, pathology and the pharmaceutical industry. His problems were characterised as involving a lack of overview and being dependent upon meticulous instructions. He was unable to benefit from feedback, spending too much time on routine activities and being unable to adapt himself to the requirements of novel or changing situations. In the study, a protected work trial was established in a hospital pathology lab and he was provided with prototypical reports on autopsy. It was noted that he tended to jump to conclusions about diagnosis and he was therefore taught a set of rules/guidelines for the systematic process of diagnosis. These rules were initially provided in the form of a written checklist, which, over time, GL learned and was able to apply without the need to refer to the checklist. GL improved his ability to diagnose correctly and to write reports. However, there was no generalisation to a novel planning task.

Another approach is to teach a more general strategy that can be applied in a variety of situations. Levine et al. (2000) described the use of a Goal Management Training (GMT) technique in two studies. Study 1 evaluated the technique with a group of head-injured patients on paper-and-pencil tasks. The second study described the use of this technique with one post-encephalitic patient seeking to improve her meal preparation abilities. The GMT technique was derived from Duncan's (1986) concept of 'goal neglect'. The principle is that patients with frontal lobe damage fail to generate goal (or sub-goal) lists of how to solve problems (and achieve goals), and/or may fail to monitor progress towards achieving sub- or main goals. The training has 5 stages, which are first defined for the patient, and include (1) Stop and think what I am doing, (2) Define the main task, (3) List the steps required, (4) Learn the steps, (5) Whilst implementing the steps, check that I am on track, or doing what I intended to do. After each stage is introduced, illustrative examples from the patient's own life are used as well as mock examples. In the first study, the GMT was applied in a single one-hour session, with testing on several target tasks undertaken afterwards. Levine et al showed improved performance on three paper and pencil tasks, but generalisation to everyday life was not examined. Study 2 addressed the question of application of GMT in a more practical task. Patient KF suffered from a meningo-encephalitic illness, which resulted in some general intellectual decline, attentional, memory and executive functioning deficits. A particular problem for KF was meal preparation, with four specific areas of difficulty; failure to assemble the necessary ingredients, misinterpretation of written instructions, repeated checking of instructions and sequencing/omission errors. The measure used to evaluate the efficacy of GMT was the number of problem behaviours evident during meal preparation tasks (as well as performance on the paper and pencil tasks used in Study 1). GMT was applied over two sessions, and was adapted so

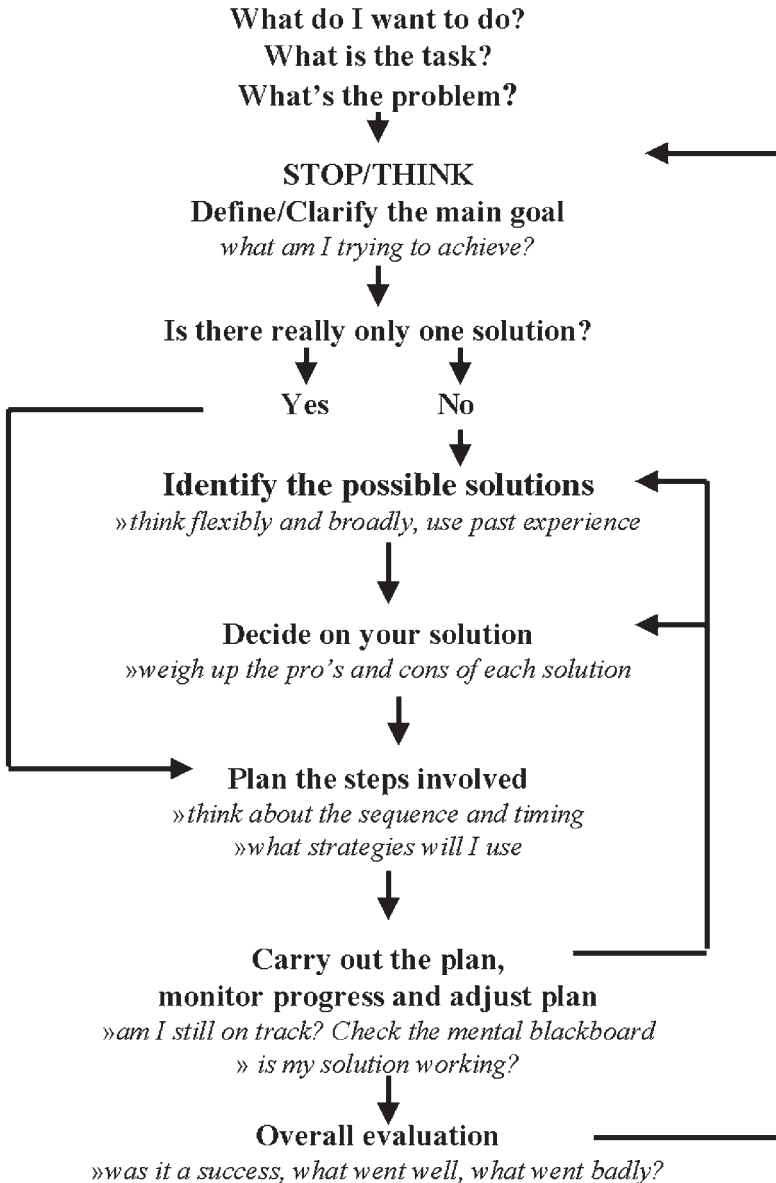
that tasks relating to meal preparation and involving the various stages of GMT were created. The results of the study were that KF showed a significant reduction in errors in meal preparation stages over the course of the intervention. Although baseline data were collected that indicated the problem with meal preparation was clearly evident and this improved post-training, the lack of control variable information means that spontaneous recovery cannot be ruled out, especially given that she was only 5 months post-illness at the time of the study. Nevertheless, the study does raise the possibility that GMT may be a useful technique (especially considering the apparent efficacy based on a relatively small amount of training time).

Evans (2001) describes a group approach, adapted from the von Cramon group described above and from the Goal Management Training of Robertson (1996; See also Levine et al. 2000) described in more detail below. The Attention and Problem Solving group is one component of a holistic rehabilitation programme. The first few sessions of the group (which runs twice a week for 8–10 weeks) primarily address attentional difficulties, and the later sessions are used to introduce a problem-solving framework to the clients. This framework is presented as a paper-based checklist of the stages of problem solving. The stages are illustrated in Figure 1. An accompanying template is also provided that can be used to proceed through the stages using a written format, but clients are encouraged, through practice at using the framework with the template, to internalise the framework so that in time the use of the framework becomes more automatic. No formal evaluation of this group has yet been undertaken, but the successful use of this framework by one client, David, is described later.

Fasotti, Kovacs, Eling and Brouwer (2000) developed a compensatory strategy training that they call Time Pressure Management. The aim was to teach brain-injured patients a technique to help compensate for slow information processing. The strategy consisted of a general self-instruction ('Give myself enough time to do the task') followed by four specific steps; (1) Ask yourself if two or more things for which there is not enough time must be done at the same time? If yes, go to step 2, if not, do the task, (2) Make a short plan of which things can be done before the actual task begins, (3) Make an emergency plan describing what to do in case of overwhelming time pressure, (4) Use the plan and emergency plan regularly, monitor performance during the task. This simple approach is essentially focused on teaching patients to be more planful and more consciously aware of their performance, with a particular emphasis on helping patients to become better managers of their environment. Fasotti et al. showed that use of the strategy helped patients improve performance on a practice task, though once again no evidence for generalisation to everyday life was provided.

Shallice and Burgess's (1996) model of the problem solving processes associated with the functioning of the supervisory attentional system highlights the importance of the retrieval from memory of past experience. When faced with a novel task or problem, the strategy of recalling incidents of tackling

# Goal Management (Problem Solving) Framework



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Fig. 1. The Goal Management Framework used to aid clients develop a systematic approach to problem solving and goal management.

similar problems in the past may help in the present situation. Dritschel, Kogan, Burton, Burton and Goddard (1998) demonstrated that people with head injury often fail to refer to previous experiences in solving practical planning tasks, such as describing how they would book a holiday, get a new job or find a new place to live. Hewitt, Evans and Dritschel (2000) hypothesised that if patients were given a brief training relating to the retrieval of autobiographical memories, they would improve in their ability to plan practical tasks. The training took the form of an illustration of the value of recalling specific autobiographical experiences from the past in practical problem-solving, a cue-card to prompt specific memory retrieval and practice at doing this in order to plan how to tackle a particular task. The performance of two groups of subjects was compared, one receiving the training and the other not. The results showed that the training group improved significantly more than the no-training group in terms of the number of specific memories recalled, the number of steps and the overall effectiveness of the plan produced in relation to a set of eight hypothetical practical demands (e.g. how would you organise a surprise birthday party, how would you find a new house). Incorporating some form of training relating to retrieval of specific autobiographical memories may be helpful in a problem-solving training programme.

### **External strategies**

The most common strategy in the rehabilitation of memory problems is to teach the use of external aids, such as checklists, diaries or electronic organisers. Such aids are also useful for people who have planning and organisational problems. For some individuals, the process of writing things down seems to be the critical step in that it prevents a more impulsive style of responding to situations. For others, the process of writing things down makes the process of generating possible solutions and weighing up the pros and cons of those solutions more manageable. For individuals with significant working memory or speed of information processing deficits, it may be difficult to use the framework 'in mind', and an external written approach may be more helpful.

Poor sequencing of tasks is a possible consequence of executive disorder and in some cases checklists prove to be useful. The case of GL, the doctor who improved his performance in writing pathology reports was described above. He used a checklist approach, but was able to internalise the checklist so that the task, even though complex, became essentially routine. Burke, Zencius, Wesolowski and Doubleday (1991) describe six case studies where checklists were used in order to help clients develop and carry out plans. For example, the case of a 38 year old man who had problems with sequencing steps in a task, such as planing timber in the wood shop. Using a multiple baseline across tasks procedure, it was demonstrated that introduction of checklists improved performance, which was maintained even after the checklists were withdrawn. This suggests that the client had learned a task routine. However, significantly, the client was also better at a task for which



the checklist had not been introduced. The authors concluded that he was able to spontaneously generalise the use of a structured approach to the new situation. What was perhaps critical was the fact that the structured checklist approach was introduced not just for one task, but across a range of tasks in a systematic fashion, encouraging the client to learn both specific tasks and a general approach to new situations.

One specific form of executive deficit is an impairment in the ability to initiate action. In this case, checklists may be useful, but may rely too heavily on the patient initiating the checking of the list and following through on actions. An aid that is more effective at prompting action is required. One such aid that appears to have this function is NeuroPage. This system was developed by Hersh and Treadgold (1994) and has been demonstrated to be effective for people with memory and executive impairment (Wilson, Evans, Emslie, & Malinek, 1997; Wilson, Emslie, Quirk, & Evans, 2000). The system utilises radio paging technology and involves the patient wearing an alphanumeric pager. Reminders of things to do are entered onto a central computer using NeuroPage software. This automatically sends out the message via a modem to a paging company, which then sends out the message to the patient's pager, which beeps and delivers a text message. NeuroPage was used with Patient RP (Evans, Emslie, & Wilson, 1998), who suffered a cerebro-vascular accident as a result of a ruptured aneurysm. Her main problem was that she had difficulty translating intention into action. She was also distractible and had difficulty completing tasks. Despite adequate memory and intelligence, RP's combination of executive and attentional deficits had a significant impact on her day to day life. Although she could accurately say what she had to do, she had to be prompted to do many things, such as take her medication, or water her plants. She was highly distractible. When she did manage to set off to do a task, she was frequently distracted by something else along the way and failed to return to the original task. She therefore took a huge amount of time to get things done. She also found it difficult to be organised and planful enough to cook a family meal. A study of RP's performance in carrying out a range of day to day tasks, using an ABAB single case experimental design, showed that NeuroPage was highly effective in helping RP to complete tasks she needed to do on time. This significantly reduced the stress on her husband. Evans et al. noted that there appeared to be two important aspects to the success of the paging system. The first was the presentation of an external text message that appeared to be important for RP and prompted behaviour in a way that an internal intention to act failed to do. This is consistent with Luria's view of the frontal lobes being involved in the control of behaviour by inner speech. The second aspect was the beeping of the pager that provided an arousal boost to facilitate RP's initiation of tasks and help her sustain attention during the course of task completion. One issue in the use of alerting devices is the possibility that the individual will habituate to the sound and it will lose its alerting effect. This is a danger if alerts are being used very frequently and so highlights the importance of managing the frequency so that it retains its alerting capacity.

Manly, Hawkins, Evans and Robertson (2002) also examined the impact of external alerting. Performance of patients who had suffered traumatic brain injury on a multi-element task was tested under two conditions. The task used, the Hotel Test, is similar in format to the Modified Six Elements Test (Wilson et al., 1996). It involves the patient completing 6 different tasks, including a prospective remembering task, that are presented as tasks that might be given to an assistant hotel manager (e.g. making up bills, arranging conference delegate cards, looking up phone numbers, sorting charity box coins, proof reading a leaflet and pushing a button to open a door). Like the Six Elements Test, not everything from all of the tasks can be completed in the 15 minutes allocated. Two parallel versions were used in the two experimental conditions. In one condition, an external alert (a tone on an audio tape) was presented at random, relatively infrequent intervals. In the other condition no tone was presented. The study used a counterbalanced, crossover design. The results showed that participants performed more effectively during the beeped condition, than the control condition. It was argued that the alerting tones improved the link between a well represented goal and current behaviour. The tones did not specifically prompt task switching, but rather seemed to improve the ability to maintain the overall task goal actively in mind, and hence switch tasks more flexibly.

For some people, particularly those with very severe executive impairments or with a combination of executive and other difficulties, the provision of external aids might not be effective and it is necessary to consider changing some aspect of their physical or social environment. Work with family, friends and colleagues is one form of environmental modification approach. Helping relatives and carers to understand the nature of executive difficulties can help to minimise negative responses to problems arising from a dysexecutive syndrome. For example one of the most difficult things for families to appreciate is that an initiation difficulty is not laziness. Another is that the person may remember some things and not others due to attentional problems rather than not bothering to remember. Education can have an important role in helping families both to understand, and modify their own behaviour in relation to clients (for a case example see O'Brien, Prigatano and Pittman 1988). A combination of difficulties can sometimes result in problem behaviour such as aggressive or stereotyped behaviour, each of which may prevent the client from participating in other rehabilitation activities and cause significant disruption for family, friends and carers. In this situation, it is often necessary to provide a highly structured environment with the opportunity for very frequent feedback in order to help clients to shape and modify their behaviour. The work of Alderman and colleagues (Alderman & Burgess, 1990; Alderman & Ward, 1991; Alderman & Burgess, 1994; Alderman, this volume) illustrates the use of behaviour modification techniques, originally developed in the context of work with people with complex patterns of neurobehavioural disability, which are relevant in the context of the combination of memory and executive impairments in this client group.

The rehabilitation interventions described here provide a range of treatment options for people with various forms of executive dysfunction. However, most people referred for rehabilitation do not have just one area of cognitive impairment. Hence for any one individual there is typically a need for a range of interventions to be used. Furthermore, a comprehensive rehabilitation programme will aim to help the individual client to identify strategies for compensating for, or coping with, cognitive impairments, and also support the client in the application of those strategies in practical, personally relevant situations. The following case example illustrates this process in the context of a neuropsychological rehabilitation programme.

### Case Example: David

At the age of 34, David suffered a cerebro-vascular accident, resulting in a right internal capsule infarct. He was a Chemical Engineer. Following an acute hospital admission, and then a period of inpatient rehabilitation, he returned home some four months post-injury. He had been unable to return to work, and had been medically retired. Eleven months post-injury David was referred to an intensive inter-disciplinary outpatient neuropsychological rehabilitation programme (Wilson et al., 2000). The main problems reported included;

- mental tiredness
- difficulty doing more than one thing at once
- difficulty sustaining his concentration (either being very easily distracted or totally focused and locked into something)
- bumping into things on the left
- poor sense of the passage of time
- difficulty thinking ahead or organising things
- difficulty initiating things (intends to do things, but doesn't do them)

Neuropsychological assessment revealed generally satisfactory verbal and non-verbal reasoning and memory skills. There was some evidence of persisting neglect, though only typically manifested in visually crowded and dynamic environments. There was however evidence of very significant problems with attention, affecting tests of visual selective, divided and sustained attention, such as those in the Test of Everyday Attention (Robertson, Ward, Ridgeway, & Nimmo-Smith, 1994). He also demonstrated difficulties on tests of planning and strategy application, such as the Key Search and Zoo Map tasks in the Behavioural Assessment of the Dysexecutive Syndrome (Wilson, Alderman, Burgess, Emslie, & Evans, 1996). On a practical test of planning and preparing an unfamiliar meal, he completed the task, but nevertheless showed evidence of difficulties with attention (failing to notice an item he was searching for) and with problem solving (e.g. in response to being unable to locate an item, and to noticing that an ingredient was not cooking fast

enough). One of his hobbies was painting miniature military figures, which he had enjoyed doing while listening to the radio. However, since his injury he had found it impossible to do these two tasks at the same time, and having become dispirited with his performance on the painting task following several attempts, had stopped painting. He was frustrated with his situation, and lacked confidence in himself. This also impacted on his relationship with his wife. David's lack of initiative and low confidence meant that the relationship with his wife lacked reciprocity.

In conjunction David, the clinical team constructed a set of rehabilitation programme goals. These were:

1. David will demonstrate an accurate understanding of the consequences of his brain injury consistent with his two week detailed assessment report.
2. David will report an accurate understanding of the effect of his injury on his relationship with his wife and have identified strategies that he could use to manage his relationship more effectively.
3. David will demonstrate effective use of problem solving strategies in social and functional situations as rated by himself, his wife and the clinical team.
4. David will demonstrate effective use of attention strategies in social and functional situations as rated by himself, his wife and the clinical team.
5. David will manage negative automatic thoughts in a range of family, social and leisure situations and rate himself as confident in specified situations.
6. David will plan his weekly schedule independently and complete 80% of activities successfully and without reporting excessive fatigue.
7. David will take responsibility for household budgeting and stay within an agreed monthly budget.
8. David will be engaged in a voluntary work trial and have a personal development plan.
9. David will be engaged in a physical leisure activity on a twice-weekly basis.

The goals reflect four key processes involved in neuropsychological rehabilitation – (1) developing insight/awareness, (2) managing mood and psychological adjustment, (3) developing compensatory strategies for cognitive impairments, (4) applying strategies in functional, 'real life' situations. These processes are dependent upon each other in order to progress. As part of his programme, David attended an Understanding Brain Injury Group, as well as working with his Individual Programme Coordinator to develop a personal report of his own brain injury, the consequences and the strategies he uses to compensate for his cognitive difficulties. In David's case, the two main areas of cognitive impairment were attention and executive functioning. He attended the group described earlier, and worked with a psychologist to develop personally relevant strategies. Two approaches were taken to attentional problems. One was to use specific strategies to compensate for deficits

and the other was to train performance on specific tasks in order to reduce the attentional load of these tasks. To compensate for difficulties with sustained attention, David learned to manage his environment better, to reduce distractions. A functional example was when having friends to visit selecting appropriate (e.g. quiet, ambient) music. He also developed a mental routine of checking his attention and where necessary re-focusing his attention to the task in hand. In order to develop this routine initially he used an alarm clock that he set for 15 minute intervals. A good example of where cognitive and mood management strategies overlapped was when watching films. Pre-injury one of his great pleasures was watching a film together with his wife. However, post-injury it had become a struggle. He would find that after 20 minutes or so, he would start to find it hard to concentrate. He would then engage in a mental battle with himself, in effect trying to 'force himself' to stay with the film. But this battle in itself was a distraction and made it harder, so that he nearly always gave up watching, but felt bad. The approach used here was to use the mental check after 15 minutes to ask himself, 'Am I still concentrating? If not do I want to re-focus my attention or take a break?' He also used video recorded films more so that he could break and return to a film if he wanted. However, what he found in general was that by giving himself permission to take a break, he more often than not actually chose to simply re-focus his attention. For some activities, he was aware that he was prone to getting 'locked into' the task. This happened most often if playing computer games. Here the problem seemed to be related to a dual-tasking problem, whereby he could not monitor peripheral stimuli and hence the passage of time effectively. In these situations he relied on using an external alarm (on an electronic organiser).

Two of the specific situations that David identified were difficult as a result of dual tasking problems were playing badminton and painting his miniature figures. When playing Badminton he found it difficult to play a shot and move to the next point in anticipation of the return shot. He also found it difficult to play and keep track of the score. Both of these he had done with ease before the injury. In this case it was hypothesised that the physical process of playing a shot was now taking more cognitive resources (it was not as automatic as it had been and required more conscious attention). The solution here was rather straightforward. David was simply encouraged to focus on the process of playing the shots and to practice regularly, to re-establish his skill level in the physical task. Then as his physical performance improved, he was able to gradually introduce the tasks of trying to think more about anticipating shots and also keeping the score. A similar approach was taken to returning to painting his figures. He began by doing short periods in very quiet environments, and building up the physical skills. Then very gradually, classical music was introduced, then music with lyrics and then talk based radio programmes.

With regard to problem solving or goal management, there were several areas of difficulty. Although some difficulty with planning had been identified

in the standard assessments, there was evidence in most practical situations that he could identify solutions to problems. However he lacked confidence in his ability and also had major difficulties with initiation of intended actions. David was therefore trained in the use of the goal management or problem solving framework, which was practiced with hypothetical problems and then personally relevant problems that arose during the course of the programme. David reported that he found the structured approach of the framework (which he could do mentally, rather than needing to write down) useful. It appeared that the formality of the process helped him to develop confidence that the solutions he derived were likely to be reasonable. He demonstrated use of the framework in coping with problems such as losing his electronic organiser, finding that some accommodation did not have his booking and was full, and in planning a weekend away with his wife. To compensate for his difficulties with task initiation, a self-instructional approach was adopted. David used a phrase that he said to himself, which was, 'Just Do It!' This seemed to provide a sufficient attentional 'kick', that David was able to follow through on a greatly increased number of tasks. Once again a key issue was the role of mood factors in exacerbating the effect of the cognitive impairment. Armed with the strategies, the tools for coping, his confidence increased, and this in turn was a significant factor in itself in facilitating the initiation of actions.

In conjunction with the development of strategies, David was also focused on the functional goals, but of course as he developed confidence in the application of strategies so he was able to apply them in a range of situations. He commenced a voluntary work placement in a Heritage Trust. He developed a planning system using his electronic organiser to schedule activities with more appropriate pacing. He took on the family budgeting role. He engaged in just one physical leisure activity per week. His increased level of confidence in problem solving and initiation meant that he felt he was less dependent upon his wife, which enabled him to engage in a more adult, equal relationship with her.

In summary, David presented with relatively circumscribed deficits in attention and executive deficits, which had a dramatic effect on his day today functioning. In terms of Shallice and Burgess's (1996) model of the supervisory attentional system, David's main impairments could be thought of being in relation to the implementation of plans and monitoring of attention and action. This knowledge lead to the development of strategies focused on improving initiation (e.g. the 'Just Do It!' strategy) and monitoring (e.g. the mental checking routine). He had less difficulty with actual planning, though lacked confidence in this, and then use of the problem-solving framework seemed to be helpful in the development of his confidence in this respect. Not all clients in rehabilitation are as successful as David. Many have even more complex combinations of problems and less insight/awareness. Nevertheless cases such as David's highlight how effective the rehabilitation process can be under the right circumstances, and the importance of the integrated mood

and cognitive management approaches in a context of practical, functional and personally relevant activities.

## Summary and Conclusions

Dysexecutive problems represent a major challenge for rehabilitation, and yet have received rather little attention, at least in the rehabilitation literature. A comprehensive tool-kit of techniques for such problems does not yet exist. This must be in part due to the lack of theoretical consistency with regard to the nature of executive functions and the problems that form the dysexecutive syndrome. Theoretical developments, partly driven by localisation evidence from functional imaging studies, are heading towards fractionation of concepts such as the Supervisory Attentional System or the Central Executive. A fractionated system means that specific problems may occur in isolation and that sophisticated rehabilitation should be able to target impaired systems. Whether such systems can be 'restored or retrained' remains to be addressed further, with pharmacological treatments and stem cell implantation techniques offering some hope for the future. There is some evidence that re-training approaches focused on teaching people problem-solving skills can be effective and have practical benefits. Furthermore, evidence is accumulating slowly that a range of specific compensatory techniques can be effective. Some techniques or strategies might be described as impairment-focused and general (e.g. NeuroPage for alerting, or self-instructional training for reducing impulsivity), where others are highly specific to a particular functional task or situation (e.g. the use of a checklist for task completion). For most individuals some combination of both approaches may be beneficial, though insight levels may be a major factor in deciding what approach to use. For those with poor (treatment-resistant) insight, who will have difficulties spontaneously using general strategies, then task specific approaches are likely to be more effective, though of course severe insight difficulties will make even these approaches problematic. It seems likely that these techniques will be most effective when applied in the context of a comprehensive, inter-disciplinary neuropsychological rehabilitation programme.

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# Chapter 5

## REHABILITATION OF MEMORY DEFICITS

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### Introduction

Memory difficulties are one of the commonest cognitive problems arising from injury to the brain and, consequently, form a large part of cognitive rehabilitation. Unlike the study of memory itself, or the interest shown in memory performance, there has been until quite recently, little scientific enquiry into the remediation or amelioration of memory problems after brain injury. Neither has there been much effort until the past few years in relating theory to the practical experiences of memory impaired people or vice versa. Although considerate effort has gone into pharmacological research in the attempt to find a drug to improve or halt memory decline, this is beyond the scope of this chapter. The interested reader is referred to Curran and Weingartner (2002) This chapter highlights successful approaches to memory rehabilitation that have developed over the past two decades, it discusses guidelines that have been established in memory rehabilitation as a result of theoretical investigations of amnesia. Reference is made to the role of theory in those cases where theory has influenced the clinical management of memory problems. The four major approaches within memory rehabilitation involve (1) environmental adaptations, (2) new technology, (3) new learning, and (4) holistic approaches incorporating emotional, social, behavioural and cognitive aspects of memory deficits. A discussion of these approaches is provided together with an example of a young man receiving a holistic programme for his memory difficulties.

## Theoretical Influences on Memory Rehabilitation

It is probably true to say that the main theoretical influences on neuropsychology and neuropsychological rehabilitation have come from (a) the study of neuropsychology itself; (b) cognitive (neuro)psychology, which provides us with theoretical models to help explain phenomena and predict patterns of behaviour; and (c) behavioural psychology, which has provided us with a number of intervention strategies that can be modified or adapted for use with people with brain injury (see Wilson, 1999 for further discussion).

Behavioural psychology has also provided strategies to help us assess everyday manifestations of neuropsychological impairments, analyse problems and evaluate the efficacy of treatments. One branch of behavioural psychology in particular, learning theory, has been important in helping neuropsychologists improve learning in people with brain injury (Baddeley & Wilson, 1994).

There are, of course, numerous other sources that have affected the development of neuropsychology and neuropsychological rehabilitation. These include neurology, psychiatry, gerontology, occupational therapy, linguistics, ergonomics, information technology and others. All of them serve to emphasise the fact that neuropsychology and neuropsychological rehabilitation are areas requiring a broad theoretical base – or, perhaps one should say, several theoretical bases (Wilson, 1997)

It is apt, I think, to point out there that it is simply not sufficient for cognitive psychologists to suggest that neuropsychological rehabilitation should be driven by theories solely from their own subdiscipline. The danger of following one model or theoretical approach too closely, without considering other possible influential sources, is that we might become too confined and constrained. (Wilson, 2002). Take, for example, the concomitant difficulties that are often associated with memory impairment such as anxiety, fear and depression. These problems need to be addressed as part of memory rehabilitation (see Chapter 7 in this volume). Here models of emotion, such as Beck's influential model of emotional disorders (Beck, 1976; 1996) are playing an increasingly important role in the rehabilitation of people with memory disorders. Prigatano (2000) believes that dealing with the emotional effects of brain injury is essential to rehabilitation success. Social factors and individual personality need to be taken into account when designing rehabilitation. Pre- and post morbid life styles will also be influential in determining the nature of treatment.

It is not always clear to what extent the problems are cognitive or emotional in origin. Howieson and Lezak (1995) for example, describe a patient who was referred for help because he 'forgot' to go to bed at night. Those responsible for the referral saw the patient's difficulties as being connected with memory failure when in fact the nocturnal activity and agitation were emotional in origin. In contrast, relatives of a patient with amnesia following head injury may believe that memory failure is due to emotional trauma

caused by the accident. The main point here is that rehabilitation needs to draw on a number of theoretical fields and models to deal with the wide ranging and complex problems faced by survivors of brain injury (Wilson, 2002).

### Ways of Understanding Memory.

Although there are several models of memory functioning and not all are uniformly accepted, the following is taken primarily from three influential models of memory namely the Working Memory Model (Baddeley & Hitch, 1974), the systems model of long term memory and associated brain structures (Squire & Knowlton, 1995) and the model of Markowitsch (1998).

#### Length of storage

The Working Memory model of Baddeley and Hitch (1974) subdivides memory into three main types depending both on time-based and conceptual differences. The first system, *sensory memory*, is a brief and rather literal trace that results from a visual, auditory or other sensory event, probably lasting no longer than a quarter of a second. This is the system we use to make sense of moving pictures (visual sensory memory) or language (auditory sensory memory). Most people with damage to this system would present with perceptual or language disorders and we would not normally think of them as having memory problems.

The second system, *working memory*, is considered to have two main components or functions. The first of these is *short-term* or *immediate* memory and lasts for several seconds. This period of time can be extended to several minutes if the person is rehearsing or concentrating on the particular information. Unlike sensory memory, information in working memory has already undergone substantial cognitive analysis, so it is typically represented in meaningful chunks such as words or numbers. We use this system when looking up a new telephone number and holding on to it long enough to dial.

The second component of working memory is a *central executive* that can be conceived of as an organiser, controller or allocator of resources. This component enables us to both to drive a car and talk to our passenger at the same time. Sufficient resources are allocated to each of these tasks, and if a demanding or unusual situation occurs on the road we stop talking while all our resources are required to deal with the unexpected situation.

The third system in the Baddeley and Hitch (1974) model is *long-term memory*, which encodes information in a reasonably robust form and can last for decades. Although there are differences in memory for things that happened 10 minutes ago and things that happened 10 years ago, the differences are less clear-cut than those between the sensory (quarter of a second) and immediate (few seconds) memory systems. All the systems described so far are connected with *retrospective memory*, that is remembering informa-

tion or events that have already occurred. Frequently, however, we want to remember to do something in the future, such as take our medicine, water the plants, or make a telephone call. The system activated for remembering to do something is known as *prospective memory*. It is significant that many of the complaints of memory impaired people refer to failures in prospective memory.

### **Type of information to be remembered**

In 1972 Tulving (1972) produced an influential paper distinguishing two types of memory: semantic and episodic. *Semantic memory* is memory for our knowledge about the world, for example, remembering that Brussels is the capital of Belgium, or that a squirrel has a bushy tail. Semantic memory is also concerned with our knowledge of social customs, the meanings of words, the colours and textures of objects, and how things smell. Most memory impaired patients do not forget this kind of information, although they may have difficulty adding to their store of semantic knowledge. Amnesic patients are often unable, for example, to learn new words that enter the vocabulary after their neurological insult.

*Episodic memory*, on the other hand, represents what most of us would think of as memory in that it refers to a specific episode that has been experienced and can be recalled. Thus, remembering what television programme you watched last night, when you last had your hair cut or what you read a few minutes ago, are all examples of episodic memory. This system is frequently damaged in people with organic memory impairment and episodic memory deficits are perhaps the most noticeable characteristic of the amnesic syndrome.

A third system that operates differently from either semantic or episodic memory is *procedural memory*, the system used for learning skills such as swimming or typing. People get better with practice and can demonstrate the skill even though they may not remember how they learned to ride swim or type. JC, a young amnesic patient of mine, successfully learned to type even though he had no conscious recollection of learning. In his words, 'Practical skills developed without me being aware of how this came about. I could do things without being able to explain how.' Procedural memory is typically normal or nearly normal in amnesic patients.

### **The stages involved in remembering**

Typically there are three stages involved in remembering: *encoding*, *storage*, and *retrieval*. Encoding refers to the registration stage, or getting the information into memory. Storage refers to the maintenance of information in the memory store, and retrieval refers to the stage of extracting or recalling the information when it is required. After a neurological insult to the brain, each of these stages can be affected.

Suggestions as to how to improve encoding, storage and retrieval include:

- Simplifying the information you give to a memory impaired person.
- Reducing the amount of information supplied at any one time.
- Ensuring there is minimal distraction.
- Making sure the information is understood – by asking the person to repeat it in his/her own words.
- Encouraging the person to link or associate information with material that is already known.
- Trying to ensure processing at a deeper level – by encouraging the person to ask questions.
- Using the ‘little and often’ rule i.e. it is better to work for a few minutes several times a day or during a session than to work for the same amount of time in one chunk.
- Making sure learning occurs in different contexts to avoid context specificity and enhance generalisation.

### **Recall and recognition**

Recall and recognition are two of the main ways we remember information. Recall involves actively finding the information to be remembered. In some situations, however, we do not need to recall the information but to recognise it. Most of us at some time have been unable to tell someone how to find a particular street, but can nevertheless take ourselves there with no trouble. Most memory impaired people find recall harder than recognition, although both systems are usually affected. Some people might have difficulty with both verbal and visual information while others might have problems in only one of these modalities.

### **Explicit and implicit memory**

In many situations we need to consciously recall information we have received. For example, if I asked someone where they spent last Christmas, and they could tell me, they would be using *explicit memory*, i.e. consciously recalling the desired information. If, on the other hand, I asked someone when and where they learned to swim, and the steps by which they gained expertise, they would probably find this difficult. They could demonstrate how to swim, that is they could have *implicit memory* of this skill, they would remember how to do it even if they were unable to explain it with any great ease or remember when and how they learned the skill. Like procedural memory, implicit memory is usually intact or relatively intact in people with organic memory impairment.

### **Retrograde and anterograde memory**

One of the questions frequently asked by relatives of memory impaired people is, ‘Why can s/he remember what happened several years ago, but not what happened yesterday?’ The short answer is that old memories are stored differently in the brain from new memories. Although information acquired before a neurological insult may be forgotten, this is usually for a specific time period

ranging from a few minutes for some head-injured people to several decades for some people with Korsakoff's syndrome or herpes simplex encephalitis. Memory loss dating from before the insult is known as *retrograde amnesia* (RA). RA is usually less of a problem and less handicapping for the memory impaired person than *anterograde amnesia*, which refers to memory difficulties dating from the time of the neurological insult (although see Kapur, 1993, for a review of RA).

It should be noted here that these are not mutually exclusive systems. Instead they are simply different ways of considering the breakdown of memory. For example, procedural memory is a subcategory of implicit memory; explicit memory covers both episodic and semantic memory and anterograde amnesia represents an impairment in the ability to add to semantic memory as well as an impairment in episodic memory. Thus competing terms are often used for similar concepts.

## Strategies for Memory Rehabilitation

### Environmental adaptations

The most that we might be able to do for a patient with widespread cognitive impairments is change or adapt the environment in some way in order to reduce the load on the patient's memory. An example of this is given by Harris (1980) when he describes a geriatric unit in the USA with a high rate of incontinence until somebody painted all the lavatory doors a distinctive colour. The rate of incontinence decreased, presumably because more people could remember that the lavatories were behind the distinctly coloured doors.

Similar approaches can be used in a variety of settings. Signposts, for example, can be placed strategically around the hospital or home. Doors can be labelled so that patients know which is the dining room, which is the bedroom and so forth. The patient's bed itself can be labelled. As well as providing signposts and labels, therapists should make sure that (a) the printing is large enough to be legible to those with failing eyesight, (b) the labels/signs are placed in prominent positions, (c) the labels are discriminable against their backgrounds, and (d) the terminology used is familiar to the patient. Further examples of environmental adaptation can be found in Wilson (1995) and Wilson and Evans (2000).

### Compensating for memory deficits

Compensation is one of the major tools for enabling people with brain injury to cope in everyday life. Wilson and Watson (1996) described a framework for understanding compensatory behaviour in people with organic memory impairment. Wilson (2000) went on to use this framework to consider compensation for other cognitive deficits. The framework was developed from one proposed by Bäckman and Dixon (1992) and further modified by Dixon and Bäckman (1999). The framework distinguishes four steps in the evolu-

tion of compensatory behaviour, namely origins, mechanisms, forms and consequences.

The origins of compensatory behaviour take place when there is either (1) a decrease in a given skill without an accompanying decrease in environmental demands, or (2) an increase in environmental demands without an accompanying increase in the skills required for successful performance.

Mechanisms are ways in which a match between everyday demands and skill deficits is achieved. One way is to offset the mismatch by an increase in time and effort; a second way is to use a substitute skill; and a third way is to adapt or adjust to the new situation by relaxing the criteria of success or by changing expectations.

Forms of compensatory behaviour refer to the manner and extent to which compensatory behaviour differs from the behaviour of a normal person in a similar situation. These forms may involve the same behaviour a normal person would use with more time and effort expended; or they may involve substitute skills and these may be ones normal people use but only infrequently; or they may be entirely new behaviours not used by the general population. Consequences of compensatory behaviour may be functional and adaptive, and reduce the mismatch between environmental demand and skill, or they may be maladaptive and fail to reduce the mismatch.

Wilson and Watson (1996) considered how Bäckman and Dixon's framework might apply to people with memory impairments. Although much of the framework was useful it was insufficient to account for all the successes and failures in learning to compensate demonstrated by people with organic memory impairment. For example, Bäckman and Dixon (1992) consider severity of impairment affects the extent to which compensation occurs and suggest compensatory behaviour follows a U-shaped curve whereby people with very mild or very severe deficits will not compensate whereas those with moderate deficits will. They provide examples of normal elderly adults who compensate better than young adults who do not need to compensate, and Alzheimer patients who do not have the wherewithal to compensate. Wilson and Watson (1996) regarded this as only partially true and cite the example of severely amnesic people who can compensate despite very severe problems provided they have few additional cognitive deficits.

Two recent studies consider factors that predict good use of compensations (Evans, Wilson, Needham, & Brentnall, in press; Wilson & Watson, 1996). The main predictors appear to be age (younger people compensate better), severity of impairment (very severely impaired people compensate less well), specificity of deficit (those with specific memory problems compensate better than those with more widespread cognitive impairments) and premorbid use of strategies (those using compensation aids pre-morbidly appear to do better).

### **External aids and new technology**

Most people without memory impairments make frequent use of external aids. A follow-up study of 45 memory impaired people (Wilson, 1991b)



showed more aids are likely to be used 5-10 years after the end of formal rehabilitation than during rehabilitation. A recent study (Evans et al., in press) interviewed 101 brain injured people and their families to find out what strategies were used to compensate for memory impairments and how effective were the compensations. The variables that best predicted use of memory aids were current age, time since injury, the number of aids used pre-morbidly and good attentional skills.

Few people in the Wilson (1991a) and the Evans et al. (in press) studies were using technological aids such as electronic organisers despite increasing use of technology in society as a whole. Nevertheless the growth in technology has benefited memory rehabilitation in several ways and this benefit is likely to increase in the future. 'Smart' houses, for example, employ computers and videos to monitor and control the living environments of people with dementia. The aim of people developing and using this technology is to increase independence and activity and to improve the quality of life for confused elderly people. If successful for this population, there is no reason why 'smart' houses cannot be adopted for other people with cognitive impairments.

Two 'smart' houses are up and running in Norway (Graeme Slaven, personal communication) addressing problems such as falls, disorientation, inadequate meals, poor hygiene, emergencies and limited home management. With the rapid development of technology, it is possible that 'smart' houses will become more important in the next decade or so, and would seem a fruitful area for psychologists, engineers, architects and computer programmers to join forces to design and evaluate new environments. Another recent and exciting tool in memory rehabilitation is NeuroPage<sup>®</sup>, developed for use with brain injured memory impaired people. NeuroPage<sup>®</sup> is a simple and portable paging system designed in California by the engineer father of a head injured son working together with a neuropsychologist (Hersch & Treadgold, 1994) NeuroPage<sup>®</sup> uses a computer linked by modem and telephone to a paging company. The scheduling of reminders or cues for each individual is entered into the computer and, from then on, no further human interfacing is necessary. On the appropriate day and time NeuroPage<sup>®</sup> automatically transmits the reminder information to the paging company who transmits the message to the individual's pager.

The system avoids most of the problems faced by memory impaired people when they try to use a compensatory aid or strategy. Employing aids or strategies involves memory, so the very people who need them most have the greatest difficulty using them. They forget to use them, may be unable to program them, may use them unsystematically and may be embarrassed by them. In contrast, NeuroPage<sup>®</sup> can be controlled by one rather large button, easy to press even for those with motor difficulties. It is highly portable, it has an audible or vibratory alarm depending on the preference of the user, it has an accompanying explanatory message and is, to many people's minds, prestigious.

In a pilot study (Wilson, Evans, Emslie, & Malinek, 1997), NeuroPage<sup>®</sup> was evaluated with 15 brain injured people whose memory difficulties followed head injury, stroke or tumour. Using an ABA design whereby the first A phase was the baseline period, B the treatment and the second A phase the post-treatment baseline, we demonstrated that all 15 participants benefited significantly from NeuroPage<sup>®</sup>. The average number of problems tackled for the group as a whole was 3.86 with a range of 1–7 and a mode of 4. Typical reminders included ‘take your medication’, ‘feed the dog/cat’, ‘pack your things for college/work’, and ‘check your diary’.

For the group as a whole, the mean percentage success for completing tasks in the first baseline period was 37.08, while in the treatment phase this rose to 85.56. Using an Odds Ratio Test (Everitt, 1995), which takes into account different underlying success rates for each target and calculates an average improvement factor, it was found that each participant showed a significant improvement. There were, however, wide individual differences, with some subjects changing from 0% success in the baseline period to over 90% success in the treatment period through to those with more modest changes such as 6.67% in the baseline stage to 22.93% in the treatment stage.

There were also wide variations between subjects in the post-treatment baseline phase. The mean success of the group as a whole was 74.46%, i.e. better than in the first baseline phase. The Odds Ratio Test indicated that 11 of the 15 participants were significantly better than in the baseline phase and 4 were not. The implications here are that some participants ‘learn’ to do what is expected during treatment, i.e. they learn to take their medication, feed the dog and pack their school bag, while other people will always require reminders to carry out tasks.

Two single case studies with NeuroPage<sup>®</sup> showed how the system can enhance independence in people with memory and/or planning problems (Evans, Emslie, & Wilson, 1998; Wilson, Emslie, Quirk, & Evans, 1999). Finally, a recently completed study of 143 people using a randomised control crossover design replicated the findings of the pilot study and showed that NeuroPage<sup>®</sup> significantly reduces the everyday problems of brain injured people with memory and planning difficulties (Wilson, Emslie, Quirk, & Evans, 2001).

In addition to NeuroPage<sup>®</sup>, recent work with pocket-computer memory aids shows that it is possible for people with memory deficits to learn to use two different types of pocket-computer (a touchscreen and a keyboard machine). There were individual preferences for one or other machine although high users tended to prefer the keyboard pocket-computer, while less frequent users made more entries with the touchscreen pocket-computer. The authors felt this demonstrated the need for rehabilitation staff to distinguish ability to use a machine from willingness to use a machine (Wright et al., 2001).

For further discussion of the use of computers and other technological equipment in memory rehabilitation, the reader is referred to Glisky (1995)

and Kapur (1995). External aids appear to work through capitalising on residual episodic memory unlike errorless learning described below which is probably more dependent on implicit memory.

### **New learning**

Useful as external aids new technology and environmental adaptations may be, they are rarely sufficient on their own. Memory impaired people need to learn some new information on some occasions. People's names, for example, can be written down in a notebook but in normal social interaction we need to greet people by name (at least every now and again). Referring to a notebook to retrieve the name would impair natural communication. Although learning names is difficult for many people and particularly so for those with organic memory impairment, a number of studies have shown that it is possible to teach names to amnesic people using strategies to improve learning. Wilson (1987) evaluated the strategy of visual imagery to teach names and demonstrated that it is virtually always superior to rote repetition. Thoene and Glisky (1995) also found that visual imagery was superior to other methods for teaching people's names to amnesic patients. More recently, Clare, Wilson, Breen, and Hodges (1999) were able to teach a 74-year-old man in the early stages of Alzheimer's disease the names of his colleagues at a social club. A combination of strategies was used including finding a distinctive feature of the face together with backward chaining and expanding rehearsal. A follow up study showed that much of this information was maintained two years after the end of treatment (Clare, Wilson, Carter, Hodges, & Adams, 2001).

Another principle, from experimental investigations into memory that can help brain injured people to learn more efficiently, is the principle of distributed practice. If learning trials are spaced or distributed, this leads to faster learning than massed practice whereby the same amount of information or practice is presented in one chunk (Baddeley & Longman, 1978; Lorge, 1930). In similar vein, Landauer and Bjork (1978) found that learning was improved if the information to be retained was tested over gradually increasing intervals. Such expanded rehearsal (otherwise known as spaced retrieval) is now a widely used procedure in helping people with memory and learning difficulties (see Camp, 2001, for a fuller discussion).

Some strategies from the field of study techniques (e.g. Robinson, 1970) and learning disability (e.g. Yule & Carr, 1987), have been applied in neuropsychological rehabilitation (Wilson, 1991a) and work continues in ways to improve learning. One series of potentially important studies in recent years has involved errorless learning.

Errorless learning has for many years been used to teach new skills to people with learning disabilities (Cullen, 1976; Jones & Eayrs, 1992; Sidman & Stoddard, 1967) but until quite recently the principle has not been employed to any great extent with neurologically impaired adults. As the name implies, errorless learning involves learning without errors or mistakes. Most people

can learn or benefit from their errors because they remember their mistakes and, therefore, avoid making the same mistake repeatedly.

People without episodic memory, however, cannot remember their mistakes so fail to correct them. Furthermore, the very fact of engaging in a behaviour may strengthen or reinforce that behaviour. Consequently, for someone with a severe memory impairment, it makes sense to ensure that any behaviour which is going to be reinforced is correct rather than incorrect.

Work on errorless learning in memory impaired adults was not only influenced by the earlier studies from the field of learning disability, but also by studies of implicit learning from the field of cognitive neuropsychology. There have been numerous studies showing that amnesic patients can learn some things normally or nearly normally even though they may have no conscious recollection of learning anything at all (Baddeley, 1990; Brooks & Baddeley, 1976; Graf & Schacter, 1985; Glisky & Schacter, 1987, 1989). Glisky and Schacter (1987, 1989) tried to use the implicit learning abilities of amnesic subjects to teach them computer technology. Although some success was achieved, this was at the expense of considerable time and effort. This and other attempts to build on the relatively intact skills of memory impaired people has, on the whole, been disappointing. One reason for failures and anomalies could be that implicit learning is poor at eliminating errors. Error elimination is a function of explicit not implicit memory. Consequently, if subjects are forced to rely on implicit memory (as amnesic subjects are), trial-and-error learning becomes a slow and laborious process.

Baddeley and Wilson (1994) published the first study demonstrating that amnesic patients learn better when they are prevented from making mistakes during the learning process. This was a theoretical study in which a stem completion task was used to teach severely memory impaired patients lists of words. Each of the 16 amnesic patients in the study showed better learning when they were prevented from making mistakes (i.e., prevented from guessing) than when they were forced to guess (i.e., forced to make mistakes). Since then, several single case studies have been carried out with memory impaired patients comparing errorful and errorless learning for teaching practical, everyday, information (Wilson, Baddeley, Evans, & Shiel, 1994). In the majority of cases, errorless learning proved to be superior to trial-and-error learning. Squires, Hunkin, and Parkin (1996) Wilson and Evans (1996) and Evans et al. (2000) report further studies.

Results from recent work (Evans et al., 2000) involving ten errorless learning experiments, suggest that tasks and situations which depend on implicit memory (such as stem completion tasks or retrieving a name from a first letter cue) are more likely to benefit from errorless learning methods than tasks which require explicit recall of new situations. Nevertheless, Wilson et al. (1994) demonstrated new explicit learning in a memory impaired head injured patient. Clare et al. (1999) also demonstrated explicit learning in a man with Alzheimer's disease. The Evans et al. (2000) studies found that the more severely amnesic patients benefited to a greater extent from errorless

learning methods than those who are less severely impaired, although this may only apply when the interval between learning and recall is relatively short. One of the implications from this finding is that errorless learning should be combined with expanding rehearsal to enhance its effectiveness. Recent work in Cambridge suggests that errorless learning works primarily by capitalising on implicit memory rather than strengthening impaired episodic memory.

### **Holistic Approaches to Memory Rehabilitation**

Wilson (1997) suggests there are currently four main approaches to cognitive rehabilitation, namely cognitive retraining through exercises or stimulation; strategies derived from theoretical models from cognitive neuropsychology; strategies derived from a combination of methodologies and techniques particularly neuropsychology, cognitive psychology and behavioural psychology; and holistic approaches that address cognitive, social and emotional sequelae of brain injury. Although each of these approaches has strengths and weaknesses, the holistic approach might be the best in terms of improving independence, employability and quality of life for people with non-progressive brain damage (Cope, 1994; Mehlbye & Larsen, 1994; Prigatano et al., 1994; Rattok et al., 1992).

Holistic programmes offer both group and individual therapy to increase the brain injured person's understanding of his or her problems, to improve insight, to help develop compensatory strategies for cognitive deficits and to consider work or other meaningful activities the brain injured person can engage in. It is important to address emotional issues because people with cognitive deficits become more distressed as they become more aware of their difficulties. Thus distress can interfere with new learning and adjustment just as it does for people without brain damage.

An example of a holistic rehabilitation programme for a man with cognitive, social and emotional difficulties is provided by Wilson, Evans and Williams (in press). They describe Carl, a young man who sustained a severe head injury in a road traffic accident when he was 21 years of age. He was in coma for 4 months and in Post Traumatic Amnesia for 2–3 months. Of average intellectual ability, Carl had some deficits of attention and fluency. He had a retrograde amnesia of several years and could remember little of his earlier life except that he was a fan of Manchester United Football Club. Despite a good immediate memory, his anterograde memory was poor, he forgot conversations, could not remember what he had been doing or was about to do. He became socially withdrawn, refused to go out because he could not remember what he had said or what others had said to him. He also became obsessive about checking things, for example, whether he had locked the door and whether he had his wallet, keys and mobile telephone with him.

During his rehabilitation programme Carl received individual and group therapy to deal with his varied problems. He attended the 'Understanding Brain Injury' group to improve insight into his strengths and weaknesses. This group meets daily, has an educational focus that teaches people about the brain and the consequences of brain injury. Clients are encouraged to take notes, learn from the handouts provided, review their progress and develop and share understanding of their own injuries. In the Memory Group, Carl was encouraged to use a filofax for daily planning, a voice organiser to record conversations and an electronic organiser to alert him (by means of an alarm and message printed on the screen) to carry out activities such as telephoning a friend or taking exercise. He also attended a group for Stress Management. Here Carl was taught (a) breathing exercises and (b) how to identify hierarchies to work through to enable him to participate in social occasions, community activities and physical exercise.

In the Attention Group, he was helped to attend more efficiently and to 'burn-in' images so that he would not need to check and re-check. He also received vocational counselling, individual psychological support and individual memory sessions to back up the group sessions.

After 4 months in the rehabilitation programme, Carl started on a college course, he was socialising with friends and going to clubs or pubs 2–3 times a week, he was independent in the local and wider community, his checking and tidying rituals were considerably reduced and he expressed greater confidence in himself in the use of strategies to manage his memory and engage in activities. Carl commented 'I have got my life back'.

### **Summary and Conclusions**

Memory should be regarded as a multifunctional cognitive system that can be understood in a number of ways. We can consider the length of time information is stored, the type of information stored, the stages involved in remembering, whether information is recalled or recognised, whether implicit or explicit information is required, or whether memories date from before or after the neurological insult.

Most memory impaired people have difficulty learning and remembering new information; they have a normal, or nearly normal, immediate memory span, but have problems remembering after a delay or distraction, and they usually have a period of retrograde amnesia that may range from minutes to decades.

Although restoration of memory functioning is unlikely to occur in the majority of people whose memory impairments follow neurological insult, there is, nevertheless, much that can be done to reduce the impact of disabling and handicapping memory problems and foster understanding of the issues involved. These include: dealing with emotional sequelae such as anxiety and depression, which are often associated with organic memory impairment;

environmental modifications that can enable very severely impaired people to cope in their daily lives despite lack of adequate memory functioning; teaching people how to use external memory aids to help them compensate for their memory difficulties; and the employment of errorless learning principles to improve the learning ability of memory impaired people.

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# Chapter 6

## REHABILITATION OF LANGUAGE DISORDERS

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Language functions are mediated by the left cerebral hemisphere in the majority of right- and left-handed individuals (Benson & Ardila, 1996). Individuals with neurologic disorders, such as stroke, trauma, tumor, and degenerative conditions, that damage left cortical and subcortical regions may incur verbal and written language impairments. Aphasia is an impairment in the comprehension and production of verbal language caused by acquired brain damage (Damasio, 1992). The language disturbance may affect grammatical (word order and word endings), lexical (word selection), semantic (word meaning), and phonological (speech sounds) aspects of language. Acquired alexia and agraphia are impairments of reading and writing that frequently co-occur with aphasia, as orthographic functions, which draw upon some of the same symbolic language mechanisms used in verbal language, are mediated by the left hemisphere as well. The right cerebral hemisphere contrib-

utes to additional aspects of communication abilities, including processing of discourse, figurative language (e.g., idioms, humor), and prosody (Myers, 1999). Therefore right hemisphere damage can lead to subtle impairments of communication as well.

Rehabilitation specialists, including speech-language pathologists and neuropsychologists, concern themselves with the treatment of language and communication difficulties encountered by individuals with aphasia and related communication disorders. In this chapter, we will restrict our discussion to the impairments of verbal language typically observed in individuals with left hemisphere damage. In the first section, we will describe theoretical approaches to the classification and interpretation of language disorders. We will then provide an overview of the rehabilitation approaches used to address impairments of verbal language functions, restrictions to communication activities posed by the language impairments, and environmental facilitators or barriers to communication, an orientation consistent with the Classification of Functioning, Disability, and Health (World Health Organization, 2001).

### **Theoretical Approaches to Language Disorders**

Researchers have devised a number of approaches to classification and interpretation of the language impairments that arise following brain damage. The earliest neurologic syndrome approaches utilized a brain ablation paradigm to correlate behavioral impairment with specific anatomical brain regions. This approach eventually gave way to cognitive neuropsychological theories which elaborated on the structures and processes involved in language processing. More recently, researchers have described distributed neural network models for analysis of language and aphasia. The approaches provide different contributions to our understanding of aphasia and have implications for clinical approaches to language assessment and treatment.

### **Syndrome Classifications for Language Disorders**

Broca in the 1860s is usually credited with recognizing that loss of spoken language is associated with lesions of the left inferior frontal cortex. Wernicke and Lichtheim (cited in Caplan, 1993) later extended notions of language impairment and developed a model in which ‘centers’ for different auditory, motor, and conceptual components of language processing are localized and interconnected in the left hemisphere. On the basis of their model, they distinguished different syndromes of aphasia that may occur following brain damage. A number of aphasia syndrome classification schemes have been proposed since that time (Benson & Ardila, 1996). Although each system incorporates somewhat different terminology, the patterns of language breakdown are similar to those originally described by Wernicke and Lichtheim.

Table 1. Aphasia Syndromes (+ intact; – impaired).

Aphasia Syndrome	Fluency	Repetition	Auditory Comprehension	Naming
Broca's	nonfluent	–	+*	–
Transcortical Motor	nonfluent	+	+*	–/+
Global	nonfluent	–	–	–
Mixed Transcortical	nonfluent	+	–	–
Wernicke's	fluent	–	–	–
Transcortical Sensory	fluent	+	–	–/+
Conduction	fluent	–	+*	–
Anomic	fluent	+	+	–

\*may have difficulty understanding grammatically complex sentences

To classify the aphasias, we must consider language functioning in four key areas: auditory comprehension, repetition, fluency of verbal expression, and confrontation naming (Table 1). Aphasia assessment batteries (e.g., Boston Diagnostic Aphasia Examination, Goodglass, Kaplan, & Barresi, 2001; Western Aphasia Battery, Kertesz, 1982) typically include subtests to evaluate language functions across these four language domains. Additional assessment tools are available to assess functioning for specific language processes such as confrontation naming (e.g., Boston Naming Test, Kaplan, Goodglass, & Weintraub, 2001) or auditory comprehension (e.g., Revised Token Test, McNeil, & Prescott, 1978).

Fluency of verbal expression warrants specific description as this dimension of language processing often poses a challenge in clinical aphasiology. Fluency in this context refers to the ease with which an individual produces fully elaborated conversational sentences, in distinct contrast to verbal fluency for single words as measured in a controlled oral word association test (Borkowski, Benton, & Spreen, 1967). At least five different aspects of verbal expression contribute to verbal fluency (Greenwald, Nadeau, & Rothi, 2000). Amount of verbal output, grammatical, articulatory, and prosodic integrity of the utterances, and ability to initiate and elaborate utterances all coalesce to provide fluent verbal expression. A serious disturbance of any one or more of these aspects of verbal expression may render the clinical impression of nonfluent verbal production. Fluent verbal expression, while adequate in overall amount as well as articulatory and prosodic flow of utterances, can be undermined in the accuracy of the lexical, phonological, and grammatical content of utterances such that verbal expression is unclear and difficult to understand. In general, nonfluent aphasias occur as a consequence of lesions affecting left pre-rolandic regions, and fluent aphasias occur following lesions involving left post-rolandic structures and sparing pre-rolandic regions.

## Nonfluent Aphasias

Four general patterns of nonfluent aphasia can be observed. In individuals with *Broca's aphasia*, both verbal expression and repetition are nonfluent and *agrammatic* due to omissions of grammatical words (e.g., auxiliaries, articles) and word endings (e.g., plurals, verb tense). Their prosody may be flattened and they may have difficulty initiating and sequencing articulatory movements, sometimes referred to as *apraxia of speech* (Kearns, 1997). Individuals with Broca's aphasia may have *asyntactic* comprehension leading to difficulty understanding grammatically complex sentences (e.g., passives). Word retrieval is impaired, especially for verbs (e.g., Damasio & Tranel, 1993; Zingeser & Berndt, 1990). Broca's aphasia is associated with large left frontal-subcortical lesions (Damasio & Damasio, 1989; Kreisler et al., 2000).

In *transcortical motor aphasia* (TCMA), verbal expression is rendered nonfluent due to lack of dynamic verbal initiation, and poor ability to elaborate utterances (Rothi, 1997). Preserved repetition sometimes leads to *echolalia* in utterances. Word retrieval in picture naming may be intact, or disrupted by perseverations in naming (Benson & Ardila, 1996). Auditory comprehension may be impaired for grammatically-complex sentences. TCMA has been described acutely with left hemisphere lesions of the mesial frontal cortex (supplementary motor area), dorsolateral frontal cortex, or thalamus (Alexander, Benson, & Stuss, 1989; Kreisler et al., 2000).

In *global aphasia*, patients are severely nonfluent, with verbal output limited to *automatisms* (e.g., cursing, I don't know) and *stereotypies* (repeated use of a nonmeaningful word) which at times are spoken with meaningful intonation (Goodglass et al., 2001). Repetition, word retrieval and auditory comprehension are severely impaired. Global aphasia is typically associated with extensive left pre- and post-rolandic damage (Damasio & Damasio, 1989; Kertesz, 1979) and persists when lesions extend into Wernicke's area and anterior periventricular white matter (Naeser, Gaddie, Palumbo, & Stiassny-Eder, 1990; Naeser, Palumbo, Helm-Estabrooks, Stiassny-Eder, & Albert, 1989).

*Mixed transcortical aphasia* is the counterpart to global aphasia in which repetition is relatively spared, whereas all other language domains are severely impaired. This infrequent syndrome occurs with damage to left anterior and posterior cortical watershed regions that preserve left perisylvian cortex (Rothi, 1997).

## Fluent Aphasias

Likewise, four fluent aphasia syndromes have been described. *Wernicke's aphasia* is characterized by fluent verbal expression in which there is a press to speak or *logorrhea*. Spontaneous verbalizations, repetition, and spoken

naming are disrupted by paraphasias and neologisms. Auditory comprehension is severely undermined. Yet it is possible for some patients to have fairly preserved comprehension and seem anosognosic or unaware of their unintelligible verbal output (Maher, Rothi, & Heilman, 1994; Marshall, Robson, Pring, & Chiat, 1998). Wernicke's aphasia is associated with lesions affecting the posterior portion of the left superior temporal gyrus (Damasio & Damasio, 1989; Kreisler et al., 2000).

In *transcortical sensory aphasia* (TSA), although repetition abilities are intact, fluent verbal expression and naming are marked by numerous paraphasias (Rothi, 1997). Lesions affect the left angular gyrus (e.g., Alexander, Hiltbrunner, & Fischer, 1989), thus TSA may be associated with Gerstmann syndrome.

*Conduction aphasia* is a form of fluent aphasia in which there is inordinate difficulty with repetition relative to other language abilities (Kohn, 1992). Phonemic paraphasias are common in verbal tasks, and patients often exhibit *conduit d'approche*, successive attempts to self-correct their mispronunciations. Individuals with conduction aphasia may display asyntactic comprehension (Heilman & Scholes, 1976). The lesions associated with conduction aphasia tend to involve the left supramarginal gyrus, insula, and underlying white matter (Damasio & Damasio, 1989; Anderson et al., 1999).

Anomia or word retrieval difficulty is common across aphasia syndromes. Some individuals, however, tend to present with anomia as an isolated symptom, or *anomic aphasia* (Goodglass & Wingfield, 1997). Word retrieval errors in conversation or picture naming tasks may include circumlocutions, semantic paraphasias, or response omissions. Nouns may be more affected than verbs (Zingeser & Berndt, 1990). Anomic aphasia may occur acutely with lesions in the left temporo-occipital junction or thalamus (e.g., Foundas, Daniels, & Vasterling, 1998; Raymer et al., 1997).

The aphasia syndrome approach has advocates who propose that syndrome classification schemes provide a common nomenclature to discuss patients and to generally represent patterns of language breakdown (Heilman & Rothi, 1987). Kreisler et al. (2000) confirmed the importance of the classical anatomical regions in the determination of aphasic symptoms, at least in the acute stage. However, there are a number of limitations to the aphasia syndrome approach. Some estimate that as few as 40% of subjects can be consistently classified into one of the aphasia syndromes (Goodglass et al., 2001). Variations across individuals in location and extent of left hemisphere lesions leads to disparities in the presentation of language symptoms across individuals with putatively similar aphasia syndromes. The lesion approach cannot account for distant effects of the lesion (*diaschisis*) in acute aphasia or compensatory mechanisms that may be operative in chronic aphasia. Finally, aphasia syndrome presentation does not necessarily indicate decisions to be made for language rehabilitation, which are guided more by the constellation of aphasic symptoms than by the overall syndrome classification. Out of the need to decipher some of the differences in language impairments across



patients with aphasia, other approaches to description of language disorders have been developed.

### **Cognitive Neuropsychological Approaches to Language Disorders**

The cognitive neuropsychological (CN) approach represents a melding of interests in cognitive psychology and neuropsychology. The goal of cognitive psychologists is to elucidate the functional architecture (representations and processes) involved in various cognitive activities, including language. Cognitive neuropsychologists study impairments of cognitive functions following brain damage, providing a converging source of evidence for the functional architecture of cognitive systems (Coltheart, 2001; Hillis, 2001). The models of language developed in the CN approach are considerably more elaborated than the Wernicke-Lichtheim model. One depiction of the language system is represented in Figure 1 where we have integrated mechanisms involved in lexical and sentence processing into one basic model of language. Details of the model are the subject of continuous inquiry, but generally, this simplified version of the language system is schematized as a set of stored representations (knowledge) and processes (procedures) that implement those representations in the comprehension and production of words and sentences. Independent orthographic and phonologic mechanisms store representations and accomplish processes involved in language functioning across modalities of input (e.g., spoken or written words, viewed objects) and modes of response output (e.g., writing, speech).

Acquired brain damage that disrupts functioning of a language structure or process can result in predictable constellations of symptoms across all language tasks that implement the impaired mechanism. Of course, brain damage often affects multiple language mechanisms, leading to a clinical challenge to disentangle the sources of dysfunction associated with an individual's pattern of disordered language. A clinical assessment battery that is available to guide assessment of language functions from the CN perspective is the Psycholinguistic Assessment of Language Processing Abilities (PALPA)(Kay, Lesser, & Coltheart, 1992).

It would be a lengthy deliberation to describe all the patterns of language breakdown that could be envisioned with disruption of the complex model of language proposed in Figure 1. (For recent reviews see Raymer & Rothi, 2001; Mitchum & Berndt, 2001; Beeson & Hillis, 2001). For the sake of this discussion, we will give some general patterns that will be observed with breakdown at various stages in the language system. Modality specific recognition impairments are likely to follow disruption of early auditory or visual analysis as well as the input lexicons. Intact performance would be observed in tasks requiring recognition through alternative input modalities and production of language responses that are not instigated by the impaired input modality. For example, impairment of either auditory analysis or the

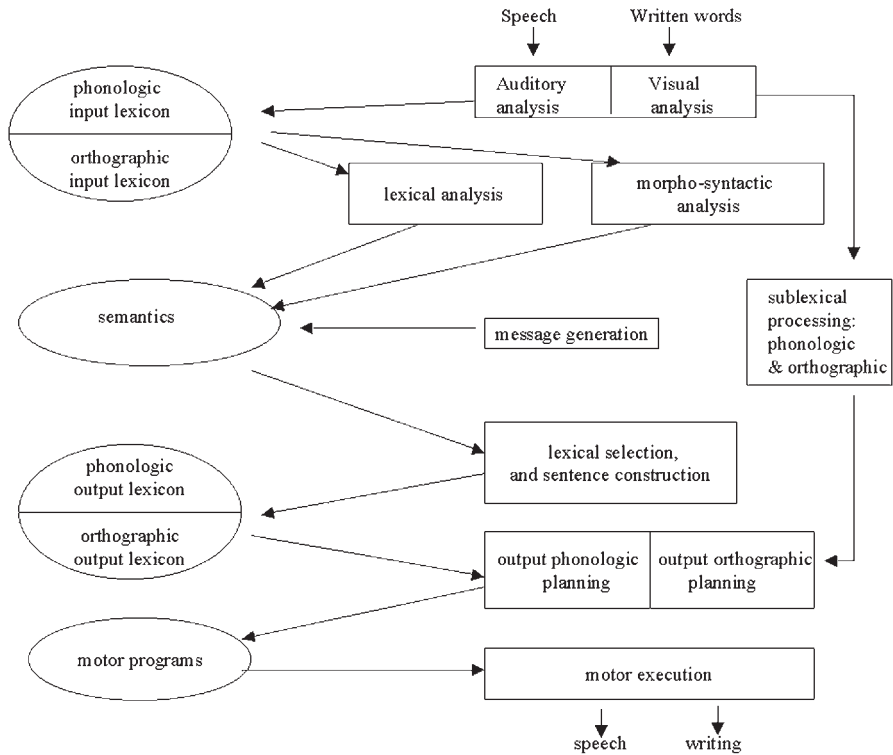


Fig. 1. Model of Language Comprehension and Production (after Caplan, 1993) with representations in ovals and processes in squares.

phonologic input lexicon would disrupt performance in all tasks requiring implementation of either of those early stages of language processing, including auditory comprehension, repetition, writing to dictation, and naming to spoken definitions. Performance for tasks using written and object input would be intact, however.

Likewise, mode-specific production impairments could be evident with dysfunction of either orthographic or phonologic output lexicons or output planning. So, for example, impairment of the orthographic output lexicon would lead to difficulty when spelling to dictation or to picture confrontation, or in spontaneous writing tasks. Performance for verbal tasks would be unaffected in oral picture naming, oral reading, and spontaneous conversation.

Semantic system dysfunction would be associated with impairment in all tasks that require processing of the meaning of words and sentences, including auditory and reading comprehension, picture naming, and spontaneous oral and written generation of words and sentences. However, the ability to

repeat spoken messages, copy written material, and read aloud and spell to dictation words with regular spelling-to-sound correspondences (e.g., lake, chin) may still be accomplished with sublexical processes that allow for translation of phonologic and orthographic information.

Morpho-syntactic processes are independent for input and output processing. Therefore, a production impairment related to sentence construction processes would lead to difficulty in sentence generation spontaneously, to picture description, or in story retelling. Auditory and reading comprehension for sentences may be preserved as input morpho-syntactic analysis processes are intact.

The clinician applying the CN approach will analyze patterns of impaired and retained performance across language tasks to develop an understanding of the levels of language dysfunction that are responsible for impaired language performance (Hillis, 2001). In turn, information garnered about stages of language dysfunction may allow the clinician to target language treatment in theoretically motivated directions to either restore language functions or to circumvent impaired functions and use compensatory means to communicate. That is, a CN analysis will orient the clinician to *what* language behavior is impaired, but not *how* to address that dysfunction. This type of detailed CN assessment can be time-consuming, however, and there are limitations to this approach as well. In particular, the language components represented in the models are likely under-specified. The clinical utility of the CN analysis has been called into question by reports indicating that language deficits that arise from dysfunction of different language mechanisms may be modified by the same language intervention, and individuals with similar language deficits may not respond in similar ways to treatments (Hillis, 1993). Finally, this approach fails to take into account other cognitive capacities that may affect performance such as attention or memory (Crosson, 2000a, 2000b). Some of these concerns have led to the generation of distributed network models of language processing.

### Neural Network Models

According to Mesulam (2000), the neuroanatomic substrates of cognitive domains take the form of large-scale distributed neural networks that contain interconnected cortical and subcortical nodes. Each major node of a network participates in multiple intersecting networks. In this way a single lesion may disrupt functioning in multiple networks, and a specific cognitive domain may be impacted by a variety of lesions. Support for this approach is found in connectionist or parallel distributed models (PDP) of language and related behaviors and impairments. Sophisticated computational simulations of language learning and language impairment have been adapted for orthographic, phonological, lexical, and syntactic processing (e.g., Plaut, 1996; Martin, Dell, Saffran, & Schwartz, 1994.)

Nadeau (2000; Nadeau & Rothi, 2001) reviewed some of the key features of neural network models that have implications for language functions and disorders. He noted that a distinction in neural network models, as compared to cognitive neuropsychological models, is that knowledge is represented in the strengths of the connections among the nodes of the network array. Processing in the array is massively parallel in that many nodes activate or inhibit other nodes in the array as a signal is propagated through the network. That is, processing derives from the activity of the nodes, and not from separate mechanisms as is implied in CN language models. Nadeau also indicated that disruption of neural network models by brain lesions leads to graceful degradation of functioning within the network. This property of neural models is consistent with the tendency for many errors in aphasia comprehension and production to be closely related, either semantically or phonologically, to the target language interpretation. It is not until there is major degradation in the network that severe language dysfunction will arise.

The application of neural network models to the study of aphasia and its treatment is still in its infancy, and at present these network models suffer from a lack of physiologic constraint (Price, 2000). However, the ability of distributed network models to account for connections across cognitive domains and to address the neural processes that might underlie these behaviors suggests they may have a significant impact in the future.

### **Treatment of Language Disorders**

The clinician analyzes a patient's pattern of language dysfunction to develop an appropriate plan for management of the consequences of aphasia in keeping with the prognosis for recovery (Benson & Ardila, 1996). Although aphasia is likely to persist, some recovery is anticipated. In general, a positive prognosis may be expected when the aphasia results from a recovering neurological disease, is in the first 6-12 months of recovery, and results from a lesion that is smaller, spares subcortical white matter, and is unilateral. Psychosocial factors such as age, gender, premorbid abilities, handedness, emotional state, and family support contribute to aphasia recovery but have a less potent impact (Benson & Ardila, 1996).

For most individuals, treatment may be beneficial for helping them to improve their language and communication abilities beyond the levels that would be anticipated from spontaneous recovery alone (Robey, 1998; Wertz et al., 1986). However, the exact approach taken for an individual with aphasia will depend on a number of medical, philosophical, and psychosocial factors. Foremost is the patient's constellation of language dysfunctions. Treatment methods have been devised to address impairment of auditory comprehension and verbal expression. Within each modality, treatment methods vary depending upon level of breakdown at single-word semantic and phonological stages of processing versus sentence-level morpho-syntactic processing.

## WHO Classification of Language Interventions

In addition to classifying language treatments according to modalities of language dysfunction, intervention strategies can be distinguished in a format consistent with the WHO (2001) International Classification of Functioning, Disability, and Health (ICF). In the most recent iteration of the WHO model, there are three distinct categories of influences on the ability of a person to successfully perform physical activities: body structure/function, activities and participation, and environmental factors. In the category of body structure/function are included the mental functions for language and other higher cognitive functions. When these mental functions are disrupted by acquired neurologic disease, cognitive disorders such as aphasia, dyslexia, and dysgraphia may be observed. Some treatment approaches that address the disability posed by disruption of language functions are aimed at restoring or restitution of specific language functions. Other approaches circumvent impaired functions and engage alternative cognitive mechanisms to assist in reorganizing or vicariously improving language functions (Rothi, 1995; Wilson, 1997, 1999) (Table 2).

A second category of influences on disability relates to activities and participation in life situations (WHO, 2001). Because of the loss of language and cognitive functions, the individual may experience restrictions and limitations

Table 2. Approaches to treatment of specific language functions in aphasia.

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### Word retrieval treatments

- Cueing Hierarchies
- Semantic Comprehension Treatment
- Semantic Feature Analysis Training
- Phonological Comprehension Treatment
- Voluntary Control of Involuntary Utterances
- Verbal + Gestural Facilitation

### Treatments for sentence production deficits

- Sentence Production Program for Aphasia
  - Linguistic-Specific Training
  - Melodic Intonation Therapy
  - Mapping Therapy
- 

Table 3: Approaches to enhance communication activities and participation:

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### Implement alternative modes of expression:

- Pantomime and Gestural codes (Amer-Ind, American Sign Language)
- Facial expression and emotional prosody
- Writing and drawing

### Promoting Aphasics' Communicative Effectiveness Group Therapy

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in their ability to use language to communicate, accomplish many daily life activities, interact with other persons, or participate in educational, employment, civic and other social opportunities. Some treatment approaches for individuals with language disorders are devised to improve general use of strategies and compensatory measures to enhance communication as an activity that allows for participation in communication interchanges (Table 3).

A third category in the WHO (2001) classification includes analysis of the environmental factors that either facilitate or provide a barrier to the use of language functions. Some approaches to aphasia treatment are geared at modifying aspects of the environment to remove barriers or to facilitate the language and communication environment (Table 4). In this realm we include treatment approaches that involve support systems as well as products such as technological and pharmacologic interventions.

## Treatments for Specific Language Functions

### **Auditory comprehension**

Restitutive treatment for lexical processing is based on the premise that systematic auditory stimulation will facilitate recovery from aphasia (Duffy, 1994; Schuell, Jenkins, & Jimenez-Pabon, 1964). Auditory stimulation training incorporates repeated practice with auditory-verbal tasks such as answering questions, manipulating objects, and pointing to command. Clinicians manipulate characteristics of the words (e.g., familiarity, semantic category, emotionality), the paralinguistic aspects of the auditory-verbal signal (e.g., rate, pauses, intonation), and task conditions (e.g., number of response choices, length of auditory input, redundancy and repetitions) to systematically increase the level of difficulty of auditory processing over time. Positive results of auditory stimulation training have been reported in single case studies (see Jacobs, 2001, for a review) and as part of group studies of aphasia therapy (Wertz et al., 1981, 1986). Computerized training programs are particularly amenable to auditory stimulation practice (Aftonomos, Appelbaum, & Steele, 1999; Katz, 2000).

In contrast to general auditory comprehension training, cognitive neuropsychological training studies address specific phonologic or semantic dysfunctions underlying impaired auditory comprehension in some individuals (Grayson, Hilton, & Franklin, 1997; Morris, Franklin, Ellis, Turner, & Bailey, 1996). In this type of auditory lexical training, patients participate in tasks that target either phonologic (sound and syllable discriminations, and matching spoken words to pictures or written words with similar sounds), or semantic (yes/no question verification regarding semantic attributes of words, and matching spoken words to corresponding picture amid semantically-related foils, or matching spoken words to associated pictures or written words), aspects of lexical processing, depending on the source of auditory comprehension impairment in a given individual. Directed semantic or pho-

nologic training may lead to improved auditory comprehension abilities in some individuals (Grayson et al., 1997; Morris et al., 1996).

Restitutive sentence comprehension treatments often incorporate a linguistic approach to sentence training (e.g., Haendiges, Berndt, & Mitchum, 1997; Jacobs & Thompson, 2000). For example, in Mapping Therapy, which incorporates the visual modality in training (e.g., Jones, 1986; Byng, 1988), patients are taught to understand syntactically complex reversible sentences by translating from grammatical word order (e.g., subject noun, verb, object noun) to the semantic roles (e.g., agent, action, object) played by words in the sentence. In sentences such as passive structures (e.g., The girl was called by the boy), there is not a direct mapping between grammatical word order and semantic roles, leading to comprehension difficulties for some individuals with aphasia. Repeated practice with syntactically complex sentences may lead to improved comprehension abilities (see Fink, 2001, for a recent review).

Other treatment methods attempt to circumvent auditory comprehension impairments by summoning alternative visual input modalities to reorganize comprehension abilities for spoken words. For example, lip-reading (Shindo, Kaga, & Tanaka, 1991), word reading (Hough, 1993), and systematic gesture processing as in Visual Action Therapy (Helm-Estabrooks & Albert, 1991) have led to improved auditory word comprehension skills in some patients with aphasia.

### **Word retrieval**

Individuals with both fluent and nonfluent forms of aphasia present with difficulties in word retrieval tasks. Because of the common occurrence of word retrieval impairments in aphasia, many techniques have been investigated to remediate this problem (Helm-Estabrooks, 1997). One of the most common approaches is the use of cueing hierarchies in the context of picture naming tasks. When a patient fails to name a picture, the clinician systematically provides cues that have more and more potent influence to assist the individual in retrieving the intended word. Cues such as sentence completions (e.g., You stir coffee with a ...), initial phonemes (e.g., 'sp'), rhyming words (It sounds like moon.), or imitation (say 'spoon') may assist the individual to retrieve intended words. With practice over time, word retrieval skills may be facilitated or the individual may learn to self-cue (see Patterson, 2001, for a recent review).

Recent investigations have examined restitutive techniques influenced by cognitive neuropsychological models that delineate semantic and phonological stages in word retrieval (Hillis, 1998; Raymer & Rothi, 2001). Some naming treatment studies target semantic stages of lexical processing in that the patient is required to act upon the meanings of target words. For example, pairing word comprehension tasks and word production may improve word retrieval abilities (e.g., Drew & Thompson, 1999; Marshall, Pound, White-Thompson, & Pring, 1990; Nickels & Best, 1996). In semantic feature

analysis (SFA) training, patients view a grid that cues them to systematically activate the semantic attributes of a target word (e.g., category, function, location), ultimately leading to production of the target word (e.g., Boyle, 2001; Boyle & Coelho, 1995; Lowell, Beeson, & Holland, 1995).

Other restitutive treatments focus on the phonological stage of word retrieval. Patients practice word production as they think about how words sound, how many syllables are in the words, initial phonemes, and rhyming words. They rehearse the words during picture naming, reading, or repetition activities (e.g., Hillis, 1993; Miceli, Amitrano, Capasso, & Caramazza, 1996; Raymer, Thompson, Jacobs, & leGrand, 1993). However, studies that have contrasted word retrieval treatments within subjects suggest that semantic treatment may have a more powerful influence than phonological treatment (Ennis et al., 2000; Howard, Patterson, Franklin, Orchard-Lisle, & Morton, 1985; Raymer & Ellsworth, 2002).

Some patients with severe aphasia and pronounced word retrieval impairments may require specialized methods to improve word production. One technique useful for some patients rendered nonverbal by aphasia is Voluntary Control of Involuntary Utterances (VCIU; Helm-Estabrooks & Albert, 1991). VCIU is based on Luria's (1970) concept of intrasystemic reorganization as clinicians train patients to gain volitional control over any retained automatically-spoken utterances, and then to modify those responses into other similar words. Systematic practice moving from automatic to volitional production of words in meaningful contexts may lead to an expanded vocabulary in some individuals.

In addition to restorative treatments, a number of reorganization treatments have been described to promote use of strategies to vicariously mediate word retrieval, circumventing impaired lexical mechanisms. One method that has been explored as an alternative means to mediate word retrieval is the use of gestural pantomimes. Consistent with Luria's (1970) notion of inter-systemic reorganization, patients are trained to combine pantomimes with spoken words to facilitate word retrieval (e.g., Pashek, 1997, 1998; Raymer & Thompson, 1991). Crosson and colleagues (Crosson, 2000a; Richards, Singletary, Rothi, Koehler, & Crosson, 2002) have reported the benefits of nonsymbolic (nonmeaningful) limb movements for word retrieval training as well. Advantages of the use of nonsymbolic limb movements in training are that they can be implemented with all types of words, regardless of the meaning, and that they are less vulnerable to disruption by limb apraxia (Maher & Ochipa, 1997). On the other hand, a benefit of pantomime training is that even when word retrieval abilities do not improve, general communication abilities often are enhanced through the use of pantomimes.

### **Sentence production**

Some individuals with aphasia, particularly those with nonfluent forms of aphasia, need training that focuses on improving the use of fluent, grammatical sentences. As in sentence comprehension treatments, the premise



of some restitutive sentence production treatments is to practice producing sentences that vary systematically from less complex to more complex grammatical structures. As patients experience production difficulty, clinicians model and expand target sentences, and patients then rehearse sentences to facilitate correct production. The methods vary in the context used for sentence practice, including story completion activities (e.g., Helm-Estabrooks & Nicholas, 1999), picture description (Haendigas et al., 1997; Kearns, 1985), or sentence reading (e.g., Thompson, 2001). With repeated practice over time, some patients improve use of complete, grammatical sentences. Contrary to methods often used in training hierarchies, Thompson, Ballard, and Shapiro (1998) have reported that practice with grammatically more complex sentence types (e.g., object relative clauses) can generalize to less complex sentence structures (e.g., who-questions) in some individuals with aphasia.

A reorganization approach to sentence production treatment is Melodic Intonation Therapy, a treatment designed to invoke the right hemisphere's intonational capacity to support sentence production (Sparks, 2001). In this systematic program, patients produce sentences while tapping rhythmically and using highly intoned, sing-song patterns. Over time the melody is reduced to a more natural prosodic pattern and the tapping discontinues. The method has been deemed effective for improving sentence production, particularly in patients with Broca's aphasia (Therapeutics and Technology Assessment Subcommittee of the American Academy of Neurology [AAN], 1994; see also Martin, Kubitz, & Maher, 2001). Evidence for the neural reorganization invoked by MIT was provided by Belin and colleagues (1996) who reported that patients showed increased left frontal activation and right posterior deactivation following participation in MIT, contrary to what might be predicted following melodic training, and suggesting that rhythmic tapping may be a critical element of the MIT procedure.

The possibility that tapping may be more important than intonation in the MIT protocol was explored by Boucher, Garcia, Fleurant, and Paradis (2001). They found that rhythmic tapping was more effective than intonation for improving sentence production in two individuals with nonfluent aphasia. Raymer, Rowland, Haley, and Crosson (2002) implemented a training procedure in which their patient made alternating tapping movements of the left hand in left space to improve sentence production in an individual with transcortical motor aphasia.

Finally, some interest has been placed on a treatment approach for verbal expression patterned after research in physical therapy advocating constrained use of compensatory measures and forced use of impaired motor systems (Taub, Uswatte, & Pidikiti, 1999). Pulvermuller and colleagues (2001) applied the principle of constrained language use during intervention in which patients were required to respond only with verbal responses, word or sentence, during intensive (3 hours/day for 2 weeks) language enrichment activities that took place in small groups. No nonverbal communication

strategies were accepted. Clinicians used shaping and modeling to expand the verbal repertoire of patients across sessions. This intensive forced use of language led to significant improvements in language functions (auditory comprehension and naming) as compared to a comparable amount of traditional impairment-oriented treatment provided on a less intensive schedule.

### **Treatments for Communication Activities and Participation**

Some approaches to aphasia treatment, sometimes termed 'functional' treatments, target the overall limitations that aphasia poses for a patient's general communication activities (Aten, 1994). These types of treatments encourage individuals to incorporate any strategies, verbal and nonverbal, to improve communication with conversational partners. Surprisingly, many patients with aphasia do not naturally attempt to use alternative means to communicate and need direct instruction and practice to improve their abilities in this area. Patients are often instructed to use writing or drawing to convey ideas (Rao, 1995). They are encouraged to use intonation or facial expressions to express emotions. Some severely impaired patients need to establish a system of body signals to indicate yes and no (head nods, thumbs up). Clinicians frequently encourage patients to use symbolic gestures or pantomimes, such as Amer-Ind (Skelly, 1979) to enhance communication.

Promoting Aphasics' Communicative Effectiveness (PACE) is a training technique that uses the functional approach as the clinician and patient participate in a communication barrier activity (Davis & Wilcox, 1981). The patient has to provide any verbal or nonverbal cues possible to convey to the clinician an item depicted on a picture card. The client/clinician interchange in PACE emphasizes use of all communication channels in a natural communicative context.

An efficient setting in which to apply functional language strategies is in the context of group aphasia therapy (Elman, 1999; Marshall, 1999). In group aphasia treatment, a small number of individuals with aphasia interact in language activities designed to promote conversation and use of communication strategies. Activities center around daily living activities, current events, hobbies, and other interests. Participation in group aphasia treatment emphasizing use of functional communication strategies has been reported to lead to significant improvements on some language and communication measures (Elman & Bernstein-Ellis, 1999).

### **Facilitating the Communication Environment**

A number of intervention strategies exist that influence the communication 'environment' for individuals with acquired language disorders. Environmen-

tal treatments are designed to facilitate language and communication abilities using external sources which can include pharmacologic interventions and technological devices as well as support provided by communication partners. In addition, some environmental modifications can be construed as means to remove barriers to successful communication.

### **Pharmacologic intervention in aphasia**

Language impairments result from disruption of neurobiological substrates of language functions. Thus clinicians have explored pharmacologic methods to maximize plasticity and recovery in the impaired neurologic system leading to improvements in language functions. The premise of this type of intervention is that drugs are necessary to replace neurotransmitters that are undermined following brain lesion (Shisler, Baylis, & Frank, 2000). Although there is some degree of skepticism in the treatment literature (Small, 1994, 2000), some studies have reported that pharmacologic interventions may enhance recovery from aphasia.

Because frontal lobe regions depend on dopaminergic input for proficient functioning, the dopaminergic agonist bromocriptine has been administered to a number of patients with nonfluent aphasia following left frontal lesions. Studies have documented improvements in verbal fluency measures, particularly in the reduction of pausing and improved word retrieval, in selected patients (e.g., Albert, Bachman, Morgan, & Helm-Estabrooks, 1988; Gold, Van Dam, & Silliman, 2000; Gupta, Mlcoch, Scolaro, & Moritz, 1995; Raymer et al., 2001). Other studies with bromocriptine, including one double-blind, placebo-controlled investigation, reported no significant benefits on language measures (MacLennan, Nicholas, Morley, & Brookshire, 1991; Sabe et al., 1995).

Cholinergic input seems to play a critical role in left hemisphere temporal and thalamic functioning, leading some investigators to explore treatments with cholinergic drugs for aphasia. Administration of cholinergic agents physostigmine (Jacobs et al., 1996) and bifemelane (Tanaka, Miyazaki, & Albert, 1997) has been associated with improved word retrieval skills in patients with fluent aphasia. Likewise, treatment with donepezil resulted in improved verbal fluency in one patient with nonfluent aphasia (Hughes, Jacobs, & Heilman, 2000).

Finally, some studies have explored the role that norepinephrine may play in increasing cortical excitability during recovery from neurologic damage. Treatment with the noradrenergic agonist dextroamphetamine has been associated with improved aphasia recovery in one double-blind placebo controlled investigation (Walker-Batson et al., 1991, 2001). The effect may relate at least in part to behavioral treatment paired with the drug administration, however (McNeil et al., 1997).

Clinicians are particularly interested in the potential that pharmacologic intervention may play in promoting recovery from aphasia and other cognitive, sensory, and motor impairments. Unfortunately, some studies have

conflated pharmacologic and behavioral interventions and it is not clear as to the relative contributions of these two distinct aspects of treatment.

### **Technological aids to communication**

Some individuals with profound impairments of verbal expression in aphasia may need to implement some type of external aid to express personal needs and ideas. Simple paper and pencil can allow some patients to draw or write messages. More often, clinicians develop inexpensive low-tech picture pointing boards or notebooks to help patients communicate by pointing to pictures or words. Software programs are available to design personalized devices with icons that are pertinent to an individual's needs and interests.

Other individuals are interested in exploring high-tech options to improve communication abilities. Specialized augmentative and alternative communication (AAC) devices or computers outfitted with appropriate hardware and software allow some patients to express themselves using spelling, mouse clicks, or touch screens. Unfortunately, some patients with aphasia may have difficulty manipulating some AAC systems as fairly sophisticated language capability is necessary to successfully operate some of these devices (Hux, Beukelman, & Garrett, 1994). Nevertheless, some researchers have been successful in training patients with severe aphasia to use computer-assisted communication programs (e.g., Weinrich, Boser, & McCall, 1999; Weinrich, Shelton, Cox, & McCall, 1997).

### **Communication support systems**

Finally, an area that addresses means to both facilitate and reduce barriers to effective communication is intervention aimed at the conversational partners of individuals with aphasia. Lyon (1997) has advocated moving communication partners into the treatment room to improve communication in the aphasia dyad through counseling and training on the use of productive strategies to enhance communication and reduce frustration. Interactions can be videotaped and analyzed for sources of breakdown and other potentially more effective communication options can be explored (Boles, 1998). A number of strategies that can be implemented by communication partners are provided in Table 4. Some options are designed to enhance the auditory comprehension of individuals with aphasia, whereas others are meant to promote resolution of breakdown emanating from the speaker with aphasia. Kagan, Black, Duchan, Simmons-Mackie, and Square (2001) have documented that conversational partners can be trained to use a variety of conversational support and repair strategies that may not naturally be used by untrained individuals during communication exchanges with individuals with aphasia.

Table 4. Partner strategies to facilitate or reduce barriers in the aphasic communication dyad.

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To facilitate auditory comprehension

- Gain eye contact and speak directly to the individual.
- Use short, grammatically simple sentences.
- Speak at a slower rate while maintaining a natural prosody.
- Do not speak louder.
- Repeat sentences and then revise the utterance if necessary.
- Talk about familiar topics.
- Signal when the topic changes.
- Embellish messages with alternative communication channels. (writing, drawing, gestures, facial expression)

To facilitate verbal expression of the speaker with aphasia

- Gently provide missing words or multiple choice options.
  - Encourage circumlocution and use of nonverbal channel to communicate messages.
  - Reiterate messages so speaker can confirm messages were understood as intended.
  - Encourage speaker to disregard simple errors when intent of messages is not disrupted.
  - Write down ideas when breakdown occurs and return to them later.
- 

### Efficacy of Aphasia Treatment

The optimal methods for exploring treatment efficacy are in randomized controlled trials or in meta-analyses (Therapeutics and Technology Assessment Subcommittee of AAN, 1994). Other types of treatment research designs, which often fail to implement subject randomization, are less favored. Developing appropriate research studies to establish the efficacy of aphasia treatment is a challenging endeavor (Holland & Wertz, 1988). Group studies are undermined by the heterogeneity of the language impairments observed across individuals with aphasia. An effective treatment for one form of aphasia or one individual with aphasia may not be effective for another, thereby reducing the aggregate effect of an aphasia treatment. A number of subject selection characteristics must be controlled. Nevertheless, a number of investigators have examined the efficacy of aphasia treatment using a variety of experimental designs with positive outcomes.

Holland, Fromm, DeRuyter, and Stein (1996) reviewed more than 200 aphasia treatment studies in the English literature. These included 20 group studies with more than 60 subjects with aphasia. They concluded that the effects of aphasia treatment for individuals with a single hemisphere stroke significantly surpass the effects of spontaneous recovery alone, particularly if individuals receive 3 hours of treatment per week for at least 5 months. Moreover, three different meta-analyses examining 45 (Whurr, Lorch, & Nye, 1992), 21 (Robey, 1994), and 55 (Robey, 1998) different aphasia

treatment studies have corroborated the view that treatment leads to greater language improvements than does spontaneous recovery alone.

The majority of aphasia treatment studies have implemented single subject experimental treatment designs (SSDs), time series designs that are well-suited to address the heterogeneous factors involved in aphasia treatment (McReynolds & Thompson, 1986). Meta-analyses of treatment effect sizes reported in SSDs have indicated that, despite the fact that most experimental subjects were in chronic stages of aphasia, large effect sizes have been reported with a variety of aphasia treatments (Robey, Schultz, Crawford, & Sinner, 1999; Robey, McCallum, & Francois, 1999).

### Summary

The language system is a complex and interactive mechanism involving representations and processes for phonologic, semantic, and morpho-syntactic aspects of language. When impaired through acquired brain damage, particularly affecting the left cerebral hemisphere, an array of language impairments may arise. Clinicians implement a variety of treatment options when providing intervention to patients with language impairments.

Some language function-oriented treatment methods are restorative in nature, attempting to re-activate language representations and processes as in normal language functioning. Others are intended to reorganize language functions by engaging alternative cognitive systems to mediate language functions. Other types of interventions address the reduction in communication activities and life participation posed by language impairment, circumventing language impairments and capitalizing upon retained communication functions. Finally, some interventions are aimed at modifying external factors in the environment to either facilitate or reduce barriers to language and communication. These have included newer types of pharmacologic interventions to increase brain plasticity and recovery of language functioning. Attempts to demonstrate the efficacy of language interventions have shown large treatment effect sizes beyond what would be expected from spontaneous recovery alone.

Clinicians are continuing research efforts to devise novel methods of behavioral and/or pharmacologic intervention. Newer methods to assess the effectiveness and outcomes of treatment will allow for a distinction between statistical and clinical significance of our treatment research findings. Technological advances are allowing for an examination of the neurobiologic bases of treatment effects. The future of treatment research is likely to be very prosperous, and our patients with language impairments are likely to benefit in substantial ways in the years ahead.

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# Chapter 7

## NEURO-REHABILITATION AND COGNITIVE BEHAVIOUR THERAPY FOR EMOTIONAL DISORDERS IN ACQUIRED BRAIN INJURY

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### **Introduction**

Survivors of Acquired Brain Injury (ABI) are at particular risk of developing mood disorders. Negative psychological reactions to neurological trauma may be caused by a complex interaction of a host of factors. The task of assessment is made even more difficult because survivors often have difficulties in reporting their own emotions accurately. Although challenging, rehabilitation of emotional disorders is acknowledged as one of the key areas for development in neurological services. In this chapter we provide an overview of the assessment and rehabilitation of emotional and mood disorders following ABI in post-acute settings. Individual cases are described, based on work conducted within cognitive rehabilitation programmes augmented with cognitive behaviour therapy.

## Rehabilitation and Emotion

In 'holistic' rehabilitation survivors are encouraged to become 'insightful' and to 'take on' an active role in their own rehabilitation. McLellan (1997) for example, noted that rehabilitation is a 'shared process between survivor and staff [in which the survivor] is to choose the destination and the route taken, but also do most of the work' (p.1). In Cognitive Rehabilitation staff attempt to engage their clients in ways that enable them to develop awareness, and acceptance, of their cognitive deficits so as to develop strategies to compensate for them (Wilson, 1997). The balancing act of engaging a person to develop insight and self-determination, yet take on board deficits and potential obstacles to plan for, is challenging, and the process of rehabilitation may well be emotionally charged. During the process of coming to understand, accept, and cope with a memory problem that perhaps threatens return to work, a survivor may grieve the loss of their skills and be anxious about the future (see Prigatano, 1986). Indeed, Wilson (2001) recently described rehabilitation as both a science and an art in the demands that it places on staff. Done without creativity and flexibility, it can appear to 'force' insight, which is not only an un-productive strategy, but is also alienating and dis-empowering for the person. In contrast, enabling a person to recognise the need to check the evidence for applying a memory strategy might lead to some possible alliances. In rehabilitation, then, the person needs to be engaged in, and guided through, a process of exploration and discovery. The gains, it is hoped, would be continued engagement with a service until meaningful goals, which are self-sustaining, self-actualising and rewarding (such as being in a job that is manageable and that one likes), are achieved. However it might also mean achieving a 'good enough' degree of insight for acceptance of on-going support, that can mitigate against a fall off in emotional well-being and further denudation of social roles.

Rehabilitation staff not only attend to general emotional issues in rehabilitation, but also work with, and through, the emotional crises of survivors and families. Referrals to outpatient and outreach programmes are not often on the basis of a circumscribed neurological issue or goal, but are usually due to lack of insight, development of mood problems, chemical dependency, or threatened (or actual) family disintegration (see Harris, 1997). A recent large-scale population-based study by Teasdale and Engberg (2001) revealed that approximately 3–4% of those who suffered Traumatic Brain Injury (TBI) later committed suicide. Consequently there have been calls for more comprehensive guidance, and indeed services, to be developed, for the assessment and management of mood disorders in brain injury (Lewis, 2001).

## Mood Disorders in ABI Groups

There have been various attempts to detail the types and frequency of mood disorders following ABI. The majority of research has been conducted in

Traumatic Brain Injury (TBI). There has been much variability between studies in terms of the measures used, perspectives taken (client and/or significant other) and timescale of assessment. From the existing evidence, there is much to indicate that mood disturbance of various forms is very common following ABI. The seminal work of Brooks, Campsie, Symington, Beattie, and McKinley (1987), revealed how the emotional and behavioural consequences of brain injury were more common and distressing for carers than purely cognitive problems. More recently, Bowen, Neumann, Conner, Tennant and Chamberlain (1998), using the Wimbledon Self-report Scale for Mood Disorders, found a 38% rate of 'caseness' for mood disorders in 77 survivors 6 months after injury. Hibbard, Uysal, Kepler, Bogdany and Silver (1998) investigated patterns of mood disorders in TBI with the Structured Clinical Interview for DSM-IV. They found that the most frequent diagnoses were major depression and specific anxiety disorders, and that co-morbidity was high, with 44% of individuals having two or more diagnoses.

A complicating factor for the general assessment of mood disorders in ABI is that there is a lack of appropriate measures of psychiatric/mental health status for TBI groups. Measures in use have usually been developed for other, non-brain injured groups, and may lack validity when used with ABI groups (see Bowen et al., 1998; Williams, Evans, & Wilson, 1999). Moreover, it is important to note that TBI leads to complex forms of emotional disturbance, often associated with dysexecutive and amnesic syndromes. Therefore, it is more likely that a person with TBI would suffer a syndrome of neurological-emotional reactions than a singular form of emotional disturbance (Berrios, personal communication). Sometimes the neurological factors are more prominent, and at other times the emotional reaction is more prominent. Due to these issues, false positives and false negative findings on psychiatric or mood measures may be common in ABI practice. Reliance, then, on 'routine' screening measures, is particularly problematic in ABI, and, as such, care needs to be taken to conduct assessment from different perspectives (the client's, the partner's, and/or significant others') with a range of techniques (interviews, cognitive tests, mood measures, behavioural checklists and observation). From such assessments it may become possible to understand how a mood disorder may represent elements of a person's overall neuro-behavioural syndrome. In terms of rehabilitation, a clinical formulation of elements that contribute to a mood disorder can inform areas for intervention, such as the symptoms a survivor is most troubled by and/or for which goals may be set.

## Depression

Depression can be viewed as a persistent state of low self-esteem, sadness and hopelessness (about the world, future and self). It has been suggested that depression may become more prevalent in TBI groups over time, given successive losses and difficulties establishing control over life post-injury (Brooks



et al., 1987). The grief literature, emphasising losses experienced, and difficulties in 'moving' through to stages of resolution, is particularly helpful in understanding depression. The coping literature provides key themes relating to the notion of learned helplessness, which may become an entrenched state for the survivor (discussed below). Studies of depression and TBI have 'consistently shown a strong association regardless of instruments or procedures used' (Satz, Forney, Zauha, Asarnow, Light et al., 1998, p. 538). Using the Beck Depression Inventory (Beck, Ward, & Mendelson, 1961), Garske and Thomas (1992) found that, of 47 TBI survivors, 55% had clinical symptoms of mild to severe depression. Kreuzer, Seel and Gourley (2000) investigated depression following TBI using standardized diagnostic criteria (DSM-IV) in 722 outpatients with brain injury. They found that 42% of patients with brain injury met DSM-IV criteria for diagnosis of major depressive disorder. In addition, they noted that fatigue, frustration, and poor concentration were the most commonly cited manifestations of depression. Research into risk factors for depression is limited. Ownsworth and Oei (1998), in a general review, suggested that the following factors made TBI survivors particularly susceptible to depression: pre-existing psychiatric disturbance; sustained injury involving the left anterior region of the brain; significant impairment of self-awareness; and unrealistic expectations of resuming pre-injury social roles and experiencing failure doing so. However, it should be noted that impairments in self-awareness has been shown to be a protective factor for mood disorders (see Williams, Evans, Needham, & Wilson (2002)). Indeed, it may well be that as survivors become more aware – over time and by rehabilitation – of the implications of the injuries for their life goal and social roles that they may suffer emotional distress (see discussion in Fleminger, Oliver, Williams, & Evans, (in press)). For example, Godfrey et al. (1993) noted that the presentation of emotional dysfunction (i.e. depression, anxiety and poor self-esteem) coincided with improved insight of behavioural, cognitive and social impairments in closed head injury (CHI) patients.

A major difficulty in assessing depression following brain injury is that apparent depressive symptoms – such as irritability, frustration, fatigue, poor concentration and apathy – may occur as a direct result of brain damage rather than due to depression. Indeed, Fleminger et al. (in press) noted that, given the paucity of studies making direct comparisons of the rates of symptom endorsement between the differing clinical groups (depressed, depressed and brain injured and brain injured) it is difficult to confirm the symptoms that specifically characterise depression following brain injury. Aloia, Long and Allen (1995) compared the symptom profiles of depression in head injured patients and non-head injured patients. The findings suggested that the picture of depression in head-injury was similar to that in non-head-injury. However, Kreuzer, Seel, and Gourley (2001) in a review of the literature, noted that the symptoms irritability, lack of interest, moving slowly, fatigue and forgetfulness as being more common after brain injury regardless of depression. Moreover, apathy, or loss of motivation, is frequently observed

among brain-injured patients and is often associated with depression. It may be helpful to note that Marin (1990, 1991) draws a distinction between apathy as a symptom of depression and 'true' apathy which 'describes only those patients whose lack of motivation is not attributable to a diminished level of consciousness, an intellectual deficit or emotional distress' (p. 22).

Suicide is, as we have noted above, disturbingly common after TBI. Depression is a major (but not only) risk factor for suicide. Harris and Barraclough (1997) undertook a meta-analysis of suicide following various medical and psychiatric conditions. They calculated Standardized mortality ratios (SMRs) for each disorder by comparing the sums of their observed and expected values. For both civilian and war brain injuries they calculated that risk of suicide after brain injury was raised over 3 fold from that expected in the general population (for further discussion see Fleming et al. (in press)). The presence of depression in the context of a neurological injury presents a volatile set of conditions for assessment and management of suicidality. Indeed, in the general psychiatric literature, a history of head injury is regarded as a risk factor for suicide in depression (Mann, Wateraux, Haas & Malone, 1999). Teasdale and Engberg (2001) noted that risk factors for suicide in their study of TBI included female gender, being aged between 21-60, and having a co-diagnosis of substance misuse. In general, the following issues may need to be addressed in suicidality in ABI: lack of planning and problem solving for 'getting out' of depressed mood; poor memory that affects ability to cope with problematic situations; emotional lability and/or dis-inhibition and impulsiveness that might increase the risk of acting without considering the consequences of actions; poor emotional expression, leading to depressed state going un-noticed; and perseveration over negative material, leading to a spiral of negative thinking (see Klonoff & Lage, 1995; Tate, Simpson, Flanagan & Coffey, 1997 for risk factors, assessment, and recommendations for management of suicide).

### **Anxiety disorders**

There are a range of anxiety disorders, such as generalised anxiety disorder (GAD), phobias, panic disorder, obsessive compulsive disorder (OCD) and post-traumatic stress disorder (PtSD). As a group, anxiety disorders are the most commonly diagnosed mental health disorder in general mental health settings. They are suspected to be common after brain injury, although possibly under-diagnosed due to difficulties in identifying symptoms in the context of other issues (see Scheutzwow & Wiercisiewski, 1999). For many, anxiety may be associated with the adjustment process to the brain injury and may, for example, be focused on feeling out of control and insecure over their future and social roles.

GAD has been reported, and is often associated with depression (see Jorge, Robinson, Starkstein, & Arndt, 1993). OCD was considered rare in brain injured groups, although there is increasing evidence of it occurring (see Lishman, 1998). OCD is characterised by symptoms of either recur-

rent intrusive thoughts and/or compulsive repetitive behaviours. It tends to present in the context of an affective disorder with symptoms of tension, rumination, self-doubt, indecision and compulsive preoccupation. McKeown (1984) found 3 of a sample of 25 survivors of mild brain injury, and a further individual from a twin study, to have severe OCD. There was an absence of any pre-morbid features in 3 of the 4 cases. Berthier, Kulisevsky, Gironell and Lopez (2001) reported a study of 10 people with TBI who had OCD. They noted that the patterns of OCD symptoms (such as a high frequency of obsessions regarding contamination, somatic symptoms, need for symmetry, and compulsions such as cleaning and checking) were relatively well specified.

Scheutznaw and Wiercisiewski (1999) described the case of a TBI survivor assessed as having a panic disorder who presented with clear anxiety symptoms, with avoidance of activities due to a fear of suffering a heart attack. Phobic reactions are infrequently reported in the literature, although, clinically, patients are often found to have stress responses in reaction to particular stimuli. Such reactions might be best understood within the literature on PtSD. Recent studies have shown that PtSD is a relatively common mood disorder for survivors of mild and severe brain injury (Bryant, 2001; Bryant, Maroszezsky, Crooks, Baguley, & Gurka, 2000; Hickling, Gillen, Blanchard, Buckley, & Taylor, 1998; McMillan, 1996; Ohry, Rattock, & Solomon, 1996; Williams, Evans, Wilson, & Needham, *in press* (a)). Bryant et al. (2000) found that 27% of 96 survivors of mild and severe TBI had PtSD. In a study of a representative community sample of 66 severe TBI survivors, 18% were shown to have moderate to severe PtSD symptoms (Williams et al., *in press* (a)). PtSD is characterised by intrusive experiences, hyper-vigilance, anxiety, fear and avoidance of activities. If left untreated it may severely limit a person's ability to function. PtSD and TBI were previously considered to be mutually exclusive, as it was thought that the survivor's lack of memory of the event negated the possibility of vivid intrusive cognitions and avoidance behaviours (Sbordone & Leiter, 1995). However, survivors have been shown to have 'islands of memory' of their trauma, such as being stuck in a car wreckage, or of later, secondary experiences, which could fuel intrusive ruminations (McMillan, 1996). Others have been traumatised by confabulated memories of the traumatic event (see King, 1996). Cases have also been documented of people with no memory of the event having traumatic re-experiences and avoidance behaviours following exposure to environments similar to their trauma (see McNeil & Greenwood, 1996). It has been suggested that if an event is unexpected, but has the biological significance of a life threat, then it may be stored in memory despite disruption to areas of the brain that store declarative memories (Markowitsch, 1998). Indeed, such theoretical mechanisms in TBI are consistent with fear-conditioning hypotheses for PtSD which hold that traumatic experiences can be processed independently of higher cortical functions (Brewin, Dalgleish, & Joseph, 1996; Bryant, 2001). Indeed, the nature of the event, for example, 'coming out of the blue' and

beyond any perceived control by the person, giving a heightened sense of threat to self, has been shown to be associated with the presence and severity of PTSD symptoms (see Williams, Williams & Ghadiali, 1998; Williams, Evans, Wilson, & Needham, in press (b)).

### **Principal Agents and Contributory Factors for Mood Disorders in TBI**

There are a host of factors that contribute to the development of mood disorders. Recent developments in this area have led to the argument that a bio-psycho-social account is needed for understanding psychosocial outcome in TBI (see Macmillan, Martelli, Hart, & Zasler, 2002). Principal factors include the following: the nature and severity of the neurological injury; the pre-injury history of the survivor; the survivor's adjustment and coping systems; the type and nature of the event suffered; and the presence of additional stresses. In addition, the forms of support available and the length of time elapsed since the injury need to be considered.

#### **Neurological factors**

The brain is the system that contains, creates and controls our reactions to the world. Injuries of any form may lead to emotional disturbance. As described above, some injuries may be more destructive to one's emotional integrity than others. An understanding of the breakdown in neurological functions is crucial for the understanding and management of any form of emotional disorder following brain injury. Two main forms of neurological deficits may lead to emotional dysfunction: composite (those involving a number of systems working together to produce functional behaviours) and specific (more circumscribed deficits of parts of a module). Of the composite problems, the most common (and crucial) is the dysexecutive syndrome, frequently seen in injuries to the frontal areas. Indeed, this disorder is particularly problematic for emotional functioning as executive systems are critical for 'handling' cognitive acts that modulate emotional processing. One crucial 'composite' result of effective executive functioning is having insight and awareness of one's circumstances and status. 'Specific' neurological deficits may lead to circumscribed forms of impaired emotional processing, including: motivation problems arising from injuries to the cingulate gyrus; inability to process others' emotional expression, associated with injuries to the amygdala; and inability to respond appropriately in situations that should be of concern, due to lesions of the ventromedial prefrontal cortex. An assessment of emotion therefore requires a consideration of neurological and neuropsychological profiles such that relevant causal agents are identified for rehabilitation. It is not within the scope of this chapter to consider such disorders in detail. Lishman (1998) provides a comprehensive overview of the assessment and management of neurologically-based emotional disorders. Eames (2001) provides insights into differentiating symptoms associated with neurological injury and

psychiatric disorders. Judd (1999) gives a lucid account of neuropsychotherapeutic approaches for such problems in community settings.

### **Pre-injury history**

In terms of predicting outcome in TBI, particularly emotional status, there is an aphorism that holds that, 'It is not only the kind of injury that matters, but the kind of head' (Symonds, 1937, p. 1092). Research on pre-injury characteristics and psychosocial outcome has focused on two main areas. Firstly, the presence of positive personality traits that might enhance psychosocial outcome (such as determination, resourcefulness and stability) and secondly, the absence of such positive elements, which may be reflected in difficult pre-morbid psychosocial histories, and could put people at risk of adverse outcomes (see Tate, 1998). The general position that a set of pre-injury personality characteristics is a major determinant on outcome was summarised as follows: 'In most cases after severe head injury, the personality and behavioural changes that occurred 'tend either to be an exaggeration of previous traits or to occur in patients that might have been expected to develop mental disorder without having had their brains damaged' (Brooks, 1984, p. 139, in Lishman, 1998, p. 174). Whilst acknowledging that there may be some likelihood of such effects, Lishman (1998) notes that, 'it has proved difficult to specify what special aspects of [premorbid] personality are important' (p. 174). He added that the evidence for personality types being associated with particular outcomes is 'impressionistic and hampered by lack of opportunity for objective assessments before the injury occurred' (p. 174).

It is, however, well established that gender and age are pre-injury risk factors. TBI occurs most frequently in the 18-25 year-old age group, with males outnumbering females by a ratio of at least 2:1 (Tate, 1998). Within this group, it is possible that anti-social and/or risk taking characteristics might contribute towards risk of injury, and might be associated with poorer longer-term outcome. However, it is also very likely that such characteristics would be transient rather than permanent characteristics of the person. As Tate (1998) noted: young men may 'frequently tend to be nonconformist, risk takers, immature, have difficulty with authority and so forth simply by virtue of their life stage' (p. 8).

Premorbid social maladjustment (PSM) indices, such as educational achievement, work history and 'nervous illness' were described in a seminal paper by Symonds and Russell (1943). It had been generally held that people with poor PSM profiles were overly represented in samples of TBI survivors. More recent research has revealed more complex interactions than had been assumed between pre-injury status and psychosocial wellbeing. Tate (1998) investigated pre-injury delinquency, conviction and substance dependency in a study with 100 head injured survivors. She found that 11 had evidence of such PSM characteristics. Furthermore she found that PSM was not predictive of psychosocial functioning 6 months post-trauma. In a further study, using the Eysenck Personality Questionnaire-Revised (including scales measuring

psychoticism, tough-mindedness, addiction, and criminality), Tate found that it was possible to identify a sub-group of participants with elevated scores for dispositional traits, but that such traits were not associated with psychosocial outcome. She found that post-traumatic amnesia (PTA) length was the only correlate of poorer outcome.

There is, however, some evidence of an association between pre-injury factors and mental health outcome both direct, and by implication. In Bowen et al.'s (1998) study, it was found that pre-morbid occupational status was associated with the development of mood disorders following injury. Deb, Lyons and Koutzoukis (1999) found that pre-injury factors such as lower social class and lower educational achievement were associated with psychiatric caseness according to the Clinical Interview Schedule-Revised. Dunlop, Udvarhelyi, Stedem, O'Connor, Isaacs et al. (1991) that found that a prior history of alcohol misuse was associated with poorer outcome. More recently, Macmillan, Martelli, Hart and Zasler (2002) found that pre-injury psychiatric status and drug use history were predictive of poorer outcome in terms of return to work.

It is likely then, that there may well be particular patterns of pre-injury characteristics that exert an influence on how the person copes with their injuries and their aftermath. It may well be that the type of head is important, but the type of resources and opportunities the person had, and has, must also be considered.

### **Grief, coping and adjustment**

Survivors of TBI have been noted to become depressed, withdrawn and anxious as a reaction to the disruption caused to their lives, their losses, and the chronic frustration associated with their acquired disabilities (Rosenthal & Bond, 1990). There has been increased interest in understanding why some survivors are protected from, and others more vulnerable to, developing such reactions. Grief models, and more recently, models of stress and coping, have been adopted to conceptualise responses to injury. The stress-coping models, which are in part evolved from grief models, and also cognitive behavioural theory, are purported to be comprehensive bio-psycho-social frameworks for understanding the complex interaction of pre-injury, injury and post-injury factors on mood and behaviour.

Grief models provide a framework for understanding how survivors might understand their losses and come to understand and cope with them (see Jackson, 1988). In general, reactions to loss may involve initial stages of shock and denial, then stages of anger and depression, leading through to adjustment and reintegration. An important aspect of such models is that there is not necessarily a progression through all stages of grief, as it is possible to have different combinations of each form of emotion at the same time, with one or other possibly being more salient. TBI leads to a particularly complicated form of grief because emotional denial (if it occurs) may well follow actual lack of awareness – anosognosia. Furthermore, the person may have

lost the very skills and opportunities for reinvestment in life, for example, when poor memory skills undermine the ability to work. Moreover, losses may also be cumulative and ongoing for survivors. In the early stages, the person may be experiencing a loss of function (cognitive or physical), but they may subsequently start to experience other losses, perhaps relating to work, and/or a partner. It is not surprising that a pervasive sense of grief may occur in the context of a disintegrated sense of self. As one client noted, 'I live in the ruins of my old self'. Individual differences in emotional reaction to loss might then be understood in terms of a person's 'stage' of grieving, tasks of grieving, and awareness.

Stress-coping theories of adaptation have as their key theme the interaction of pre-injury coping styles and stress caused by the demands and conflicts of the aftermath of the neurological event (see Kendall & Terry, 1996). An individual's adjustment may be influenced by successive efforts to master the demands and conflicts triggered by their trauma with, over time, adaptive or un-helpful coping styles being developed. Such conceptualisations are argued to be consistent with the general stress and coping literature (Folkman, Lazarus, Dunkel-Schetter et al., (1986) and the literature on coping in physical illness (Moos & Schaefer, 1984). Moos and Schaefer, for example, described three key coping skills in the context of physical illness: appraisal-focused coping – finding a pattern of meaning in a crisis; problem-focused coping – seeking to confront the 'reality' by constructing a more satisfactory situation; and emotion-focused coping – focusing on managing emotional reactions. The adoption of particular styles of coping may be related to the development of mood disorder and general psychosocial outcome.

Moore and Stambrooke (1992, 1995) examined how long-term outcome may be mediated by coping styles. They followed up 131 survivors of TBI and found two main clusters of 'coping' styles related to outcome. They reported that one group tended to have an external locus of control, and used an indiscriminate variety of all styles of coping and tended to have poor psychosocial outcome (with reports such as, 'I'd do anything to stop the pain...Life stopped...I'm being punished'). The second group tended to have a mainly problem-solving approach, and good outcomes ('it was a terrible day...I appreciate life and family more... take a day at a time'). In a similar vein, Malia, Powell and Torode (1995) reported a study in which 74 ABI survivors were shown to be less likely to have good psychosocial outcomes if their coping styles were avoidant, emotion-focused or 'wishful'. More recently, Finset and Andersson (2000) investigated coping styles of 70 ABI survivors and a non-injured control group. They reported that the ABI group tended to have a less differentiated coping style than the controls. They also found two main dimensions to coping responses in the ABI group – approach and avoidance. A lack of active-approach coping responses was associated with apathy, and avoidant coping was associated with depression. They suggested that apathy was related to sub-cortical and right hemisphere lesions. Unfortunately, it was not possible to control for dysexecutive problems contributing to the

un-planful coping responses described in these studies. What is important in the context of rehabilitation, then, is that styles of coping might not necessarily represent 'static' pre-injury dispositions, and need to be understood in the context of the survivor's neurological profile, and general post-injury psychological reactions.

### **Trauma of the event**

As described above, it has become more widely accepted that the event leading to a brain injury can be emotionally traumatic. Many survivors of traumatic events have great difficulty in developing adaptive ways of coping with changes in their lives and their emotional trauma, and typically become isolated and withdrawn (Brewin, 1984). Within the context of a 'stress and coping' model described above, it can be argued that some survivors may have had a combination of factors that have enabled them to adjust to changes in their lives caused by their trauma. However, their adjustment might also be influenced by having suffered emotional trauma during the event itself. There is evidence in non-TBI groups that some survivors have greater risk of developing PTSD under less severe trauma conditions than others. However, under severe trauma conditions both 'at risk' and 'not at risk' groups appear equally likely to develop the disorder. In a recent study Williams et al. (in press, a) found that pre-injury factors (such as educational achievement and occupational status) did not predict the development of PTSD. However, attribution to others for the event was associated with the development of symptoms, whilst poor insight was a protective factor in the development of symptoms.

### **Additional issues & stresses**

It is beyond the scope of this chapter to cover the myriad sources of stress for ABI survivors. However, it is important to note some additional critical issues for assessment and management of mood disorders. Firstly, many survivors may suffer relationship problems, with breakdown of partnership and/or changes in family roles (see Kendall & Terry, 1996). In many cases of ABI there may be physical disabilities causing additional stress. Survivors may often have problems with pain, particularly headache, and in TBI, pain due to orthopaedic injuries (see Andary, Crewe, Anzel, Haines, Kulkarni et al., 1997), which may be associated with the maintenance of emotional distress, such as PTSD symptoms (see Bryant, Marosszezecky, Crooks, Baguley, Gurka, & Joseph, 1999). Symptoms of sleep disorder are also very frequent, and may exacerbate problems in cognition and affect (Cohen, Oksenberg, Snir, & Stern, 1994). Furthermore, as has been noted above, misuse of alcohol and/or drugs may become significant problems for survivors, either as an exacerbation of a pre-injury condition, and/or a maladaptive coping strategy (see Kreutzer, Witol, & Marwitz, 1997).



## Neurorehabilitation and Emotion

In this section there will be a consideration of the neuro-rehabilitative input required for the management of mood disorders in ABI groups. However, it is important to note that psychopharmacological interventions are often used in combination with other modalities, such as CBT.

### Pharmacological intervention and considerations

Reviews of recent psychopharmacology for depression and anxiety in ABI are available (see Fleminger et al. (in press) and Williams, Evans, & Fleminger (in press) respectively). In general, there appears to be evidence for the efficacy of anti-depressant medication after stroke in treating depression (see Turner-Stokes & Hassan (2002)) and there is anecdotal evidence to support the use of SSRIs in brain injury (Sloan, Brown, & Pentland, 1992). Unfortunately, there do not appear to be any RCT evaluations of antidepressant efficacy for depression after traumatic brain injury (see Fleminger et al. (in press)). There is an indication that depression following brain injury may be more difficult to treat than when in isolation. For example, a controlled comparison study by Dinan and Mobayed (1992) found that patients who were depressed following head injury appeared to respond less well to amitriptyline than depressed patients without a head injury. Fleminger et al. (in press) noted that 'neuropsychiatrists would recommend starting with an SSRI, partly because these drugs probably have less effect on reducing seizure threshold particularly when compared with tricyclic antidepressants'.

Psychological treatments are considered to be the mainstay of the management of anxiety in those with a brain injury – as those without brain injury (see Lishman, 1998). With severe symptoms, or symptoms that do not respond to psychological treatment, a pharmacological strategy may be suggested. Antidepressants with sedative properties may be valuable in some patients with anxiety, and may also help the insomnia which is often present (Williams et al., in press). Zafonte, Cullen, and Lexell, (2002) provide a review of the mechanisms, efficacy, and side effects of serotonin agents in traumatic brain injury for the treatment of depression, and for panic disorder, obsessive-compulsive disorders, agitation, sleep disorders, and motor dysfunction. Williams et al. (in press) noted that Benzodiazepines should be avoided in those with chronic symptoms or in those with evidence of substance abuse, also that the potential side effects of the anxiolytics appear to dictate which drug is chosen. Indeed, caution must be exercised in general with the use of psychotropic medication with brain injured groups. First, such medications might exacerbate the symptoms of the brain injury. For example, psychotropics may produce derealisation – a common symptom after brain injury, therefore such survivors are particularly vulnerable to this side effect. Second, because of the cognitive problems experienced by such survivors many may have difficulty in maintaining appropriate management of a pharmacological regime.

### **Case Illustrations of Cognitive Rehabilitation and Cognitive Behaviour Therapy (CBT):**

The following cases are provided to illustrate how cognitive rehabilitation and CBT may be integrated for the management of mood disorders in ABI. Two individuals were treated at a centre for cognitive rehabilitation. In both cases there was a diagnosed mood disorder (OCD and PtSD), and co-morbidity with other disorders (depression, and depression with alcohol misuse respectively), in the context of general neuropsychological deficits.

### **General cognitive rehabilitation programme**

The assessment process consisted of neuropsychological evaluation, multi-disciplinary therapy assessments interviews, clinical psychology and neuropsychiatric evaluations, administration of mood and behaviour inventories, and self and observer ratings of cognitive, mood and behavioural symptoms over a two week period (for further details see Williams, Evans, & Wilson, 1999). Mood and psychiatric assessments followed DSM-IV guidelines for diagnoses of psychiatric disorders (American Psychiatric Association, 1994). The rehabilitation programme consisted of five components: (1) goal setting procedures; (2) coordinating therapists for facilitating survivor's understanding of intervention and goals; (3) intervention on awareness of impairments and emotional reactions; (4) therapeutic group milieu for encouraging awareness and acceptance and use of strategies; and (5) supported social re-integration for follow-through of strategy use in home or work settings.

For each survivor, the individualised programmes contained an intensive rehabilitation phase followed by a community re-integration phase (attending the centre on 1–2 days per week, for example). Family members, partners and/or friends of the participant were invited to attend a support group to facilitate their understanding of the participant and to derive mutual emotional support. In cognitive groups survivors were encouraged to develop their understanding of their brain injury and its consequences, and how to manage and compensate for cognitive problems, for example, in a memory group.

### **CBT and rehabilitation**

In the programme, clients were provided with individual and group sessions designed from a CBT perspective. CBT has been shown to be highly effective for the management of a range of mood disorders in the general mental health groups (see Roth & Fonaghy, 1996). Importantly, CBT has at its centre, a Socratic, metacognitive process of guided discovery that enables a person to share in an examination of their cognitive, emotional and behavioural experiences. CBT provides systematic means for addressing such issues as: negative automatic thoughts; negative cognitive schemas; unhelpful behaviour profiles; social engagement and, importantly, hope. CBT is advocated as particularly suited for people with ABI as it contains systems for managing generalisability of 'therapeutic work' from the treatment session (diaries and workbooks etc.)

and promotes social and emotional control skills learning (Ponsford et al., 1995; Williams & Jones, 1997). Moreover, cognitive rehabilitation and CBT both have an emphasis on enabling survivors to gain skills, record progress, challenge pessimism and promote self-efficacy. CBT appears particularly well-suited for integration with cognitive rehabilitation as it provides systems and strategies for structuring interventions for people with cognitive disabilities (Ponsford, 1995; Manchester & Woods, 2001; Williams & Jones, 1997).

### **Case Illustration; OCD and Depression**

CBT for OCD includes behavioural exposure, response prevention and management of negative intrusive thoughts. CBT has shown to be effective, in general, and in prevention of relapse (Roth & Fonagy, 1996). Davey and Tallis (1994) described additional features to a CBT treatments, including attentional strategies for managing self-doubt.

#### **History**

DC was a security system officer at the time of injury. He had suffered a TBI in an RTA (coma of 4 weeks, PTA of 2-3 months). He also suffered orthopaedic injuries. He was seen two years post-injury. His family had become concerned over his withdrawn state, lack of purpose, and low mood. He had a dense retrograde amnesia and a poor anterograde memory. He exhibited a range of compulsive behaviours, involving tidying, and checking. He did not have any premorbid psychological or psychiatric history of note.

#### **Neuropsychological status and mood state**

DC's pre-injury and current IQ, and processing speed were in the average range. His attentional skills and memory were impaired. He noted that he did not 'trust' himself to remember activities, of which there were few. He had a limited daily routine. He often 'tidied up', and on rare trips from the house, checked that the cooker was off and that the doors were locked, up to 20 times. He socialised with difficulty, 'checking himself' for personal possessions 'constantly'. He believed himself to be 'a mess' and therefore socially unacceptable. He also had fears over harming his legs if he engaged in any activities. His scores on the Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983) were in the moderate and mild ranges for anxiety and depression, respectively. However, in interview, he was assessed as being at risk of suicidal depression in the longer term.

#### **Formulation**

DC had a dense amnesic disorder with attentional difficulties consequent upon his TBI. His immediate visual recall was a particular strength. OCD symptoms appeared to be related to the following: (1) cognitive disorders triggering self-doubt and rumination with checking as an overcompensation

for poor memory; (2) checking and tidying, providing a means of controlling aspects of his immediate environment and sense of safety in the absence of other, more meaningful, activities; (3) behaviours being negatively reinforced by avoidance (the behaviour 'saved' him from social demands); (4) distorted self-image being maintained, and exacerbated, by avoidance of activities, with core beliefs being highly negative and leading to negative automatic thoughts; (5) health fears contributing to general avoidance behavioural pattern; (6) problems being maintained and exacerbated by a lack of opportunity for developing adaptive responses.

### **General intervention**

DC was provided with support for developing an external memory system which included: filofax for long term memory; voice organiser for supporting delayed memory; and electronic organiser for prospective memory/reminding. He was also supported in developing stress management skills, including: relaxation skills; management of negative automatic thoughts (NATs); and attentional skills for 'burning in' what he had 'just done'. A graded exposure programme was developed based on his least to most worrisome situations in 3 domains: social-leisure; community-mobility; and physical activities. Over a period of 8 months, DC was provided with a programme that progressed from developing basic emotional and cognitive control skills through to integrating their use in functional situations. He was provided with specific clinical psychology input to develop his integrated use of such skills, with interdisciplinary input across all areas of his hierarchies.

### **Specific interventions**

For socialising, DC had a hierarchy that included the following situations, and associated negative automatic thoughts: calling a friend ('they're only putting up with me...anyway, I'll forget what we talked about'); going to a pub, and staying for 40 minutes ('I'll repeat myself...I'll look a mess') and going to a club ('I'll get pushed and hurt my legs'). Over the course of intervention, DC became skilled at using relaxation to prepare for situations and answer NATs, and became engaged in activities. For example, for making a call, he had a plan of using breathing exercises and getting a note-pad for questions to ask and noting responses. On 'checking the evidence' for 'being a nuisance' to friends, he found that, when reviewing his mood diary on his organiser, he had examples of friends asking his advice, joking, and making joint plans.

For socialising and community mobility, DC initially needed to develop his skills for leaving the house. This included 'over-attending' to indications that the door was locked (when closing the door, he was instructed to listen to the click, and the serrated key making a scraping sound when coming out of the lock). He also practised making a visual image of where things were before leaving the house, so he could 'recreate' the image later ('I left the phone on the tabletop, picture it, don't worry'). When socialising he used

his voice-corder to note any future plans (where to meet later, for example), and relaxation skills if needed. Regarding his physical health worries, he was supported in identifying and managing catastrophic NATs.

### **Outcome**

DC reported increased confidence in integrating such skills to achieve his goals. At discharge from the programme he had made progress in all areas, socialising regularly, travelling independently, and being engaged in a range of physical activities. His scores on anxiety and depression ratings were reduced to the non-clinical range. He noted: 'I've had my life back...I spent all the time since the accident at home watching TV..afraid that if I do something I'd look foolish... [I'm now with friends or] making new friends...using strategies...that was confusing for a while but over time you get used to the new habits, and what technique to use where and when, and you get to trust it...and [you] get confident...[but] you've got to watch for that vicious cycle, of withdrawal.' DC had maintained his progress at a 6 months review.

### **Case illustration: PTSD, alcohol misuse and depression**

CBT is widely accepted as a treatment for PTSD and includes a combination of exposure therapy, stress inoculation training and cognitive therapy (Rothbaum, Meadows, Resick, & Foy, 2000). McMillan (1991) described the successful use of a behavioural approach for managing intrusive and avoidant symptoms in the case of a survivor of severe head injury who had complete amnesia for the event. McNeil and Greenwood (1996) described a CBT package with a survivor of severe brain injury from a road traffic accident (RTA). It was found that treating the PTSD symptoms lead to changes in behaviour, which had been originally thought to have been un-modifiable due to organic 'personality changes'.

### **History**

KE was seen 2.5 years following a TBI in a RTA. His girlfriend, a passenger, died in the accident. He had a coma of 1–2 days and a post-traumatic amnesia of up to a week. He suffered multiple skull fractures, and facial and orthopaedic injuries. He lost his job as a sales person and had had two unsuccessful returns to work. He had started a new relationship, which was under threat due to anger outbursts.

### **Assessment**

KE's verbal and visuo-spatial reasoning skills were largely intact although he had mild executive problems and a reduction in processing speed. His memory and attentional skills were poor. His cognitive difficulties were compounded by mild diplopia. There was no prior history of psychiatric disturbance or substance abuse. He reported that he could recollect an island of memory for the trauma event: '[I was] coming around for a short period...[I]

felt I was dying...I remember...I was in the car. Smoke ...there was blood...I couldn't see...couldn't breathe...I reached for my girlfriend, she was lying there...[passenger seat]...she was dead.'. He reported nightmares every night and frequent flashbacks during the day. He admitted alcohol misuse to cope with his problems, especially for aiding sleep. On the Impact of Events Scale (IES) (Horowitz, Wilner, & Alvarez, 1979) his score was in the severe range. On the HADS, his score for anxiety was in the severe range, and depression in the moderate range.

### **Formulation**

KE had executive, memory and attentional difficulties. He was noted to have severe PTSD, including intrusive re-experiences, avoidance behaviours and emotional blunting. PTSD symptoms were contributed to by survivor guilt and a grief reaction. He had mild generalised anxiety and mild to moderate depression, and a moderate alcohol dependency. He had moderate insight into his mood disturbance. His symptoms were maintained in the absence of opportunities to develop adaptive responses. Without appropriate support, he was assessed as being at risk of continuing to experience PTSD symptoms and to develop more severe depression in the long term.

### **General intervention**

KE attended the programme to pursue goals related to managing his anger, alcohol, and PTSD symptoms, and for developing occupational opportunities. Through cognitive groups KE identified and later demonstrated the use of systems and strategies for managing his planning, memory and attentional difficulties. For example, he used a palm-top computer to plan and monitor activities at home, such as undertaking basic DIY tasks. This was particularly helpful for providing him with reminders to stop working and take breaks and spend time with his step-children. In mood groups KE developed his awareness of factors that influenced his mood from a CBT perspective. He was also supported in developing coping skills, such as relaxation strategies, 'thought catching' and evidence checking. He also received twice-weekly individual CBT sessions with a clinical psychologist focusing on identifying immediate triggers and background mediators for his mood and developing his coping skills. Using the palm-top computer he was supported in recording the following: alcohol intake; sleep pattern and problems; arguments, including antecedents, behaviour and consequences; and nightmares or flashbacks. He received individual and group input regarding alcohol misuse and anger management techniques.

### **Specific interventions**

As KE became reliable in recording his emotional status he progressed to achieving specific input on his PTSD symptoms, with goals including addressing his monitoring and management of intrusive re-experiences. For example, he received individual sessions in which he was asked to describe current

trauma re-experiences in increasingly more detail whilst being prompted to use relaxation strategies. On one occasion he had reported (from notes on his palm top) being distressed after watching a television police drama involving a car chase. He had become breathless and agitated. Whilst recounting the episode in a session, he recounted his 'island of memory' from the trauma event, and noted how the steering wheel had trapped him. With guidance to use relaxation techniques to 'stay in the present', he continued to explore the memory to become increasingly exposed to it. In later group sessions he reported being more able to process the event without the expected surge of anxiety. KE was also supported in identifying a part-time work placement (in a Do-It-Yourself (DIY) store). He was encouraged to develop a paced, planful approach to managing the demands of this work placement, and counselled to maintain a part-time role.

### **Outcome**

At discharge, KE had achieved goals regarding his emotional status and work. He managed his anger, alcohol, and PTSD symptoms consistently. For example, he had nightmares occasionally rather than nightly, and could use relaxation strategies for aiding sleep, which meant he drank less alcohol, and was more able to function during the day. He was also holding down a part-time job in a DIY store. His score for depression was reduced from the clinical to non-clinical range, although his anxiety score remained somewhat elevated. His scores on the IES were reduced from the severe to the moderate range. These gains were maintained at a 6-month review, and his alcohol intake had continued to reduce (down by 50% to 'safe' levels). However, as suggested by his IES scores, he continued to have some trauma-related nightmares and intrusive thoughts. He noted that he did not misuse alcohol to avoid such intrusions, and felt much more able to control PTSD symptoms. KE was referred on to case management services locally.

### **Conclusions**

Neurological trauma can lead to many forms of emotional distress and survivors frequently develop mood disorders. Recent advances in cognitive rehabilitation, in combination with developments in CBT, have yielded the possibility of systems and strategies for managing cognitive and emotional disorders for many ABI survivors. It must be emphasised that the assessment and management of mood disorders in ABI is complicated by a host of factors, and needs to be comprehensive in order to arrive at realisable goals. However, given the mental health risks of survivors of ABI, services need to be developed which provide screening for mental health issues such that more detailed management plans, including in-depth assessments, can be conducted. With such developments, more people may have access to services that could protect, and even promote, their social and psychological well being.

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# Chapter 8

## ENHANCING OUTCOMES AFTER TRAUMATIC BRAIN INJURY: A SOCIAL REHABILITATION APPROACH

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‘Adults with disabilities and their families want the same things other people do  
– a place to live, a job, an education, recreation, friendships and family life.’

Racino & Williams (1994, p. 39)

### Concepts and principles

Social functioning after traumatic brain injury (TBI) can be conceptualised from at least two perspectives. Firstly, disturbance in social functioning as an *impairment*, directly caused by the TBI. These executive impairments that straddle the domains of cognition and behaviour frequently arise as a result of frontal systems dysfunction. Included are difficulties with social skills (Godfrey & Shum, 2000; Marsh, 1999), pragmatic communication (McDonald,

Togher, & Code, 1999; McGann & Werven, 1995), social problem solving (Levine, van Horn, & Curtis, 1993; Kendall, Shum, Halson, Bunning, & The, 1997), and behavioural controls (Alderman, Fry, & Youngson, 1995; Medd & Tate, 2000; Wood, 1987). An alternative perspective conceptualises disturbance in social functioning after TBI as *disablement*, affecting three broad domains in particular: occupational activities, interpersonal relationships, and independent living skills. It is not only impairments in executive functioning that may cause disablement in social functioning – any type of motor-sensory or neuropsychological impairment may also adversely affect social functioning; for instance, hemiparesis restricting a person’s ability to play sport, amnesia limiting a person’s capacity to engage in and remember conversations, thereby impacting on their capacity to maintain interpersonal relationships and so forth.

This volume contains a number of chapters that are relevant to the first perspective of social functioning, impairments, (see in particular Chapter 4 on executive deficits and Chapter 9 on behaviour and conduct disorders). Rehabilitation of impairments in social aspects of executive functions is becoming more widely discussed and incorporated into rehabilitation programs (see above chapters and also Grattan & Ghahramanlou, 2002; Sohlberg & Mateer, 2001). In order to avoid repetition, the present chapter focuses on the second perspective: social functioning as disablement after TBI, much of which also applies to acquired brain injury in general. We present our rehabilitation approach to maximising a person’s social functioning after TBI and provide an overview of our clinical practice.

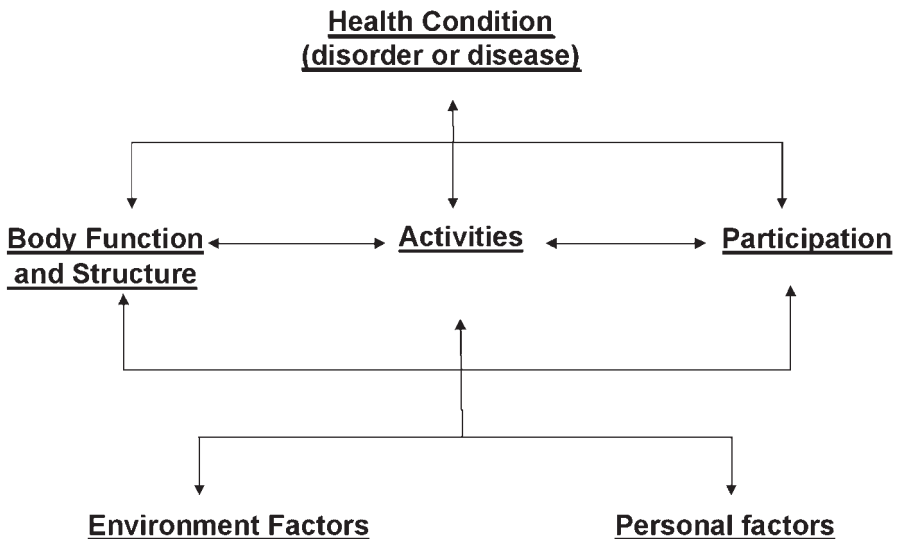


Fig. 1. International Classification of Function.

There is not a direct correspondence between impairments and their effects upon social functioning. The International Classification of Functioning (ICF, WHO, 2001) provides a helpful framework to understand the complex set of factors contributing to social functioning after TBI and other health conditions. The ICF differs in significant ways from the original model, the International Classification of Impairments, Disabilities and Handicaps (ICIDH, WHO, 1980), including: (1) the use of neutral terminology (Activity replaces Disability; Participation replaces Handicap), (2) use of the term Disablement in a generic sense, without specific demarcation between limitations in Activity and restriction in Participation, and (3) the introduction of Contextual Factors (both environmental and personal) which may exert a facilitating effect or cause barriers to participation (see Fig. 1).

Figure 2 illustrates the way in which the ICF is interactive and different outcomes may be achieved depending on various configurations in impairments, disablement and contextual factors. Impairments caused by TBI (whether neuropsychological e.g., memory impairment, or motor-sensory e.g., dysarthria) may cause limitation in activities (e.g., at the general level, work) and restriction in the person’s capacity to participate in everyday life situations (e.g., at the specific level, unable to do their job as a receptionist). Contextual factors will influence the outcome, however: an understanding employer may alter the work duties so that they are compatible with the person’s impairments (e.g., changing reception work for clerical duties).

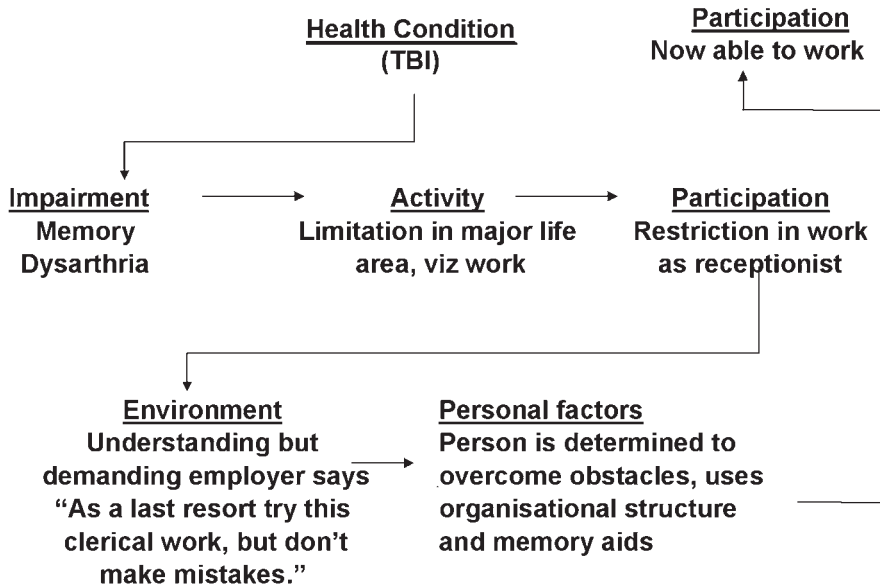


Fig. 2. International Classification of Functioning: Contextual factors.

Moreover, the individual's personal qualities in terms of, for example, their level of drive and determination to be employed may result in them using organisational strategies and memory aids as part of their work practice to compensate for their memory impairment, thereby reducing or even eliminating disablement in the work and employment domain.

The ICF has many comparable features to other models of adjustment after TBI described in the literature. Thirty years ago Lishman (1973) drew a distinction between direct effects of the injury (in WHO terms, impairments and disabilities) and indirect effects of the injury (in WHO terms, contextual variables). Recent work (e.g., Godfrey, Knight, & Partridge, 1996; Kendall & Terry, 1996; Moore, & Stambrook, 1995) has seen more refined analyses of the way in which outcome and adjustment are influenced by impairments, disabilities, and contextual variables (personal and environmental resources), collectively termed antecedents. An important contribution of this research describes the way in which the impact of the antecedent variables on outcome and adjustment is mediated by the individual's cognitive appraisals of the situation and particular coping strategies.

Thus, for the purposes of the present chapter, 'social' refers to the effects of impairments on the person's daily activities and participation in everyday life, as mediated by contextual and other factors. Thence, social rehabilitation refers to procedures used to maximise resumption of social aspects of participation in daily activities, particularly for independent living, interpersonal relationships, work and leisure activities. This perspective of disablement in social functioning has considerable overlap with the literature on community integration. The aforementioned three broad domains (occupational activities, interpersonal relationships, and independent living) are those we used in our earlier work examining psychosocial outcomes after TBI (Tate, Lulham, Broe, Strettle, & Pfaff, 1989) and later in developing a measuring instrument of psychosocial reintegration (Tate, Hodgkinson, Veerabangsa, & Maggiotto, 1999; Tate, Pfaff, Veerabangsa, & Hodgkinson, in submission). Subsequent to our initial report, other researchers have independently affirmed the relevance of these three areas of social functioning for the TBI group (McColl, Carlson, Johnston et al., 1998; Willer, Rosenthal, Kreutzer, Gordon, & Rempel, 1993).

In the opinion of Ylvisaker and Feeney (Feeney, Ylvisaker, Rosen, & Greene, 2001; Ylvisaker & Feeney, 1998, 2000), traditional rehabilitation models use a hierarchical treatment approach: first addressing neurologically-based impairments; then, if difficulties persist, activity limitation; and finally participation restriction. Their clinical practice reverses the hierarchy so that the first line of attack is to increase participation (in ICIDH terminology, reduce handicap). They enumerate a number of principles or 'critical intervention themes', summarised in Table 1, which guide their rehabilitation practice, and they argue for rehabilitation that is contextualised, collaborative, and person-focused. Their approach arises from their experience with individuals who frequently exhibit challenging behaviours (generally premor-

Table 1. Critical intervention themes.

Adapted from Ylvisaker and Feeney (2000)	
Context	The context of delivery of rehabilitation needs to involve personally meaningful themes, activities, settings and interactions.
Everyday routines and everyday people	Appropriately structured everyday activities provide the best context. People relevant to the life of the person with TBI (eg. family, work supervisors) should be involved in their rehabilitation
Apprenticeship training and collaboration	Information and skill is acquired <i>during</i> task completion. Supports and mediation are provided initially, then systematically withdrawn at appropriate times. Professional staff work in collaboration with clients to achieve goals.
Reconstructing a sense of self	Impairments and the associated activity limitation and participation restriction necessitate that the individual restructures their sense of self and have successful experiences associated with their new identity.

bid, which are then compounded by impairments from the TBI). It addresses the aforementioned multifactorial contributions to adjustment, and thereby provides a helpful model for clinical practice after discharge from inpatient rehabilitation.

It is well known that TBI spans the gamut from the most minor of injuries to those of extreme severity, in which a person can be unresponsive for many months. Our work focuses largely on those with severe injuries, with durations of posttraumatic amnesia (PTA) usually in excess of one week. Yet the nature and degree of impairments and levels of recovery, as measured by scales such as the Glasgow Outcome Scale (GOS, Jennett & Bond, 1975; Jennett, Snoek, Bond, & Brooks, 1981), show extreme individual variability. Confusion has often arisen in distinguishing between severity of the initial injury and severity of outcome, but it is far from the case that a person with a severe injury necessarily has severe impairments or severe disability. Although there is a significant correlation between severity of injury and degree of recovery, levels of outcome of individuals with severe injuries span the ranges of GOS categories. For example, at an average of six years posttrauma, our consecutive series of 100 severely injured rehabilitation admissions (mean duration of PTA 11.6 weeks, with PTA in excess of one month in 74%) comprised 49 individuals with Good Recovery, 27 with Moderate Disability, 17 with Severe Disability, none were in the Persistent Vegetative State and seven had died (Tate et al., 1989). It thus follows that goals of social rehabilitation will be very much dependent upon, in the first instance, the nature and degree of disablement.



Within this constraint, the philosophical tenet that guides our rehabilitation service is that all individuals are entitled to work or have alternative meaningful occupational activity, be part of a social network, and live in their own home in the community. Also implied, is that they have access to community resources and activities, in the form of transport. It is helpful to put these principles in the context of those other clinicians have described to empower people with disability from TBI, as summarised in Table 2. At a more specific level, Durgin (2000) provides a thought-provoking analysis of strategies to combat traditional, over-restrictive practices, as well as those to permit considered and reasonable risk-taking to enable the person's return to community living.

Table 2. Principles guiding community integration after TBI.

Racino and Williams (1994)	Willer and Corrigan (1994)
1. People using the services and their families know themselves best	1. No two individuals with acquired brain injury are alike
2. Services must promote self-sufficiency and community membership	2. Skills are more likely to generalize when taught in the environment where they are to be used
3. Services should be functional and take place in relevant environments	3. Environments are easier to change than people
4. People using services should have the option to hire, manage, and fire their own staff	4. Community integration should be holistic
5. All people with TBI have a place to participate and contribute in the community	5. Life is a place-and-train venture
6. Support resources includes 'natural' supports, community supports, and personal assistance services	6. Natural supports last longer than professionals
7. People should live in generic, affordable, and accessible housing within communities and neighbourhoods	7. Interventions must not do more harm than good
8. The provision of support services should be separated from the selection of a place to live	8. The service system presents many of the barriers to community integration
9. Medical services should only be provided for medical issues	9. Respect for the individual is paramount
10. Hope is an essential fuel for the future	10. Needs of individuals last a lifetime; so should their resources

## Social Rehabilitation in Practice: the Liverpool Hospital Approach

### a) Structure of the service

The following overview of our clinical practice draws upon the infrastructure provided by a government-funded, regionally-based, specialist TBI rehabilitation service located at Liverpool Hospital in Sydney, Australia. This service, originally established at Lidcombe Hospital in the 1970s (inpatient unit in 1976 and community service in 1979), has been described elsewhere (Broe, Lulham, Strettles, Tate, Walsh, & Ross, 1982). Since 1989, the Liverpool service has been one of the 13 participating units in the New South Wales Brain Injury Rehabilitation Program – a state-wide program initiated as a partnership between the Department of Health and the Motor Accidents Authority of New South Wales.

As shown in Table 3, selection criteria to the service are few and liberal: age, place of residence, and having sustained a TBI. The admission criteria are occasionally waived in exceptional circumstances. For example, young people from the region with other types of acquired brain injury, most commonly hypoxia or stroke, are admitted if there are no other suitable services to meet their needs, such as dealing with confusion and agitation in a mobile patient

Table 3. Liverpool hospital brain injury rehabilitation service.

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#### Admission criteria:

- Age at injury 16-60 years
- Resident in geographical catchment area (South Western and Southern Sydney Area Health Services – population approx. 1.1 million)
- Sustained traumatic brain injury

#### Clinical service components:

- 16-bed inpatient unit
- 4-bed transitional living unit located in the community
- 4-bed respite cottage located in the community (Camden House)
- multi-disciplinary inpatient team
- multi-disciplinary community team
- *Head-2-Work* program located in the community in an industrial factory

#### Staffing levels for community team (16.7 full-time equivalents):

- 0.6 team leader
  - 5 case managers
  - 1 clinical psychologist
  - 1.6 medical rehabilitation specialists
  - 1.5 neuropsychologists
  - 2 occupational therapists
  - 1 physiotherapist
  - 1 recreation officer
  - 1 speech pathologist
  - 2 social workers
-

during the post-acute stages. In its current configuration, the rehabilitation service has a number of components, with the community team drawing heavily upon the transitional living unit (TLU), respite cottage, and *Head-2-Work* program. This integrated service allows for a continuum of care from the time of inpatient admission.

The focus of the present chapter on social rehabilitation describes services provided by the community team, after the person has been discharged from inpatient rehabilitation. This service has not arisen because it is a cheaper option than inpatient rehabilitation, as appears to be driving the agenda of some programs described from North America, but rather the service exists because many people are discharged from inpatient rehabilitation with continuing limitations and restrictions in everyday living that call for continued therapy and provision of services.

### **b) Cornerstones of the service**

There are four essential clinical features of the community service. It is nonselective, and the rehabilitation programs are needs-driven, community-based, and largely individually-focused.

#### *(1) Individuals are unselected*

The underlying philosophy of the service is one of equity of access to rehabilitation. Thus, it is nonselective and all individuals are accepted who meet the previously described very liberal admission criteria. People are not rejected on the basis of the nature or severity of impairments, nor their psychosocial and economic backgrounds. Consequently, individuals are often admitted who are difficult to work with and who may not have favourable prognoses: those with challenging behaviours, problems with awareness, current substance usage, history of and/or current psychiatric symptomatology, criminal histories, previous unemployment, as well as those who do not have private health or other type of insurance or compensation.

#### *(2) Needs-driven rehabilitation*

There are three aspects to a needs-driven rehabilitation service. Firstly, all eligible people are admitted to the service who have needs, irrespective of the time posttrauma. One implication of this is that the number of people involved in the service at any one time is large. During the calendar year 2000, 467 individuals received services from the community team (Tate, Strettles, & Osoteo, in submission). The workload for the 17 staff in the team is thus intense, with 8,046 occasions of service provided during 2000. Secondly, it is recognised that no single profession has the requisite skills and expertise to address the diverse range of needs presented by people with TBI and their families. Thus, a multidisciplinary team is necessary to effect social rehabilitation and maximal community reintegration.

Finally, a needs-driven approach means that there is no designated time-frame for an individual's involvement in a program. Essentially, an individual

and/or family can be a member of the service while-ever that person has needs that the service can meet. Thus when some goals are met (e.g., accommodation in the community), others goals can be set which build upon previous ones (e.g., being able to travel independently by public transport). Furthermore, as circumstances change new issues arise that are addressed, as the following example illustrates:

In 1987, at age 45, Bill sustained a minor brain injury, but subsequently deteriorated and at two days posttrauma was in status epilepticus. Left temporo-parietal subdural haematomata were repeatedly evacuated, both before and after insertion of a ventriculo-peritoneal shunt. In 1988, after 12 months inpatient rehabilitation, he was discharged to the care of his parents and referred to the community team. Although independent in basic self-care activities, Bill was not otherwise independent, largely because of his neuropsychological deficits (memory disorder, cognitive rigidity, perseveration and marked inertia). The community team continues involvement in Bill's case at the time of writing. Over this 14-year period, there have been 119 occasions of service from the community team. These were not evenly spread across the years, but rather waxed and waned – there have been years when Bill has been discharged from the service, but re-referral occurs when specific issues arise, such as the death of his mother in 1998 and father's subsequent illness. At that point, respite care was made available, he was re-assessed in the TLU for independent living, accommodation options and community activities were explored, with input from the case manager, occupational therapist and social worker.

Thus a second philosophical tenet is the commitment to provision of services throughout the person's life, based on the recognition that needs and circumstances change over time. In our experience, rehabilitation after TBI is not usually a discrete 'repair and fix' job; rather, for many people it is a lifelong process of adaptation.

### *(3) Community-based therapy programs*

When rehabilitation is community-based, there is the opportunity for it to be conducted in context. Clinicians have often pointed to the importance of contextually-based therapies (Cervelli, 1990; Hayden, Moreault, LeBlanc, & Plenger, 2000; Sloan, Balicki, & Winkler, 1996; Ylvisaker & Feeney, 2000). Opportunities for social rehabilitation in inpatient settings are often fairly contrived and artificial, and hence social rehabilitation is best conducted in the community after the patient has been discharged from inpatient rehabilitation. Moreover, during inpatient rehabilitation the energies of the patient and family are usually focused on recovery of more basic functions – mobility, communication, cognition and activities of daily living. It is generally the case that they are not emotionally ready to tackle the social consequences

of TBI until around the time of discharge. The risk is, however, that once the patient is discharged from inpatient rehabilitation, social rehabilitation is not conducted at all. This is because the focus of many outreach teams is on the coordination and liaison component of case management, in which the person is referred to other services as required, rather than the provision of those services within the team. The Liverpool approach is distinctive in that case managers work in partnership with therapists. The advantage is that the individual receives a holistic, coordinated, integrated and planned service. The people and their families become well known to team members, who are then in a position to address current needs and anticipate future ones.

A central aspect of the rehabilitation program is networking with other government and non-government agencies and working in tandem with generic services provided in the community. Frequently, there are barriers to accessing generic services because, in Australia at least, these focus on older persons or those with disabilities from other causes that make such services unsuitable for the group with TBI. Closely related, is the fact that staff members involved in generic services generally do not understand issues pertaining to acquired brain injury. This applies both to accessing services to enhance community living (e.g., housing support, recreational options), as well as getting assistance in times of crisis, such as suicidality. Recommended practice in the latter domain is for specialist brain injury services to work together with generic mental health and other services (Kuipers & Lancaster, 2000; Tate, Simpson, Flanagan, & Coffey, 1998). By providing services within the team we can support people while they are accessing services to optimise the chances of success, as Bill's previous example demonstrates:

When Bill's mother died and his father's health was failing, the goal of independent housing was explored. Following a four-week assessment in the TLU, the case manager sought the social worker's involvement, who met with Bill and made application to the Department of Housing. This was not restricted to completing the forms and paperwork, but rather involved a counselling approach to help Bill become more aware of the issues involved in independent living, and assist him to generate his own solutions to potential problems. The social worker attended meetings between Bill and the Department of Housing to ensure correct information was given and that Bill was not disadvantaged by staff not understanding his disabilities and his inability to follow through the process. Because of the social worker's advocacy role, she became an important support person for Bill at this time. The occupational therapist's involvement initially focused intensively on household management, particularly the development of strategies for financial management and budgeting for bills, which had arisen from his independent living assessment as an area of special difficulty.

#### *(4) Individually-focused rehabilitation*

An individually-focused approach allows for establishing an active rehabilitation program, driven by goal planning, which is specific to the individual's unique constellation of impairments, functional limitations and restrictions, environmental circumstances, and personal characteristics. The individually-focused approach does not imply that the person is treated in isolation, nor that he or she is a passive entity who has therapeutic procedures *applied* to him or her. Rather, the rehabilitation process is tri-level involving the person, their family and their culture/community. The therapist or case manager acts as a facilitator, with the ultimate aim being to gradually withdraw supports during a transition phase so that the person becomes more independent.

A hierarchical approach is adopted which guides the plan of action:

- first provide information,
- then provide the means (depending on the issues and the person's level of disablement, this may range from assisting with transport, making funds available, establishing environmental structures or using verbal prompts),
- and deal with issues that interfere with independent functioning,
- to ultimately enhance the individual's independence with the aim of the person generating their own outcomes with staff facilitating the process.

The level of disablement is important and for a proportion of the group with severe disability the rehabilitation program may be confined to the first three steps because their cognitive limitations mean that the best they can achieve will be access to services, and it may not be possible for them to generate their own outcomes. The goal for other clients with less disability is to optimise their independence, as shown in the following example:

Mick, a 25-year old jockey who lived in the country, fell from a horse in 1999 and was admitted to a local regional hospital. His initial Glasgow Coma Scale (GCS, Teasdale & Jennett, 1974) score was 15, but he was transferred to (another) Sydney hospital for neurosurgical management of a right frontal haemorrhage. Duration of PTA was 10 days. Mick's progress and functional recovery was good, and he was discharged home where he lived with his cousin, with referral to the regional brain injury rehabilitation outreach team. By 13 months posttrauma, Mick's family were concerned that he seemed to have difficulties coping and he moved to Sydney to live with his parents. The regional brain injury team referred him to our service. The assessments identified a constellation of problems: speech and language impairments, memory, planning and organising difficulties and depression mainly because he was unable to return to his former job. Therapies and strategy training with the speech pathologist, neuropsychologist and clinical psychologist were successful and the occupational therapist and case manager addressed vocational options. Mick was initially

assessed and retrained at the unit's *Head-2-Work* program, and subsequently enrolled in an animal attendant course at a local community education college. Requirements of the course involved a workplace component and Mick was referred to *BreakThru*, a community supported work program. They arranged a job at Wattle Tree Farm, a local tourist attraction with bush animals, and provided job coaching and support. Mick's program with the community team spanned a 14-month period, and he was discharged from the service in April 2001, at that point still working at Wattle Tree Farm.

**c) Clinical pathways**

The clinical pathway of the service is described in Figure 3. Individuals are referred to the service either directly from the inpatient unit or the community, the latter including referrals from other services (such as general practitioners, solicitors, health services) and self/family referral. Referral to any part or stage of the service is possible, and is independent of whether, where or when they received other services related to their brain injury. Persons who are accepted to the service may be new admissions, or previous members of the service who were discharged but have been re-referred, usually because new issues have arisen with which they require assistance.

All persons accepted by the service attend a clinic, run by rehabilitation physicians four times during the week. The purpose of the clinic is not only for medical reasons, but also to identify pertinent issues via a psychosocial interview. New referrals are discussed at the weekly case conference, from

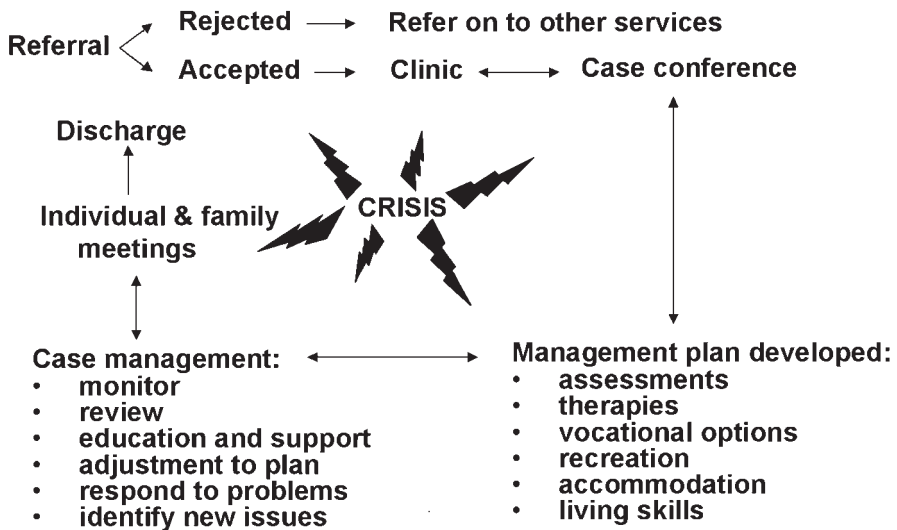


Fig. 3. Clinical pathway of Brain Injury Rehabilitation Unit.

which a management plan is developed. The management plan may include referral to staff of the community team for other services, which are both centre-based and provided in the home or community. Goal planning is conducted with each individual by various team members, along the lines of the process described by McMillan and Sparkes (1999).

The rehabilitation process is dynamic and involves initial fine-tuning and adjustment of the goals and rehabilitation plan to suit the individual/family needs. Adaptations to the management plan may occur for a variety of reasons, common ones being family dynamics and cultural expectations of the client and family, as the following example shows:

Omar was a 28 year-old man of Middle Eastern background who sustained severe cognitive and physical disabilities as a result of a car accident in 1998. Following extensive inpatient rehabilitation, he remained severely disabled and was admitted to the TLU, specifically to increase his independence in personal care. Upon discharge home to his family he was able to manage personal care, requiring only minimal supervision. But these gains were soon eroded because the family insisted on doing everything for him, and this was Omar's expectation also. In their culture, a 'sick' person is cared for, and allowing such a person to do activities that are difficult for them is not the way a loved one should be treated (see Simpson, Mohr, & Redman, 2000). After negotiation, the family allowed a roster of paid carers to be involved in supervising and monitoring Omar's personal care, thereby implementing the discharge plan of maintaining his level of independence in personal care. Introduction of the carers was not without its difficulties, however, because the family did not understand their role – the family perceived that the carers, in merely 'watching' Omar, were not busy enough to earn their salary and so extra duties, such as housework, were requested. This necessitated the case manager negotiating a structure for the carers and educating the family about the carers' role, that Omar was not 'sick', and the importance of him doing things for himself.

The community case conference, combined with case management, mainly serves as the reporting mechanism for program monitoring, review and adjustment. As such, the case conference does not include the person or family, although we acknowledge that some clinicians advocate the active involvement of the individual and family in case conferences. Kneipp (1995) describes this process in detail, but she recognises that it is time consuming: team meetings are usually held monthly and the report described one three-hour meeting for a single individual, held in his or her own home. Our constraint is one of sheer numbers, with an annual caseload of around 500 individuals and their families.

Case management is integral to the organisation and coordination of the



person's program, but additionally case managers are also the front-line people who frequently provide education and support to the individual and family, assess and respond to problems, resolve conflicts, and identify new issues as they arise. Hence, they work with the people in a very personal way, and there is nothing that the service will not do, literally adopting the 'whatever it takes' (Willer & Corrigan, 1994) philosophy or 'what can we do to make this happen?' (DePompei, Frye, DuFore, & Hunt, 2001, p. 236). Regular meetings with the person and family, as well as other service providers, are held with relevant community team members. At these meetings progress is reviewed and new goals, including discharge, are discussed. As Figure 3 shows, the process is not unidirectional, but rather is interactive and recursive. Moreover, in some instances the process can stop along the way, and intensity of involvement can also vary, until all issues are solved, goals are achieved and no further goals are identified, at which point discharge is an option. However, if goals are continuing or new goals are identified and new plans developed, then the individual will remain in the system. Crisis management is an important part of the service and will cut across established plans and programs. The following example shows the typical range of issues seen by the community team and methods of management:

Lee, aged 24, sustained severe TBI and other injuries (soft tissue and loss of vision in her left eye) as a result of a motor vehicle accident in 1998. She had migrated to Australia from South East Asia 10 years previously with her husband, 13-year old sister, and parents, and had been working in a retail factory for the previous two years. Initial GCS score was 8, duration of PTA was 58 days, and she required craniotomy to evacuate right extradural and subdural haematomata. On admission to the rehabilitation unit at 7 weeks posttrauma, she was agitated and percutaneous endoscopic gastrostomy (PEG) and tracheostomy tubes were in situ. Lee received a range of therapies and by the time of discharge at 4 months posttrauma, she was independently mobile, independent in self-care and cooking activities, but continued to have language impairments (word finding and keeping on track in conversations). The consequences of her continued neuropsychological deficits (in particular, impulsivity, slow processing speed, cognitive rigidity and limited attentional, new learning and planning skills) had been difficult to handle during inpatient rehabilitation, had not significantly responded to intervention, and additionally caused family friction during weekend leave.

Following discharge from inpatient rehabilitation, the community team took over Lee's management and continued rehabilitation: an attendant carer was arranged to allay concerns about Lee being by herself all day; the physiotherapist organised a home-based program to improve fitness and treatment of pain for the soft tissue injury; the occupational therapist continued working on independent living skills

in the community and, along with the Royal Blind Society, the effects of Lee's visual impairments, and she attended a group-therapy program targeting social skills; the speech pathologist continued work on Lee's communication skills, and introduced memory retraining strategies; the recreation officer organised a structured weekly program because she was not yet ready to commence work retraining; the clinical psychologist targeted Lee's emotional and temper control problems; and the social worker provided support and strategies to the family to assist them to deal with her cognitive and behavioural changes. The overall program was coordinated and monitored by the case manager via home visits with the family, at first on a frequent basis, and then as the situation stabilised, less intensively.

Just on one year posttrauma, after eight months with the community team and three sets of rehabilitation plans later, Lee's situation was much improved. She was engaging in an Asian speaking social program, was fully independent in activities of daily living, with strategies in place for budgeting. She was still involved with the clinical psychologist, but was able to control her temper and anger in most situations. At this point in time she became depressed and therapy incorporated this focus. Social work involvement with the family increased due to family conflicts and Lee's husband's difficulty in adjusting to the situation. Respite at the Camden House was organised. The subsequent two years have focused on relationship issues between Lee and her husband. Lee's neuropsychological disabilities particularly impact upon her capacity to share intimacy and sexual relations. There are constant high levels of stress and unhappiness, but neither Lee nor her husband are prepared to end their marriage, and at the time of writing the clinical psychologist, social worker and case manager remain closely involved with Lee and her husband.

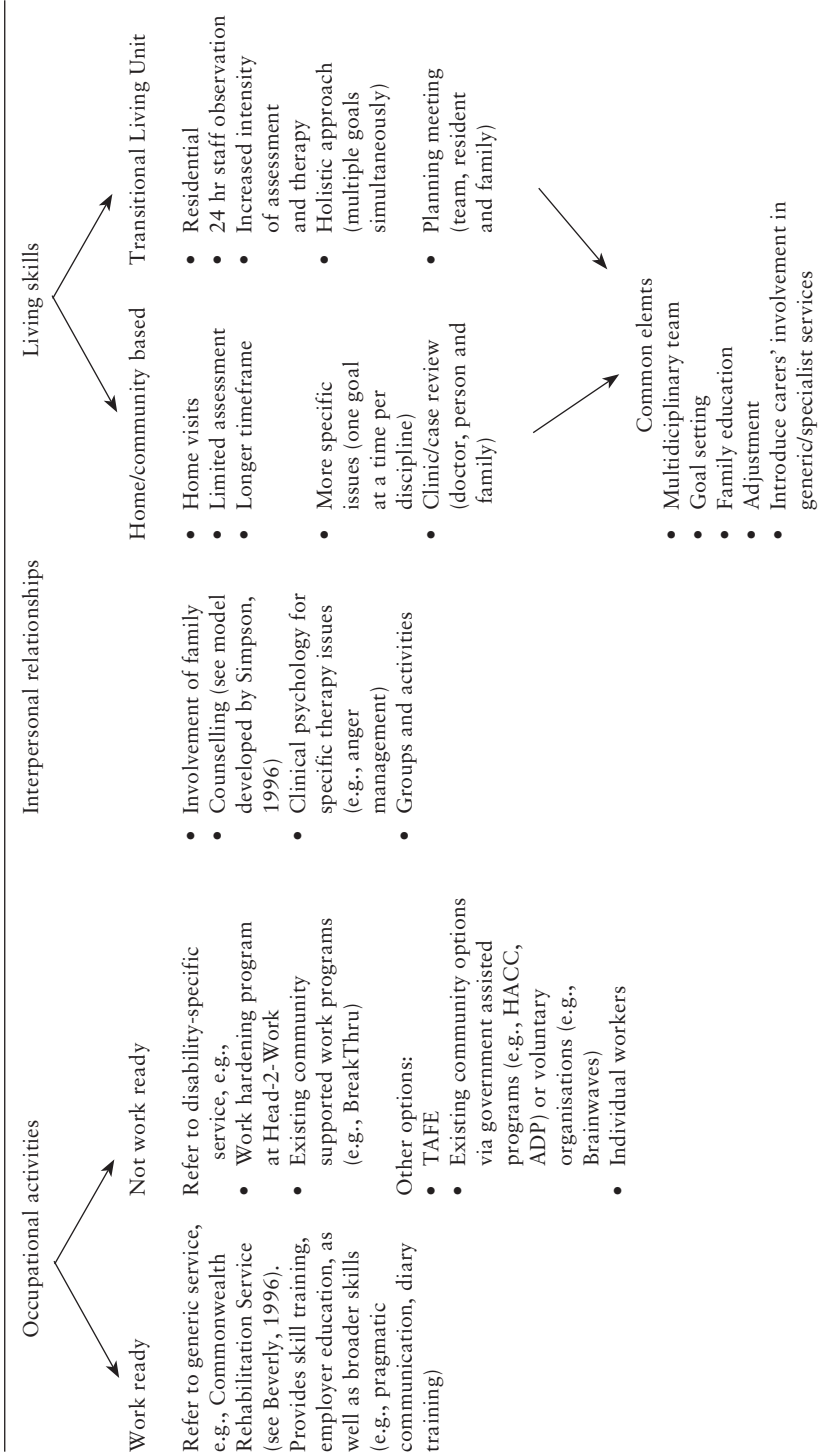
#### **d) Specific components of the service**

The components of the service addressing social rehabilitation as defined (viz. occupational activities, interpersonal relationships and independent living) are described in Table 4.

##### *(1) Occupational activities*

The occupational area is probably the most straightforward of the three social domains to effect changes, largely because of the range of options currently available. The review of Malec and Basford (1996) demonstrates the wide range of return to work rates, 0-79% in the 17 programs they reviewed. One reason for the variability is sample differences, particularly with respect to severity of injury and disability – samples with large proportions of people with less severe injuries or disabilities have better outcomes. For instance, Prigatano, Klonoff, O'Brien et al. (1994) reported 62.9% were working (full or part-time) on average at 3.5 years posttrauma, but 32% of their sample

Table 4. Specific pathways: Issues identified from the clinic or elsewhere.



had an injury of only moderate or mild severity, with GCS scores greater than 8. Similarly, 48% of the sample of Malec, Smigielski, DePompolo and Thompson (1993) were in competitive work at one year after program completion, but selection criteria excluded those who were not independent in mobility, continence, communication, memory, and safety. By contrast, rates in unselected series of people with very severe injuries, such as our own, tend to be low (22% in full-time employment at, on average, six years posttrauma, Tate et al., 1989). This figure is comparable to those reported by other groups: 23% at one year reported by Harrison-Felix, Newton, Hall and Kreutzer (1996); 25% at seven years reported by Brooks, McKinlay, Symington and Beattie (1987); 38% at 2-5 years posttrauma found by Fleming, Tooth, Hassell and Chan (1999); 38% at four years found by Sander, Kreutzer, Rosenthal, Delmonico and Young (1996). More alarming, however, is that a large proportion do not work and have no alternative occupational activity in lieu of work (39% in our series).

In Australia, vocational rehabilitation services are either generic or disability specific. The main generic service is provided by a government-funded organisation, the Commonwealth Rehabilitation Service, with 170 sites throughout the country (Beverley, 1996). All persons with disability (physical, psychiatric, sensory and/or cognitive) of any aetiology are eligible and the service has a number of specialist acquired brain injury teams. A range of services is provided: workplace assessment, training and intervention; employer and co-worker education; developing job seeking plans for those who do not have a job to return to or who have not yet started work, as well as broader skills training including pragmatic communication (cf. Carlson & Buckwall, 1993), diary use in the workplace, counselling for psychological adjustment, fitness training to improve conditioning for job requirements, school and study interventions and so forth.

For those who are not yet ready to return to work or where the work re-entry process is likely to be protracted, a number of pre-work options are available through disability-specific programs, such as the rehabilitation unit's *Head-2-Work* program, a government (Workcover) accredited program of assessment and training which is located in an industrial factory, or community supported work programs for people with disability, including mental health, such as *BreakThru*. The latter service adopts a supported work philosophy, with job coaching and on-the-job support similar to other programs reported in the literature (Buffington & Malec, 1997; Kowalske, Plenger, Lusby, & Hayden, 2000; Kreutzer, Wehman, Norton, & Stonnington, 1988; Stapleton, Parente, & Bennett, 1989; Wehman, Kreutzer, West et al., 1990).

Avocational options are explored with the community team's recreation officer, using external agencies: study skills programs offered through community education colleges (Technical and Further Education, TAFE) or government assisted programs (Home and Community Care, HACC; Headway Adult Development Program, ADP). The recreation officer also promotes

involvement of people who may be socially isolated by getting such people together and engaging in activities that are peer interactive, for example through the Brainwaves group, all with the aim of assisting individuals to manage their own leisure better. One exciting development is Potential Unlimited, a nine-month program developed by Thomas (1999) in conjunction with Outward Bound Australia, as a means to increase self-esteem and quality of life after TBI. The Headway ADP, an initiative the Brain Injury Unit launched in 1982, is probably the closest equivalent to the clubhouse model described by Jacobs (1997). It is now one of six community access programs in our state, offering both centre-based and community activities (as well as access plans from the home if the individual resides in the geographical area), and has participants involved in its management. Like the clubhouse model, there is no set timeframe for involvement, membership is open to all people irrespective of degree of disability or time posttrauma, and costs are low (\$AUD100 per year or pro rata for those without insurance, but even then the fee is often waived if necessary). The main focus of the ADP is on community participation and access, but the program does not have the day-to-day member direction of the clubhouse model, or the structure of their various units (e.g., communication, kitchen, maintenance).

## *(2) Interpersonal relationships*

Difficulties with interpersonal relationships are extremely common after TBI. Indeed, the impact of TBI upon family relationships can be dramatic and results in high levels of marital breakdown in rehabilitation samples – 55% in our series at six years posttrauma (Tate et al., 1989), 40% reported by Oddy, Coughlan, Tyerman and Jenkins (1985) at seven years, 49% over a 5–8 year period reported by Wood and Yurdakul (1997), 78% in Thomsen's (1984) group at 10–15 years posttrauma, and so forth. Detailed and specific interviewing of spouses reveals the 'severe problems' many of them have in their marital relationships (Gosling & Oddy, 1999). Interpersonal difficulties affect friendships, and social isolation is a frequent legacy of TBI as old friendships fall away and are not replaced by new ones (see review by Rowlands, 2000). Emotional distress after TBI has been consistently documented (see Chapter 7 of this volume), with high proportions showing symptoms indicative of depression, anxiety, anger, fatigue and mood disturbance, ranging from 44–60% in the sample of Perlesz, Kinsella and Crowe (2000), and slightly lower levels in their primary carers (35–49%).

A number of books on rehabilitation of acquired brain injury include chapters addressing interpersonal relationships, from perspectives of both personal adjustment to the effects of the injury, as well as altered interpersonal interactions that may arise from cognitive and behavioural impairments (see for example, Ponsford, Sloan, & Snow, 1995; Prigatano, 1999; Sohlberg & Mateer, 2001). The selection of methods (cognitive-behaviour therapy, solution-focused therapy, psychotherapy, narrative therapy, family therapy) will be dictated largely by the needs and cognitive limitations of the client.

Simpson (1996) has described a model of counselling adjustment that is drawn upon in the Liverpool service, which involves four components:

- understanding the nature of the injury and its sequelae,
- restructuring lifestyles and learning to adapt to changes in occupational activity, interpersonal relationships and living skills, described as 'learning through living',
- reintegrating identity in order to synthesise the premorbid sense of self with posttrauma changes that often involve a devalued identity, and
- acceptance that the future is hopeful, albeit not necessarily as it would have been had the injury not occurred.

The process of reintegrating identity, or 'reconstructing identity' to use Ylvisaker and Feeney's (2000) phrase, is far from easy. They use strategies, such as metaphor to effect positive change in the person's concept of self, e.g., eschewing 'self-as-victim' and developing 'self-as-master' models. They describe this model in a number of case studies: 'Jason willingly worked at developing scripts, strategies, systems of support and explicit rules of self-direction that he then practiced in his everyday interactions and activities.' (p. 21). At a more general level, rehabilitation interventions to address social isolation include very practical initiatives, such as Circles of Support (Wertheimer, 1995; Willer, Allen, Anthony, & Cowlan, 1993), whereas participation in occupational activities (e.g., Brainwaves, Headway ADP, clubhouse) also has an indirect effect on reducing social isolation.

### *(3) Independent living*

It is not only disability in basic activities of daily living (i.e., personal care) and mobility that create barriers to people living independently after TBI, but it is also problems with instrumental activities of daily living (e.g., skills in shopping, use of transport, financial management) which are often due to impairments in executive functions. Difficulties with basic activities of daily living affect only the minority, in the order of 10% of rehabilitation samples (Ponsford, Olver, & Curran, 1995; Tate et al., 1989), whereas problems with instrumental activities are much more common: for example, Ponsford et al. report that 34% were not independent in community activities such as shopping, and 35% showed restriction in use of transport.

There are two components to our approach to independent living. Much of the work is home and community-based. Using home visits, programs are established and reviewed, specialised equipment is trialled, paid carers are inducted into the family situation, and families are educated and helped to adjust to changed circumstances. The second component uses the TLU as a resource for (usually a four-week) assessment and training period when an out-of-home program is more useful. A range of circumstances may point to the latter alternative: e.g., family dynamics precluding proper assessment, intensity of therapy required, complex situations involving behavioural regulation (e.g., not only *can* they do tasks, but also *do* they do them?), social

interactions (e.g., attitudes and abilities when living in a shared household) and so forth. At the completion of the living skills program, either home-based or at the TLU, there is discussion of living options based on the outcomes of the assessment and training information as well as available supports, to enable people to make choices and decisions about where they want to live and with whom.

The main frustration, however, is the lack of suitable, community-based, long-term accommodation options, particularly for those people with significant disability (any of physical, cognitive or behavioural). For people from this group it is not only a matter of *locating* such accommodation, it is also the process of *maintaining* the person in that situation by providing whatever care and supports are necessary. These range from personal care through to budgeting skills, through to being able to get along with neighbours.

This chapter and its case illustrations show the types of strategies our team uses to continue supporting individuals to enable them to live in the community. In our experience, it is easier working with people from the outset of their injury, but even when people are admitted to the service many years posttrauma, it can still be possible to provide them with the necessary therapies and skills to enable them to live in the community, as shown by Bell and Tallman (1995) in their own program. They reported on five cases who were transferred directly from acute neurosurgical wards to long-term nursing homes. Following initial rehabilitation, which commenced at least 12 months posttrauma (and for two people more than nine years posttrauma), these individuals who were slow-to-recover were able to achieve significant gains and move out into the community. Similarly, in Gray and Burnham's (2000) sample of 306 patients who were slow to recover and did not commence rehabilitation until, on average, one year posttrauma, 86% was discharged to the community after, on average, one year of inpatient rehabilitation. See also McColl, Davies, Carlson and colleagues (1999) for a detailed, qualitative analysis of factors contributing to difficulties and success in community living in four people who made a transition from 24-hour supervised living.

Yet, independent living is more than simply *living* in the community. As Johnston and Lewis (1991) note, degree of supervision is an important consideration: 'although nominally 'in the community' the burden of such placement approximates that of institutional care' (p. 153). In their sample (n = 82), 24 people (29.3%) participating in their community re-entry program were already living in the community but required 24-hour supervision. At one year after program completion, this number decreased to five people (6.1%) who required such supervision. Moreover, Wood, McCrea, Wood and Merriman (1999) make the further comment that in their group of persons with serious neurobehavioural disability, a proportion of whom lived in the family home prior to rehabilitation, one criterion of success of the program was returning people to the family without the tension and disharmony that characterised the pre-rehabilitation situation.

### Profile of a 12-month Cohort

A further issue relevant to this chapter pertains to evidence for the efficacy of the interventions and services delivered. While recognising this imperative, there are challenges in its implementation in systems such as the rehabilitation service provided by the community team. Our program is moving towards more targeted evaluations of the service, but specific, prospectively collected evaluative data are not currently available. The standard approach to program evaluation cannot be readily applied because the service is not a discrete program of intervention, but rather is an intricate and diverse network of services, extended over a protracted timeframe if necessary. Thus our philosophical approach, organisational structure and configuration of therapies/services for our very heterogenous group of clients, does not easily lend itself to measuring 'outcomes', as that term is traditionally used. Sometimes a successful outcome will refer to *maintaining* a person's level of independence, as the case of Omar demonstrated. Other times it will be *providing supports* to a person to enable him or her to continue living in the community, as Bill's case illustrated. As all the case illustrations in this chapter showed, however, the team does deal with identified needs and issues of the individual clients, and so in the absence of specific program evaluation data, we are able to examine some descriptive data documenting service delivery.

Earlier in this chapter we made reference to the survey we conducted of the 467 clients receiving services from the community team during the calendar year 2000 (Tate, Strettlles & Osoteo, in submission). From this large group we extracted a computer-generated random sample of 50 clients and conducted a detailed file search on this subgroup. Table 5 provides descriptive data comparing the random sample and remaining 417 clients served during the year 2000; there were no statistically significant differences on any of the variables. By the end of the year 2000, median time posttrauma for the group was 24.5 months range 2.3 months to 36.0 years posttrauma: half the group (n = 26, 52%) was more than two years posttrauma, 15 (30%) were between 12 and 24 months posttrauma, with the remainder (n = 9, 18%) less than 12 months posttrauma. In spite of injury severity (76% of the random sample had duration of PTA of one week or more, and 30% greater than one month), 27 clients (54%) were classified as Good Recovery (all lower level) on the GOS, 14 (28.0%) as Moderate Disability (eight upper level; six lower level), and nine (18.0%) as Severe Disability (five upper level; four lower level).

As may be expected from the levels of disability experienced by the clients, the effects of the injury impacted dramatically upon their lives. Table 6 compares the premorbid and posttrauma status of the group. Premorbidly, four clients (8%) were unemployed, but posttrauma this escalated to 72%, a figure comparable with our other consecutive series described earlier in this chapter (Tate et al., 1989). Posttrauma return to work was closely linked to GOS category: with a single exception, the 11 people in competitive employment posttrauma were from the Good Recovery group. The occupational



Table 5. Demographic and injury variables of 467 clients receiving services from the community team during 2000.

	Random sample (n = 50)	Remaining clients (n = 417)
	Median (Range)	Median (Range)
Age	33.5 (15-69)	34.85 (15-78)
Duration of PTA (days)	20.0 (1-183)	21.0 (0-183)
Number of occasions of service during 2000	9.0 (1-106)	8.0 (1-167)
	n (%)	n (%)
Sex		
Male	40 (80.0)	336 (80.6)
Female	10 (20.0)	81 (19.4)
Cause of injury:		
Road traffic accident	20 (40.0)	224 (53.7)
Fall	14 (26.0)	91 (21.8)
Assault	10 (20.0)	52 (12.5)
Other	6 (12.0)	50 (12.0)

status for three of these 11 clients was skilled, and for the remainder was unskilled. Moreover, whereas 12 clients were students at the time of their injuries, there were only three students posttrauma, and each of these was in the Good Recovery group. There was not a lot of change in marital status (no change for 84%), or living situation (no change for 76%), but these gross indices do not reflect differences that may well have occurred in the quality of interpersonal relationships (e.g., marital unhappiness and stress, cf. Case Lee) and living situation (e.g., caring for very disabled people in the family home, cf. Case Omar).

Figure 4 shows the admission and discharge details of the random sample during the course of the year 2000. It clearly demonstrates the long-term and ongoing nature of the clients' involvement with the community team. At the commencement of the year, 32 clients (64%) were already in the service; the earliest admission to the community team for this group receiving services during 2000, occurred in February 1992. Twenty-eight of these 32 clients were still active members of the service at the end of the year, and four were discharged during the course of the year. The other 18 clients (36%) entered the service at some point during the year 2000, and 16 clients from this group were still receiving services at the end of the year. Thus only two clients (4%) were admitted to and discharged from the Community Service during the year

Table 6. Change in circumstances in the random sample (n = 50).

	Work			Marital status			Living arrangements	
	Pre n (%)	Post n (%)		Pre n (%)	Post n (%)		Pre n (%)	Post n (%)
Full Time*	26 (52%)	4 (8%)	Single	25 (50%)	28 (56%)	Parental home	23 (46%)	22 (44%)
Part Time*	6 (12%)	7 (14%)	Married/ de facto	18 (36%)	16 (32%)	Own home	19 (38%)	23 (46%)
Unemployed	4 (8%)	36 (72%)	Separated	7 (14%)	6 (12%)	Rent	8 (16%)	4 (8%)
Student	12 (24%)	3 (6%)				Group home	0	1 (2%)
Other	2 (4%)							

\* Work status for those in competitive employment:

Premorbid: Professional/managerial (n = 4), Clerical (n = 2), Skilled (n = 10), Unskilled/semiskilled (n = 16); Posttrauma: Skilled (n = 3), Unskilled (n = 8).

2000. In all, there were three times as many admissions to the service (n = 18) than discharges from it (n = 6) during the course of the year in the random sample, which is a typical pattern to that of other years, and indicates the growth of the service over time.

From our file search we identified 11 types of issues representing social rehabilitation as described in this chapter. In keeping with the distinction drawn by McMillan and Sparkes (1999), many of the issues would be classified as staff action plans, rather than being client goals per se. The types of issues with active involvement from the team that were dealt with in the random sample during the course of the year, along with their 'outcomes' or action status, are displayed in Table 7. We classified the 11 types of issues within three domains, representing social rehabilitation as described in this chapter: occupational activity (work, study, recreation/leisure), interpersonal relationships (both intrapersonal for adjustment/mood, as well as behaviour/social skills and family/friends issues), and living skills (including accommodation, transport, financial/legal, mobility/fitness/self-care, cognitive strategy training).

On average, clients received 17.2 occasions of service (median = 9.0, range 1-106) during the course of the year, and 2.4 (median = 3.0, range 0-6) social rehabilitation type issues were addressed. As anticipated, those clients remaining with the service over time had more severe injuries, as measured

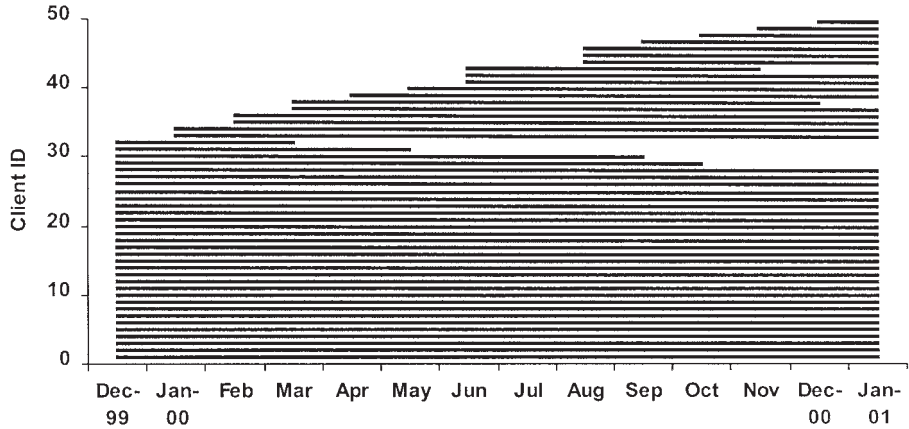


Fig. 4. Admissions to and discharges from the service during the year 2000.

Table 7. Social rehabilitation type issues addressed with clients from the random sample.

	Number of clients with issues addressed during the year 2000	Percent of issues with action completed
	n (%)	
Occupational Activity	22 (44.0)	
Work	15 (30.0)	100.0
Study	3 (6.0)	100.0
Recreation/leisure	5 (10.0)*	100.0
Interpersonal Relationships	27 (54.0)	
Psychological adjustment/mood	13 (26.0)	92.3
Behaviour/social skills	12 (24.0)	91.7
Family/friends	15 (30.0)	100.0
Living Skills	33 (66.0)	100.0
Accommodation	9 (18.0)	100.0
Transport	11 (22.0)	100.0
Financial/legal	8 (16.0)	100.0
Mobility/fitness/self care	17 (34.0)	100.0
Cognitive strategies	14 (28.0)	100.0

\* Note: This figure is lower than usual because the staff position of Recreational Officer remained vacant during 2000.

by duration of PTA ( $r = 0.69$ ,  $p < 0.001$ ) and greater disability on the GOS (Good Recovery versus Moderate/Severe Disability,  $r_{pb} = 0.32$ ,  $p < 0.03$ ). Also as expected, the total occasions of service was associated with greater disability ( $r_{pb} = 0.35$ ,  $p < 0.02$ ), but not with chronicity ( $r = 0.14$ ). There were, however, no associations between frequency of social rehabilitation type issues and injury severity ( $r = 0.06$ ), degree of disability ( $r_{pb} = 0.18$ ), or length of time since injury ( $r = 0.01$ ).

Twenty-two clients (44%) had issues that were addressed in the occupational domain, 27 clients (52%) in the relationship area, and 33 clients (66%) in the living skills domain. In virtually all instances some resolution of the issue occurred during that year. This does not necessarily imply that an independent outcome occurred, such as return to work or independent living in the community. Moreover, although a specific issue was successfully dealt with, the client may not have been discharged from the service (cf. Fig. 4), because other issues may arise, as the case of Lee demonstrated. The following illustrations show the types of issues and action taken. In the occupational activities area, work issues, for example, were addressed with 15 clients, most of whom ( $n = 9$ ) were in the Good Recovery group, and most ( $n = 9$ ) were also less than 18 months posttrauma (seven of these nine were also in the Good Recovery group). In four clients, the work issues were fairly straight-forward, involving referral and limited liaison with vocational programs (*Head-2-Work* and the Commonwealth Rehabilitation Service). Three clients had specific difficulties (loss of job due to the client's errors, inability to cope with the workload, and memory impairments), which required targeted interventions in the workplace for the last two cases, each of which resulted in successful outcomes. The remaining eight clients with work issues required intensive monitoring, liaison and support, such as Brian, a 24 year-old skilled worker, who was injured seven months previously and admitted to the community team at 5.5 months posttrauma. He received 16 occasions of service relating to work issues over a four-month period. The nature of the contact with Brian was to develop a rehabilitation plan for him resuming work, then altering his work duties as a consequence of a seizure, and implementing strategies for him to combat his fatigue, physical intolerance, agitation, and organisational difficulties.

In the relationships domain, adjustment issues, for example, were addressed with 13 clients (seven of whom were classified as Moderate/Severe Disability), and included ongoing management of anxiety and/or depression in each client. Therapy was usually undertaken by the clinical psychologist, in association with the case manager, and often included the consultant psychiatrist. Not infrequently, issues needed to be worked through using an interpreter; 48% of the sample was from a non-English speaking background. It was not unusual for the management of adjustment and emotional issues to occur in the context of multiple problem areas, such as in the case of Tim, a 49-year old unemployed married man, who was almost four years posttrauma and was classified as Moderate Disability (upper level). His anxiety issues needed

to be managed in the context of other social factors including impulsivity and anger management problems, family conflict, social isolation, changes in sleep and appetite, excessive alcohol use, and noncompliance with medication.

With reference to living skills, the accommodation area, for example, was an issue for nine clients, all of whom were classified as either Moderate or Severe Disability. Three clients required arrangements for a period of respite and for an additional two clients their situations were more complicated requiring respite while other interventions were implemented (restructuring of mortgage payments and applying for funds to improve inappropriate housing). For another client the accommodation issue pertained to building extensions to the existing house that necessitated discussions with the Office of the Protective Commission to release funds for this purpose. For three clients, challenging behaviours were jeopardising existing accommodation arrangements requiring liaison with the family and local Mental Health team.

In summary, these descriptive data provide a snapshot of the community team caseload in the random sample, representing some 10% of the workload in a typical year. At a general level, there is initial support for the efficacy of continued rehabilitation in the community from other programs run over shorter timeframes than our own. Seventeen of the 28 treatment studies reviewed by Hall and Cope (1995) focused on rehabilitation provided in the community, either day treatment or residential programs. Yet, while all studies reported improved posttreatment functioning on various outcome measures, commonly including health status measures such as independence and employment, only two of the studies used a matched control group (Fryer & Haffey, 1987; Prigatano, Fordyce, Zeiner, Roueche, Pepping, & Wood, 1984). The remaining investigations compared pre-intervention and postintervention measures in a single group of treated individuals. Moreover, as High, Boake and Lehmkuhl (1995, p. 23) remind us 'it is not enough to show that rehabilitation is effective; one must also be able to justify the effectiveness and expense of the individual components.'

Subsequent to the Hall and Cope (1995) review, a number of other treatment studies addressing rehabilitation for TBI in a community setting have appeared in the literature using stronger research designs, including Willer, Button and Rempel (1999) who conducted a case-controlled study comparing community-based residential treatment and home-based rehabilitation, and Powell, Heslin and Greenwood (2002) who conducted a randomised controlled trial comparing a goal-planned, individualised program at home (or other community setting) with written information regarding available services in the community. This methodologically superior study provides the strongest evidence to date to enable critical analysis of the relative strengths and weaknesses of interventions. Although there was no test of the specific components of their treatment package, the pattern of results provides some indication for future research directions. Of interest, improvements in general functioning did not occur, but rather were specific to activities of daily living (Barthel index) and some aspects of psychological well-being.

It is clear that the current pressing need is to use strong methodological designs and focus attention on evaluating specific components of programs that tap into the socialising and productive employment domains, the very essence of social rehabilitation. A new focus in the continued development of our service is strengthening the evaluative component, using specific projects. One relevant study currently in progress examines family education about living with a person with TBI, incorporating evidenced-based learning principles, as well as evaluating efficacy. Findings from this study will enable analysis of the way in which training and education are conducted and provide a basis to incorporate the results into our work practices. At the broader level, the Liverpool service, as part of the state-wide Brain Injury Rehabilitation Program, is in the process of obtaining consensus on standards of outcome measures at various times posttrauma that will be entered onto a statewide database. This will not only yield systematic documentation of progress at an individual level, but also enable service planning and development at a socio-political level.

### **The Broader Perspective**

In summary, our approach to social rehabilitation, described within the context of a community rehabilitation team in this chapter, aims to enhance outcomes by increasing independence and self-determination, particularly in relation to occupational activities, interpersonal relationships and independent living. In so doing, we make a distinction between ‘rehabilitation’ and ‘maintenance’. Because of the potentially large number of individuals served by community or outreach TBI teams, the focus can often be ‘maintenance’ – i.e., case management, liaison, addressing practical issues and crisis management. In our view, community teams also have the opportunity to include an active rehabilitation component, including isolated bursts of therapies (e.g., a finite number of sessions for anger management), as well as providing opportunities for individuals to ‘get better’ (i.e., ‘cope better’, ‘feel better’, ‘act better’), not merely ‘keep busy’. The essence of our approach is based on identifying issues, and then dissecting, what for the individual and family, can often appear to be huge, complex, insurmountable problems into manageable portions and thence into specific goals that can be addressed.

This approach has similarities to some elements of a number of other programs described in the literature (see the case management role as described in DePompei et al., 2001 and La Marche, Reed, Rich et al., 1995; and the interdisciplinary approach in Pace, Schlund, Hazard-Haupt et al., 1999), but in overall terms our program is unlike others reported in the literature. In particular, our model differs from other (predominantly neuropsychological) therapies that are conducted in an outpatient setting (see, for example, programs described in Christensen & Uzzell, 2000). In one sense, such programs are an extension of inpatient programs in that the clients come to a centre and participate in timetabled sessions addressing multiple potential impairment

areas – communication, social skills, memory, attention, problem solving and so forth. Usually these types of programs are run over a set number of sessions, such as a three or six-month package, with some, such as New York-based Rusk Institute program (Daniels-Zide & Ben-Yishay, 2000), having fixed entry and exit dates.

Within the framework we adopt, there is also the argument to be made that social rehabilitation after TBI must to go beyond the clinical focus of the individual/family in order to encompass a broader socio-political perspective to effect social change. To this end, the Liverpool system has a fifth essential component that was not described in the foregoing, namely non-clinical services. One focus of activity of the non-clinical services that pertains to social rehabilitation is the development of information kits for consumers and professionals. Those currently available address information needs (Strettlles, Simpson, & Mead, 1995), living skills (Shepherd & Strettlles, 1999), sexuality (Simpson, 1999), and suicidality (Simpson, 2002). Submissions and consultations to government and non-government organisations are another way to address gaps in clinical services and improve quality. Submissions have been made on public housing, criminal justice, respite accommodation, and long-term care needs. Listing of submissions, research activities and other information about the service is available through their web site ([www.swsahs.nsw.gov.au/biru](http://www.swsahs.nsw.gov.au/biru)).

In conclusion, this chapter has described our conceptual framework for social rehabilitation after TBI and provided an overview of our clinical practice. The distinctive features of the service are a commitment to ongoing and long-term involvement while-ever there are needs, along with a multidisciplinary team approach in which case managers work in partnership with therapists. For reasons previously outlined, we believe that rehabilitation to address social disablement in the areas of occupational activity, interpersonal relationships and independent living is best conducted in the community. The community-based component of our TBI service has evolved over more than 20 years and in its present configuration is a resource-intensive program. This, however, is largely a function of the volume (around 500 clients and their families per annum), rather than being an inherent requirement of the program, and hence does not impose a limitation to the implementation of the program in other services where the caseload is a fraction of our own. The clinical and nonclinical components of our service are dynamic and continue to evolve and develop to assist in realising our vision for better health, good health care and achieving the maximum quality of life for the person, their family and community.

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# Chapter 9

## REHABILITATION OF BEHAVIOUR DISORDERS

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### Introduction

The presence of behaviour disorders amongst people who have sustained some form of neurological insult, particularly traumatic brain injury (TBI), has been well documented. Whilst confusion and agitation observed during the acute stage of recovery resolves in the majority of cases, a wide range of behavioural problems may emerge with the resolution of consciousness. These are varied, ranging from passivity to aggression, whilst others mimic symptoms characteristic of psychiatric disorders. Whilst behaviour disorders are not atypical following TBI, a reasonable expectation is that these will resolve with time. Unfortunately, studies, which have investigated long-term outcome, paint a picture that is contrary to this belief. Instead, the worrying trend is not only that behaviour disorders persist, but that they also become more severe (for example, see Brooks, McKinlay, Symington, Beattie, & Campsie, 1987; Johnson & Balleny, 1996). The number of TBI cases with severe, persistent behavioural problems is small (estimated as 0.3 per 100,000 per annum by Greenwood & McMillan [1993]). However, tenfold this figure are thought to retain persistent behaviour disorders which, although less severe, nevertheless serve to handicap everyday functioning (Johnson & Balleny, 1996). Not surprisingly, behaviour disorders constitute a considerable source of stress within families (McKinlay, Brooks, Bond, Martinage, & Marshall, 1981; Oddy, Coughlan, Tyerman, & Jenkins, 1985); in addition, neurological patients who are behaviour disordered are unpopular and tend to be avoided by rehabilitation professionals (Miller & Cruzat, 1981). An

immediate consequence of this is that people in need of rehabilitation are excluded from such programmes. A longer term corollary may be that once discharged to the care of their families, persistent behaviour disorder renders management of such people at home untenable, and as a direct consequence they gravitate to placements that are clearly inappropriate for their needs, such as psychogeriatric, learning disability and long-stay secure psychiatric units, as well as prison (Eames & Wood, 1985a).

The range and type of behaviour disorders observed amongst neurological patients is extensive. However, some are more characteristic. For example, Wood (2001) refers to problems of labile mood, impulse control and personality change that are often associated with TBI, amongst a wider constellation of cognitive and behaviour symptoms that he collectively labels 'Neurobehavioral Disability'. Development of aggression has been especially highlighted (for example, see Miller, 1994) because of the impact this has on families and its poor prognosis regarding success in rehabilitation (Burke, Wesolowski, & Lane, 1988).

### **When does behaviour become a disorder?**

There is little doubt that behaviour which is clearly harmful to the environment, and which places either the perpetrator or others around them at risk, can be more easily labelled as 'problematic' or a 'disorder'. People whose behaviour falls beyond the cultural and social limits of what is acceptable within their community may be highlighted (often by the judicial system) and identified as being likely recipients of treatment whose purpose is to reduce social handicap. A tendency has grown in clinical circles in recent years to label such disorders 'challenging behaviour', especially in the literature pertaining to learning disability. For example, in the UK Emerson, Barrett, Bell, Cummings, McCool, Toogood and Mansell (1987) defined challenging behaviour as that which jeopardises the safety of the person exhibiting them, or limits access to ordinary community facilities. Alderman (2001) embraced this view and argued that many of the post-acute behaviour disorders observed amongst neurological patients fall under the umbrella of 'challenging behaviour'. Alderman argued that behaviours should fall within this definition if they served to deny a person access to neurological rehabilitation services, as well as community facilities. In this way, disorders of initiation and passivity which characterise some forms of brain injury, and even the general coarsening of social behaviour which is often typical of TBI patients, are also classed as 'challenging' as their effect can be just as disabling as aggression if they function to exclude people from services of which they are in need.

### **Aetiology of Behaviour Disorders**

There are many possible causes that drive behaviour disorders that are the sequelae of neurological insult. Identifying these, as they apply to the indi-

vidual patient, is an ideal to be pursued if effective treatment is to be delivered. Unfortunately, this process is thwart with difficulty. One reason is that there are many different neurological conditions, each with their own distinctive neuropathology: behaviour disorders that characterise each condition will vary because of differences in the location and extent of the structural damage incurred. However, behavioural problems observed in people with similar neurological conditions may vary further because such patients do not constitute a homogenous group. This point was made by Mateer and Ruff (1990) who pointed out that no two brains are damaged in exactly the same way; consequently, not only are there differences regarding neuropathology, but also the probability that underlying cognitive systems are disrupted in identical ways is low. For example, Colthart (1991) estimated that the naming system could be impaired in up to 16,383 separate ways. Another set of factors that contributes to lack of homogeneity concerns other sequelae arising from insult. These may be extensive and include cognitive, emotional, physical and functional impairments, as well as overt behavioural problems. Wilson (1991) argued people rarely have just one or two specific problems arising from brain injury: instead, they routinely present with a combination of these difficulties, which are rarely identical.

The point is that whilst within specific diagnostic groups (for example, stroke and TBI) the location and extent of the neuropathology will initially dictate types of behaviour disorder, these will be subjected to a wide array of secondary influences which modify, sometimes considerably, how they are eventually manifested. The range of variables which influence development of behaviour disorders is considerable, but includes cognitive deficits, reactive disorders, denial and poor awareness, post-injury learning, poor frustration-tolerance, environmental factors, and exacerbation of pre-morbid traits. Space does not permit extensive elaboration of these here (see Alderman, submitted): however, the influence on behaviour of some of these will be illustrated through discussion of case material later in this chapter. Thus, behaviour disorders will invariably be the product of complex interaction between many factors. Seeking to find a single cause is probably not only conceptually too simplistic, but is fraught by methodological problems attributable to poor homogeneity.

### **A note on the 'Frontal Lobe Syndrome'**

A little will now be said about the Frontal Lobe Syndrome simply because behaviourally disturbed neurological patients, particularly those who have sustained TBI, continue to be almost routinely ascribed this label. There is little doubt that this area of the brain has received most attention regarding cerebral correlates of behaviour disorder. An extensive breadth of anecdotal social and other changes observed after damage (actual and assumed) to the frontal lobes is evident in the literature. The case of Phineas Gage (see Kimble, 1963) remains one of the earliest and most striking examples of behaviour and personality changes which followed a penetrating injury



of the brain which resulted in a large bilateral lesion of the ventromedial prefrontal cortex.

The range of symptoms historically attributed to frontal lobe syndrome is exhibited through a wide range of difficulties in everyday life. These may include problems with abstract reasoning, making decisions and showing good judgement; difficulties in maintaining attention; inappropriate social behaviour; difficulties in devising and following plans and with situations involving some forms of memory, for example, remembering to carry out intended actions at a future time (for review, see Levin, Eisenberg, & Benton, 1991; Stuss & Benson, 1986; Shallice, 1988).

However, whilst 'frontal lobe syndrome' implies the presence of a consistent pattern of behaviour disorder and other difficulties with a single cause, this is plainly not the case. Examination of patients with known frontal lobe damage demonstrates the presence of not just one, but a variety of different clusters of behaviour disorder, personality abnormality and functional problems. In addition, disorders attributed to frontal lobe damage are often found in the absence of frontal lobe pathology, or cannot be specifically attributed to them alone in the case of generalised, diffuse damage (Stuss & Benson, 1984; Bigler, 1990). Instead, recent advances in functional imaging have helped to emphasise how different brain areas work together as a system in the performance of all but the very simplest of tasks, a finding which questions the integrity of the concept of the frontal lobe syndrome. Indeed, Baddeley (1986) and Baddeley and Wilson (1988), have argued that it is a mistake to try and account for those functional changes attributed to this syndrome on the basis of localisation alone. These authors remind us that deficits associated with damage to other brain structures are not classified according to location, but instead by function. Baddeley and Wilson argue that a functional definition should be sought regarding types of deficit that arise following damage to the frontal lobes and the myriad of rich connections they have with posterior structures: hence their proposal of the term 'dysexecutive syndrome'.

A further advantage of this reconceptualisation of the frontal lobe syndrome to that of the dysexecutive syndrome, is to reduce the emphasis on attempting to ascribe deficits to specific brain sites, whilst highlighting that it is problems with function that should form the basis of most clinical activity, particularly when conducted within a rehabilitation environment. The focus on observable phenomena has led to the development of cognitive models that have attempted to account for behavioural manifestations of the underlying organic damage, irrespective of the site of injury. The models proposed by Shallice (1982) and Baddeley (1986) have achieved the greatest prominence, and have endeavoured to explain the presence of a range of functional problems through impairment of attentional control mechanisms. These models have proven very useful to clinicians in conceptualising the cause of some types of behaviour disorder, and have driven the development of a range of successful treatment programmes (for example see, Burgess & Alderman, 1990; Alderman, 1996; Alderman, Fry, & Youngson, 1995). An example of

how the concept of the dysexecutive syndrome and cognitive models can be applied to the rehabilitation of behaviour problems will be presented later in this chapter.

Burgess, Alderman, Evans, Emslie and Wilson (1998) demonstrated that behaviours symptomatic of the dysexecutive syndrome are prevalent amongst people with acquired neurological damage. However, they also found evidence that it is a mistake to conceptualise the dysexecutive syndrome as a single clinical condition. Burgess and colleagues showed instead it fractionates at the level of behaviour into at least five discernible sub-syndromes or components. These were *inhibition* (behaviours arising through difficulties with response suppression), *intentionality* (those attributable to altered insight and the creation and maintenance of goal-related action), *executive memory* (behaviours resulting through impairment of those memory processes directly involved in executive function, for example confabulation), *positive affect* (those consistent with emotional and personality changes seen in people with dysexecutive problems, including aggression and euphoria) and lastly *negative affect* (emotional and personality changes that include shallowing of affect and increased apathy).

This work confirms that it is just as erroneous to simplify the dysexecutive syndrome to the level of a single unitary disorder, as has been implied when the term frontal lobe syndrome is employed. This highlights the need for detailed and thorough assessment to determine what sub-components of the dysexecutive syndrome are evident in order that effective treatment can be planned. For a wider discussion of the dysexecutive syndrome and rehabilitation see Alderman and Burgess (2003).

## Treatment Options

Because behaviour disorders are likely to result from complex interactions between a wide range of factors, by necessity treatment should be designed to meet the unique needs of each separate person. There are a number of diverse methods available for the treatment of behavioural problems amongst neurological patients, including pharmacological and rehabilitative interventions (Rao & Lyketsos, 2000). However, not all of these will necessarily be appropriate to all people. For example, with regard to the UK McMillan and Oddy (2001) make the point that very few services exist that are specifically designed to meet the needs of people for whom personality changes and cognitive impairment are the primary disabilities. These authors also argue that people who present with severe behaviour disorders should always be admitted to a specialised neurobehavioural service for treatment. Whilst few units offering such a service are required, it remains the case that places may be restricted to people who happen to live within particular catchment areas (Greenwood & McMillan, 1993). Furthermore, those services that do exist in the UK fall predominantly in the independent sector where the costs neces-

sary to deliver effective neurobehavioural programmes may serve to further exclude people who should be in receipt of them. In other countries with different funding systems, access to more specialised services may be easier in principle, but often they do not exist, or sufficient funding is not available for the time needed.

It is clearly beyond the scope of this chapter to attempt a comprehensive review of all available treatment methods available: a substantial account of the state of current practice can be found in Wood and McMillan (2001). However, principle mainstream approaches include the following:

### **Pharmacological**

Scope for pharmacological intervention is considerable and drug therapies have an important role to play in the treatment of behaviour disorders (see Eames, 2001; Rao & Lyketsos, 2000). However, a number of factors need to be considered regarding these. First, less is known about the effectiveness of drug therapies because relatively few controlled studies have been conducted, whilst single case studies presented in the literature generally lack sufficient methodological rigour to enable objective evaluation of efficacy (Rao & Lyketsos, 2000; Alderman, Knight, & Morgan, 1997). Second, a major problem highlighted by Eames (1990, 2001) is that symptoms of organic brain injury can sometimes be mistaken as evidence of mental illness and lead to administration of an inappropriate drug regime. It is therefore essential that assessment is made by an experienced neuropsychiatrist; unfortunately, few are available at this time in the UK (Alderman, 2001).

Despite these notes of caution, it is clear that pharmacological intervention has a significant contribution to make towards the management of behaviour disturbance amongst people with brain injury. It is beyond the scope of this chapter to examine the role of medication in-depth; however, there are many examples in the literature to illustrate what benefits there might be. For example, amantadine has been shown to be beneficial in the treatment of a range of neurobehavioral sequelae, including aggression (Nickels, Schneider, Dombovy, & Wong, 1994; Gualtieri, 1991). Anticonvulsants are especially relevant in the management of irritability, aggression, and paroxysmal mood disorders (Hirsch, 1993; Mooney, & Hass, 1993; Giakas, Seibyl, & Mazure, 1990). Carbamazepine appears to have special relevance (Foster, Hillbrand, & Chi, 1989; Mattes, 1990; Azouvi, Jokic, Attral, Denys, Markabi, & Bussel, 1999). Valproic acid is also commonly used and reported to be equally as beneficial as carbamazepine (Rao & Lyketsos, 2000).

### **Psychotherapy**

This is a broad and multiply defined concept (Jackson & Gouvier, 1992) which encompasses various therapies that have arisen from different models of psychopathology (Patterson, 1996). Certainly, successful outcomes have been reported which have led to positive psychosocial outcomes: well known and successful programmes have been reported by Ben-Yishay, Rat-

tock, Lakin, Piasetsky, Ross, Silver, Zide and Ezrachi (1985), and Prigatano (Prigatano, 1986; Prigatano, Fordyce, Zeiner, Roueche, Pepping, & Wood, 1984). However, Wood and Worthington (2001a) argued that these programmes can only be employed with articulate patients with less debilitating handicaps. Neurological patients with serious behaviour problems are usually excluded from them because of intransigent problems with insight and motivation (Burgess & Wood, 1990; Sazbon & Groswasser, 1991), and because the severity of the challenging behaviour they exhibit is too great (Wood, 1987).

### **Cognitive therapy**

Despite the widespread use and well-known efficacy of the cognitive therapies based on the earlier work of influential clinicians such as Beck (1976), little is known about their effectiveness regarding behaviourally disturbed neurological patients. One reason for this, as with pharmacological interventions, is that this area remains poorly researched to date (Manchester & Wood, 2001). Other factors may also exclude people from participating. Cognitive therapy approaches are essentially concerned with information processing. Belief systems may bias interpretation of experience which in turn alters and shapes behaviour. This can sometimes account for behaviour disorders, such as aggression. Cognitive therapy is concerned with helping patients understand that thoughts and beliefs can be maladaptive, to identify their own thinking distortions, and to help them generate more rational interpretations of events. Patients are helped to become their own 'therapist' and encouraged to test the validity of their automatic thoughts; attempts are made to modify these through a process of hypothesis testing in the real world, and dysfunctional emotions and behaviours subject to change as a consequence. It is certainly the case that reduced awareness and impairment of those cognitive skills necessary to engage in the hypothesis-testing process central to cognitive therapy, create special challenges for cognitive therapy to overcome. These may impede access to this form of therapy for some neurological patients with severe behaviour disorders. However, Kinney (2001) reports methods that enable cognitive therapy to be adapted for use with people with brain injury, and parallels with its successful employment in helping people with severe learning disability (Williams & Jones, 1997; Jones, Williams, & Lowe, 1993) suggest it may prove helpful. For a more comprehensive discussion of the application of cognitive therapy to people with brain injury see Manchester and Wood (2001) and Alderman (2003).

### **A Neurobehavioural Approach to the Rehabilitation of Behaviour Disorders**

Treatment of behaviour disorders amongst neurological patients using behaviour therapy has received considerable attention in the rehabilitation literature

during the last two decades. This approach has many advantages (see Powell, 1981; Wilson, 1989): for example, there are techniques available to both increase and decrease behaviours of interest; and the methodologies routinely employed enable objective evaluation of treatment outcome to be made.

However, there are particular reasons why behaviour therapy has special relevance to this clinical population. One of the most obvious is because people have been excluded from psychotherapy and cognitive therapy through lack of awareness, poor motivation, cognitive impairment, or the severity of behaviour disorder. These problems do not necessarily constitute a barrier to the effective use of behaviour therapy.

### **Neurobehavioural rehabilitation**

A problem emphasised earlier in this chapter was lack of homogeneity within the neurological population. This was illustrated with reference to behaviour disorders where the complexity of reasons driving behaviour disorders was emphasised. Poor homogeneity necessitates individual assessment so that treatment is designed to meet the unique needs of every person. However, lack of homogeneity, the sheer number of possible variables concerned, and their complex interactions renders assessment itself highly problematic. Wood and Eames (Wood, 1987, 1990; Wood & Eames, 1981) argued that this problem can be countered in part by casting the brain itself in the role of dependent variable, subjecting it to environmental manipulation, and then studying the effects. In this way the nature of causative factors which underlie behaviour disorders are more likely to be determined, and inferences drawn about the nature of brain-behaviour relationships. This data-driven, objective, analytic approach to the study of brain-behaviour relationships is of course borrowed directly from behaviour therapy. An extension of this model, which incorporates principles from behaviour therapy, neuropsychology and behavioural neurology, are combined to form what Wood has described as a *neurobehavioural paradigm* to rehabilitation (Wood, 1987, 1990; Wood & Worthington, 2001a, 2001b). Neurobehavioural rehabilitation encompasses systems that address cognitive and physical sequelae of brain injury, in addition to targeting behaviour disorders.

It is beyond the scope of this chapter to provide a very detailed description of the neurobehavioural model, or how different therapy disciplines function within this. The most recent comprehensive accounts of the paradigm and the ways in which it is operationalised can be found in Wood and Worthington (2001a; 2001b), and Alderman (2001); Giles and Clark Wilson (1999) provided specific explanations of the ways in which wider therapy requirements (physical and functional) are met within services that are organised to meet social and behavioural needs using neurobehavioural principles. Concepts that differentiate neurobehavioural practice from both the medical model and traditional clinical rehabilitation (Wood & Worthington, 2001a) are that it happens post- acutely (i.e. when medical management is no longer the priority), it is community based, it employs an inter- or transdisciplinary team,

and it demands a structured environment. Behaviour modification techniques are used, including stimulus control methods, chaining and shaping, and response-consequence learning technologies (Wood, 1990).

### **The importance of structure**

The concept of structure is of paramount importance within neurobehavioural practice; consequently, this will be elaborated here. Alderman (2001) conceptualised structure within specialised neurobehavioural units as falling at four levels:

#### *1) Structure Provided by the Physical Environment*

The goal of neurobehavioural practice is the resolution of handicaps that result from disorders of social behaviour; learning plays a central role, whether it be in reacquiring old skills, or gaining new ones (Wood & Worthington, 2001a). As persistent cognitive problems, including difficulties with attention and memory, are endemic to many chronic neurological conditions, the process of learning is both slow and fragile (Wood, 1987). Given these constraints it is therefore essential that the physical environment is organised in such a way to maximise learning. For example, it should be as quiet as possible and free from extraneous 'clutter' to minimise problems with distractibility. The layout of the unit should be unambiguous and locations of bedrooms, therapy rooms, and so on, should be clear-cut. It is particularly important that the physical environment should emphasise cue-saliency, a subject matter we shall return to again later.

The three remaining levels of structure refer to what happens within the physical environment.

#### *2) Structure Provided by a Transdisciplinary Team*

Within neurorehabilitation units the clinical team should be transdisciplinary in organisation so that a unified, seamless service is provided to each patient, focussing on their individual needs (Doyle, 1997; Wood & Worthington, 2001a). Within these teams there is substantial blurring and sharing of roles. Therapists and nurses work within the same physical environment together to achieve the same set of shared goals for each patient. Achieving behavioural goals early in admission is the priority; without this, the ability of the team to engage the patient in wider rehabilitation will remain compromised. Consequently, all staff act as behaviour therapists and have an equal and joint responsibility for ensuring behaviour modification interventions are implemented as and when necessary. An transdisciplinary team facilitates good communication, a co-ordinated approach to rehabilitation, and maximises consistency.

#### *3) Structure Provided by the Routine Imposed on the Day*

A timetable of events throughout the day is employed to provide structure through routine. This typical consists of meal times, formal sessions and

'free' time. Routine facilitates a means through which individual rehabilitation needs are met and provides opportunities to practice skills throughout the day. It promotes consistency and facilitates creation of an environment in which there is an expectation for people to attend sessions and participate at an appropriate level.

#### *4) Structure Imposed Through Behaviour Modification Interventions*

This serves to provide a framework through which appropriate behaviour and effort are actively encouraged. Probably most importantly, these interventions are vehicles which facilitate appropriate interactions between staff with patients in a way that is helpful and therapeutic, as the experience of the latter is likely to have been negative (see Alderman, 2001; Alderman, Davies, Jones, & McDonnell, 1999). In addition, behaviour modification interventions raise the saliency of cues that normally regulate social behaviour; variable monitoring and poor processing of these cues can explain some of the behaviour disorders exhibited by this clinical group (see Alderman, 1996, 2001; Alderman & Knight, 1997). Utilisation of behaviour modification interventions also increases the likelihood that new learning will take place, even in the presence of cognitive impairment, through increased consistency in how staff interact with patients, by ensuring clarity of rehabilitation goals and the means by which these are achieved, and by knowing what the contingencies to patients' actions and behaviour are (Alderman, 2001).

When services are organised in this way, the net effect is the provision of a daily routine within which skills that aim to maximise independence and quality of life are repeatedly practised and acquired through procedural learning in the form of new habits. Effective communication within the transdisciplinary team, together with a programme that is grounded in behavioural methods, helps ensure rehabilitation is established at an appropriate level for each individual, that goals are shared, and that management, including contingencies to behaviour, is consistent. Good outcomes have been demonstrated regarding reduction of behaviour disorders amongst neurological patients admitted to specialised units which have operationalised the neurobehavioural paradigm (for example see Eames & Wood, 1985a, 1985b; Eames, Cotterill, Kneale, Storrar, & Yeomans, 1996).

### **Examples of Reduction of Behaviour Disorders**

#### *1) Inappropriate Means of Obtaining Attention from Other People*

Some 'problematic' behaviours arise in part through how the environment responds to the actions of the person with brain injury. The point was previously made that people with TBI are not popular among rehabilitation professionals because of their often irritating, threatening and embarrassing behaviour, as well as their general lack of motivation (Miller & Cruzat, 1981). This can lead to situations where such people are routinely ignored.

However, one consequence of this may be that other people may inadvertently reinforce less desirable behaviours intermittently shown by a patient. For example, a natural response elicited by shouting, screaming, masturbation and aggression may be a social reprimand, such as being told ‘...don’t do that’. Whilst feedback which takes this form would normally be expected to lead to a change in behaviour, under circumstances devoid of regular positive social contact the attention received by the person, even when it is delivered in the form of criticism, may be welcome. When this is the case, behaviour disorders can become reinforced and thus inadvertently maintained.

Figure 1 illustrates this point. It concerns HC, a young man who had sustained TBI and had acquired a range of characteristic cognitive and behavioural problems. Sequelae of his injury included coarsening of his social behaviour and a general reduction in inhibitory control. HC was noted to be unresponsive to normal social cues; a particular handicap was his lack of ability to join social interaction appropriately. In particular, he failed to wait

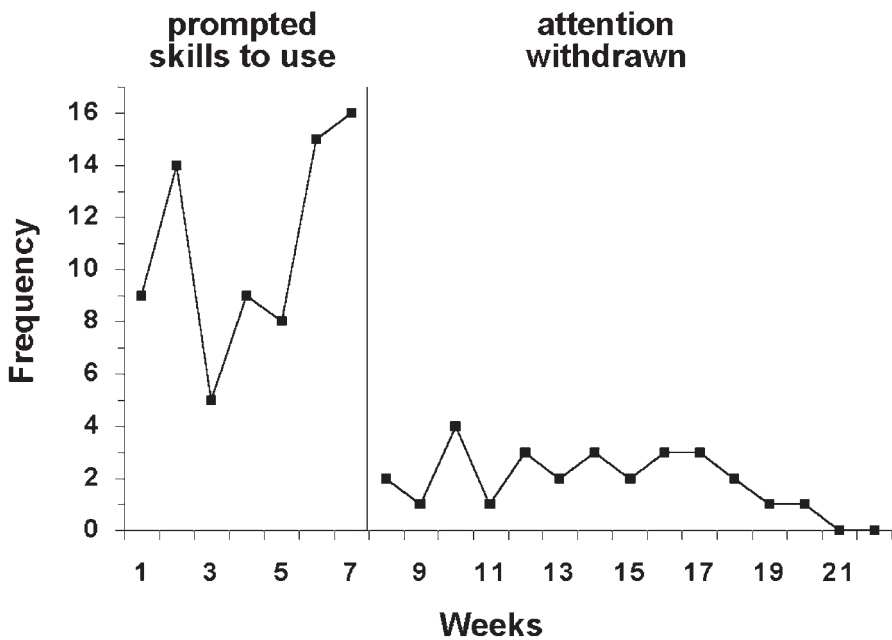


Fig. 1. Reduction in the frequency with which HC interrupted conversation. (NB. Data reflects frequency 15 minute periods in which this behaviour was observed at least once.) Contingent response to interruption in the second half of the figure was withdrawal of attention by means of TOOTS; however, appropriate skills were taught in specific sessions for this purpose, and subsequent use of these skills was reinforced through enriched social praise and attention.



for an appropriate pause in conversation and interrupted others constantly. Staff felt HC needed to relearn the rules which govern social behaviour which it was believed had been lost as a result of his brain injury. It was therefore decided that every time HC interrupted conversation, he would be consistently reminded by staff what these rules were, and what he should do to obtain attention appropriately. On the face of it this plan seems perfectly reasonable, and most people would probably take such feedback on board and use it to modify their behaviour. However, Figure 1 shows this response did not lead to a reduction in the frequency with which HC inappropriately interrupted others conversations (note that data points reflect the number of fifteen minute periods in the day in which HC engaged in this behaviour: the actual frequency was much higher). If anything, Figure 1 suggests the frequency of the behaviour increased.

Of course, what was probably happening was that HC's poor social skills were being reinforced because staff consistently gave him attention every time he interrupted. In contrast, his coarse social behaviour and general lack of inhibition rendered him unpopular with other people to the extent that his social needs were poorly met. Under these conditions, it is easy to understand how reprimand, criticism, or, as in this case, instruction intended to correct undesirable behaviour, might actually work to reinforce it. Accordingly, an intervention was designed whose aim was to change the contingencies to HC's behaviour. The principle of "Time-Out-On-The-Spot' from positive reinforcement' (abridged to 'TOOTS': see Wood, 1987; Burgess & Wood, 1990) was used: as staff attention was maintaining HC's inappropriate behaviour, they were required to consistently withdraw giving him attention whilst he attempted to interrupt conversation. In this way, reinforcement was no longer available. In addition, HC was taught the correct skills to use in formal social skills training sessions. Most importantly, staff were required to consistently reinforce use of appropriate means of getting other peoples attention whenever HC chose to use them. Figure 1 confirms that the frequency of interrupting decreased in response to this intervention.

## *2) Reduction in Physically Aggressive Behaviour*

HC illustrates how the environment may reinforce inappropriate social behaviour and how a simple intervention can be used to reverse contingencies maintaining it. Aggressive behaviour disorders represent the greatest challenge to rehabilitation services, especially when this involves physical assaults on other people (Burke, Wesolowski, & Lane, 1988) and it is this, probably more than any other behaviour disorder, that is likely to result in exclusion from rehabilitation. However, within specialised services, the neurobehavioural paradigm may be sufficiently embraced to enable management of severe aggressive behaviour disorders (see Alderman, 2001, for a description of the requirements of such a service).

There are many reasons why neurological patients exhibit aggression. Miller (1994) summarised three of the most cited. First, it may be attribut-

able to an episodic dyscontrol syndrome, in which disturbance of mood and behaviour is a consequence of electrophysiological brain disturbance. Second, damage to anterior brain structures decreases ability to inhibit or regulate emotional responses, leading to a lower threshold for aggressive behaviour. Third, brain injury exacerbates negative premorbid personality traits: people who were aggressive are likely to be more so as a consequence of neurological damage. An additional reason is that aggression may be negatively reinforced as it leads to avoidance of, or escape from, situations which are perceived as threatening or undesirable. For example, poor awareness and lack of insight regarding extent of disability amongst neurological patients may result in poor motivation to engage in the rehabilitation process (Prigatano, 1991; Wood, 1988; Sazbon, & Groswasser, 1991). Spontaneous bouts of aggression directed at a source of frustration, usually a nurse or therapist, may initially occur because of reduced tolerance levels. The understandable response of staff will be to withdraw. When this takes place in therapy situations the patient with little insight regarding the need for this may learn that purposefully aggressing against staff will lead to withdrawal of treatment: this behaviour may consequently become negatively reinforced (see Alderman, 1991; Alderman, Shepherd, & Youngson, 1994).

In these cases, treatment of patients within a specialised neurobehavioural service in which expectations are gradually increased, has been demonstrated to be effective in reducing aggressive behaviour disorders (Alderman, Davies, Jones, & McDonnell, 1999). The net effect of the levels of structure described by Alderman (2001) and summarised earlier will be to provide a therapeutic framework within which aggression may be safely managed. Methods are employed whose purpose is to reverse contingencies which have led to avoidance and escape from rehabilitation activities in order to deliberately elicit aggressive behaviour (with the minimum of risk). Use of behaviour modification methods is fundamental. They are used to create conditions which encourage motivation and success, by reinforcing appropriate behaviour and skills. Whenever possible, the desirable consequence to aggression is the withdrawal of attention through TOOTS whilst maintaining the required level of expectation. In this way, only behaviours that are consistent with the aims of rehabilitation are reinforced. One way of achieving this is by using a token economy (Wood, 1987), or programmes based on the principles of differential reinforcement (Alderman & Knight, 1997; Knight, Rutterford, Alderman, & Swan, 2002).

An example of the effectiveness of such an approach is illustrated in Figure 2. This concerns MW, a 43-year-old male who had sustained TBI two years previously. Severity of neurobehavioural disability proved sufficient to exclude him from the usual range of rehabilitation services, and a placement in the community proved untenable. Neuropsychological problems were evident, especially with regard to memory and executive function. He was consequently admitted to a specialised neurobehavioural unit and his aggressive behaviour monitored using the Overt Aggression Scale – Modified

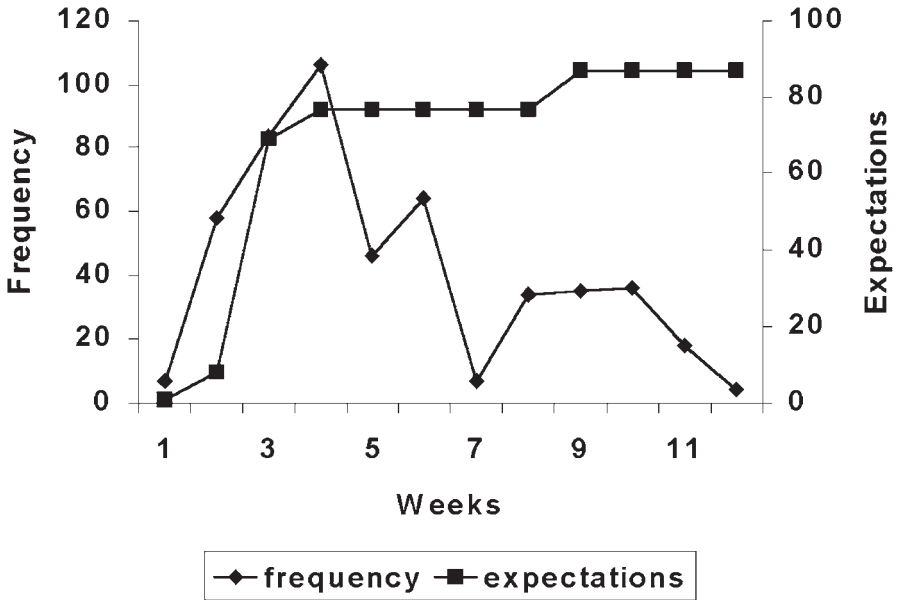


Fig. 2. Reduction in the frequency of physical aggression directed at other people by MW. Concurrent measurement of rehabilitation demands shows that aggressive behaviour decreased despite gradual increase in expectations.

for Neurorehabilitation (OAS-MNR: Alderman, Knight, & Morgan, 1997). The OAS-MNR enables recording of type of aggression, its frequency, severity, and methods used to manage/treat it. It also enables recording of antecedents, and quantifies the intrusiveness of interventions employed. It has proved useful in clinical work with aggressive patients (Alderman, Davies, Jones, & McDonnell, 1999), and in audit and research (Alderman, Knight, & Henman, 2002). In addition, the levels of expectation placed on MW in rehabilitation are also represented in Figure 2, through ratings made using the Neurorehabilitation Expectations Scale (NES: Swan & Alderman, in press). In brief, the NES consists of ten activities and demands that most patients admitted to neurobehavioural units would be exposed to. They are ranked from least demanding (1 – ‘invited to attend meals’) to most demanding (10 – ‘each separate behaviour modification programme used’). Other examples of items include having a toileting programme (ranked 5) and having a formal supervised hygiene programme (ranked 8). A gross indication of the level of expectation for any patient can thus be obtained by summing the ranks of those items that apply for each week of admission.

During the twelve-week assessment period represented by Figure 2, recordings made on the OAS-MNR showed MW was frequently aggressive.

Physical aggression towards other people was the main category of aggressive behaviour recorded: of the 1138 recordings made, 53% (603) were assaults on others. Figure 2 confirms that expectations regarding MW were initially low during the first week of admission, but gradually increased thereafter (see Alderman, Davies, Jones, & McDonnell, 1999, for details of the admission process concerned). Figure 2 also shows a concurrent increase in the frequency of physically aggressive behaviour, peaking in week 4. OAS-MNR recordings suggested that increased aggression was primarily a function of rising expectations as 66% of this behaviour followed prompts and requests made by staff. However, Figure 2 confirms that whilst levels of expectation remained consistently high, the number of times MW was physically aggressive substantially decreased after the fourth week.

This brief account confirms findings reported elsewhere that aggressive behaviour disorders can be successfully reduced through exposure to a holistic neurobehavioural programme (Wood, 1987; Alderman, Davies, Jones, & McDonnell, 1999; Alderman, Bentley, & Dawson, 1999; Swan & Alderman, submitted). When aggression has previously been reinforced because it has led to avoidance of or escape from rehabilitation activities, a gradual increase in expectations, reinforcement of behaviours incompatible with aggression, and consistency of staff response, all combine to promote conditions which promote co-operation.

One major advantage of a behaviour modification approach is the substantial effect it has on achieving consistent response-sets from staff interacting with people who present with challenging behaviour (Alderman & Knight, 1997; Alderman, 2001). An important outcome in substituting what Alderman (2001) called a spontaneous, or natural, system of feedback, with a structured system, is to change staff behaviour. In the absence of structured feedback systems (of which behaviour modification interventions are part) differing staff expectations and responses will contribute to the evolution and maintenance of aggression. Variability attributable to individual staff differences will be significantly reduced through adherence to a prescribed intervention. The programme becomes a vehicle to achieve consistency amongst staff which ultimately has an impact on patient behaviour. The philosophy of the neurobehavioural approach is the reinforcement of positive behaviour, whereby behavioural programmes are vehicles that facilitate positive staff-patient interaction where previously the tendency would have been to avoid interaction or for it to be negative. When this is the case, as MW has shown, the likelihood of successful outcome in the treatment of aggression is optimised.

### *3) Remediation of Behaviour Disorders Resulting from Monitoring Difficulties*

Enhanced cue-saliency is an integral feature of neurobehavioural rehabilitation. A consequence of enhanced structure and the availability of regular feedback is the ability to maintain a prosthetic environment. Inappropriate

behaviour can arise when social cues are missed. In addition, neurological patients may have poor awareness and lack insight regarding behaviour problems, and thus lack motivation to change. Both inefficient processing of cues and reduced awareness regarding consequences of behaviour may be the result of monitoring impairment. Both these difficulties are likely to diminish when people are immersed within the specialised environment of a neurobehavioural service because cues are exaggerated. This may be one reason why token economies and differential reinforcement programmes are successful, as they enable feedback about behaviour to be presented clearly, frequently and regularly (see Wood, 1987; Alderman & Knight, 1997). In this way, behavioural strategies enable individuals to obtain feedback from the environment which they may otherwise miss; the net effect of the prosthetic environment in which rehabilitation takes place will be to circumvent difficulties with monitoring, enabling greater recognition of cues and awareness of the impact of behaviour to take place. It could be said that the regular feedback provided to patients by staff through the structure of the behavioural programmes circumvents cognitive problems, especially those concerned with attention and memory, which would normally give rise to symptoms characteristic of the dysexecutive syndrome.

For many patients, the structure of the neurobehavioural service described earlier is sufficient to enable management of behaviour disorder and full exploitation of individual rehabilitation potential. However, it was recognised some time ago that some patients remain unresponsive to neurobehavioural paradigms in which feedback is managed using various forms of positive reinforcement programme (Alderman & Burgess, 1990).

Impairments in attention and working memory have been especially highlighted in relation to the evolution and maintenance of some behavioural problems. Explanations for these have recently been proposed using the concept of working memory proposed by Baddeley and Hitch (1974). This is conceptualised as consisting of several temporary storage systems whose activities are co-ordinated by a central executive (CE), aided by a number of subsystems which include the articulatory loop (which deals with verbal information) and the visuospatial sketchpad (which processes non-verbal material). The CE allocates attentional resources to these subsystems. CE impairment results in inefficiencies in the allocation of attentional resources which are evidenced in a range of behavioural and other symptoms seen in patients that are characteristic of the 'dysexecutive syndrome' (Baddeley, 1986; Baddeley, & Wilson, 1988). Impairment of CE functioning may result in difficulties in scheduling two or more concurrent tasks, distractibility, poor monitoring of performance, problems utilising feedback, and attention and memory problems.

Alderman and colleagues (Alderman, 1996; Alderman, Fry, & Youngson, 1995) attributed some behaviour disorders amongst neurological patients to deficits in CE function, whereby difficulties with attending to multiple events are evident functionally through people having problems in monitoring

changes in the environment, their own behaviour, and internal (physiological) changes. Opportunities to receive and process feedback are reduced which results in failure to modify behaviour in response to changing circumstances: individuals with the dysexecutive syndrome therefore present as impulsive, distractible, unresponsive to cues from others, and behave inappropriately in social situations. For many patients, the provision of feedback provided through the combination of the structure and positive reinforcement programmes within a neurobehavioural unit, is sufficient to circumvent the cognitive impairment which underlies some behaviour disorders. However, Alderman (1996) argued that when CE deficit is severe only one stimulus set at a time may be routinely attended to. This may explain why a characteristic feature of the dysexecutive syndrome is a reduced ability to change behaviour in an adaptive, flexible way, in response to changes in the environment. It has also been used to account for why some patients do not respond to use of positive reinforcement methods, a hypothesis which has received some experimental validation (Alderman, 1996).

Consequently, specific approaches have been used in the treatment of behaviour disorders thought to arise from profound difficulty in the allocation of attentional resources to the extent that only one stimulus set at a time may be routinely attended to. Use of a behaviour modification technique known as response cost is believed to have particular relevance and a number of single case studies with intransigent behaviour disorders have been described in the literature which have been successfully treated using this method (for example see Alderman & Ward, 1991; Alderman & Burgess, 1990; 1994). Typically, the person who is the recipient of treatment is given a number of 'tokens' (plastic discs, or whatever else is appropriate). One of these can be subsequently removed on each occasion a target behaviour (for example aggression) is observed (see Alderman, 2001, Table 9.3, p. 195 for an illustration of the operational procedure concerning removal of tokens). After a predefined time has elapsed the number of tokens left in the persons possession are checked; providing these exceed or equal a specified target (for example 10/20) they are exchanged for an agreed reinforcer.

It has been argued response cost benefits patients with severe CE deficit because feedback is immediately contingent on behaviour (thereby reducing memory load), requires little understanding of reward contingencies, and has both verbal mediation and procedural learning components.

Alderman, Fry and Youngson (1995) used the CE model to successfully develop what is arguably a five stage cognitive rehabilitation technique used for the treatment of behaviour disorders that are secondary to severe impairment of monitoring function. Their programme of Self Monitoring Training (SMT) has some advantages over response cost, both ethically and practically; as it is directly concerned with developing cognitive skills in order to produce behaviour change, rather than simply trying to change behaviour alone, SMT is also believed to be more advantageous than response cost in that its benefits are more likely to maintain and generalise (see Knight, Rutterford, Alderman,

**Table 1. Summary of the five stages of self-monitoring training.**

(\*Differential Reinforcement of Low rates of behaviour: see Alderman & Knight, 1997)

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Each session within which SMT is conducted lasts the same time (for example, 20 minutes) and takes place within the context of some secondary task (for example, an orientation session). The frequency with which target behaviours occur are usually recorded by both patient and therapist using hand-held mechanical tally counters.

Stage 1	<i>Baseline</i> Therapist maintains covert frequency count of target behaviour.
Stage 2	<i>Spontaneous Self-monitoring</i> Patient asked at beginning of session to maintain frequency count of target behaviour; therapist also maintains covert count. At end of session therapist shares and compares their recording with that of the patient.
Stage 3	<i>Prompted Self-monitoring</i> As stage 2: however, when the therapist observes that the patient does not make a record of a target behaviour immediately after they have engaged in it, they are given one clear verbal prompt that they should do so.
Stage 4	<i>Independent Self-monitoring and Accuracy Reward</i> As stage 2 (therapist prompts are now withdrawn). Reinforcer available to patient dependent on the accuracy with which they have self-recorded the target behaviour (for example, if within 50% of that made by the therapist).
Stage 5	<i>Independent Self-monitoring and DRL*</i> As stage 2 with the addition of a DRL intervention. Reinforcement is now available only if frequency of the target behaviour (as determined by therapist recording) has not exceeded a specified target.

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& Swan, 2002, regarding a further example of use of SMT ). Table 1 outlines in brief what is entailed in each of the five stages of SMT.

The potential success of using treatment programmes which provide consistent feedback to patients immediately contingent upon behaviour disorders secondary to poor monitoring is well illustrated by the case of FO. FO was a 27 year old male who sustained very severe brain damage through viral infection. He presented with a wide range of behaviour disorders which prevented him exploiting his rehabilitation potential in all but a specialised neurobehavioural service. Neuropsychological examination reflected memory and executive difficulties: problems with the ability to monitor both his own behaviour and cues within the environment were especially highlighted. Behavioural assessment suggested the latter played a key role in the maintenance of the problems with behaviour he showed (see Alderman, 2002, for details of this). Accordingly, two interventions were successfully employed which aimed to reduce the frequency of behaviour disorder through enhancing FO's monitor-

ing skills. First, response cost was employed for the purpose of decreasing the rate of occurrence of a number of bizarre behaviours. Frequency counts made during the course of a week prior to intervention clearly convey the detrimental impact these behaviours were having on his rehabilitation: hip thrusting (2050); intermittent use of a bizarre gait pattern (769); and body patting/rubbing (77). Use of response cost proved highly successful (see Alderman, in 2002).

Second, SMT was used in an attempt to reduce the frequency of self-initiated verbal output evident in structured rehabilitation activities. This was pretty much constant and served to distract both FO and others, thereby interfering with skill acquisition. It proved unresponsive to a range of reinforcement and other behaviour modification interventions. As both behavioural and neuropsychological assessment had highlighted the role of poor monitoring, it was hypothesised that impairment of this important cognitive skill accounted for both the maintenance of this problem and FO's poor response to differential reinforcement. Consequently, an attempt was made to enhance monitoring skills using SMT. FO was exposed to stages 1–4 of this as described by Alderman, Fry and Youngson (1995). Training further highlighted the magnitude of FO's monitoring difficulties: initially, he underestimated the frequency with which he initiated verbal output by as much as 161 times within a 15 minute period (average discrepancy = 84.4). By stage 4 of training, his ability to self-monitor this aspect of his behaviour had significantly improved (median discrepancy between FO's recording of initiated verbal output and that of staff = 0). Stages 1–4 of SMT are directly concerned with improving self-monitoring skills; stage 5 then attempts to successfully use these skills to reduce the target behaviour using a differential reinforcement of low rates of behaviour (DRL) programme. Equipped with new skills, this stage of training was carried out within other rehabilitation sessions from which he had previously been excluded because of the disruption he caused. Figure 3 demonstrates the success achieved.

It can clearly be seen that during the pre-treatment baseline period (in which the target behaviour was given as little social attention as possible) the frequency of FO's self-initiated verbal output was increasing. Following training of monitoring skills in separate sessions, stage 5 of SMT was carried out in-situ in a range of other rehabilitation sessions. Figure 3 demonstrates that the upward trend in this behaviour was reversed and its frequency significantly reduced. Stage 5 was stopped after FO had participated in 186 such sessions (each an hour in duration). Follow-up three months after SMT had been withdrawn confirmed that the frequency of self-initiated verbal output remained low and the improvement seen during training had maintained.

The net effects of using both response cost and SMT were that FO was able to successfully participate in the wider rehabilitation programme. Through this he acquired sufficient behavioural controls and new skills to enable him to be discharged to a smaller, less structured unit for long-term placement which otherwise his behaviour would have denied him.



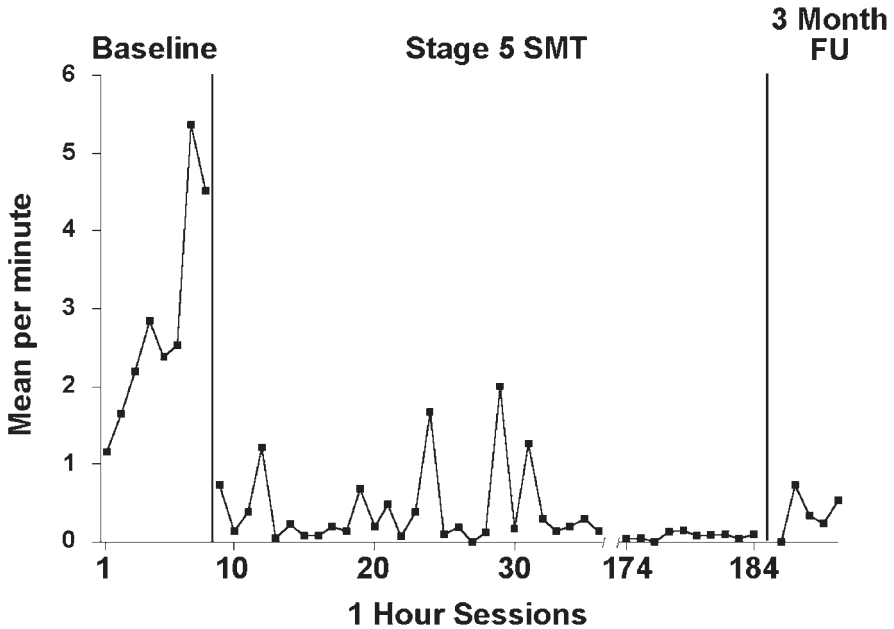


Fig. 3. Reduction in the frequency of self-initiated verbal output made by FO during rehabilitation sessions using SMT. Note that stages 1-4 of SMT were conducted in specific daily sessions for this purpose after data shown in the baseline stage were collected. Increased inhibition of verbal output had maintained relative to baseline three months after SMT had been withdrawn.

### Concluding Remarks

In this chapter a very brief review of a range of treatment options available for the management of behaviour disorders characteristic of people with acquired brain injury has been attempted. Given the complexity of the population and the reasons underlying why behaviour disorders arise and are maintained, little will have been achieved other than to equip the reader with all but the minimum of knowledge regarding the issues touched upon here.

Whilst a rich variety of different types of treatment, arising from a number of diverse theoretical and applied frameworks have been put forward as options, interventions arising from the neurobehavioural paradigm have been especially highlighted. In part, this reflects the authors own clinical training and experience. However, this is also because many people referred for treatment because of behavioural problems will be excluded from participation in other types of programme. This may be because they lack the necessary cognitive skills to take part in cognitive and other verbal psychotherapies, or because they do not have the necessary insight, awareness of deficit, or

motivation to undertake the active role required. However, probably the most common reason is that people are excluded from such programmes because they are behaviourally disturbed. Whilst medicine has much to offer, shortage of sufficiently trained and experienced specialised practitioners, and the relative lack of good empirical evidence regarding different pharmacological interventions, limits this at present. However, as Wood and Worthington (2001a) have argued, lack of homogeneity within the acquired neurological population and the multivariate nature as to reasons underlying behaviour disorders, renders a purely medical approach to the problem inappropriate.

The neurobehavioural paradigm can be successfully applied partly because it integrates medical, psychological and cognitive approaches under one theoretical umbrella. In addition, cognitive impairment, lack of insight and awareness, poor motivation, and severity of behavioural disturbance do not necessarily lead to exclusion. On the contrary, neurorehabilitation programmes lend themselves well to the challenges imposed by the very factors that prevent access to more traditional therapeutic orientations. In part, this is because the structures within neurobehavioural programmes act in such a way that cognitive problems that can drive and maintain behaviour disorders are circumvented. However, equally important is the influence they exert on the rehabilitation environment itself in that provision of programmed feedback systems through behaviour modification interventions changes the behaviour of those people working with a patient. The tremendous impact this can have on behaviour and functioning cannot be overstated.

Whilst neurobehavioural rehabilitation has much to offer in the treatment of this very challenging clinical population, it is not without its critics, both on ethical and practical grounds. For example, the demands of the neurobehavioural approach are such that although there are exceptions (for example, see Wood, 1988; Goll & Hawley, 1989; Watson, Rutterford, Shortland, Williamson, & Alderman, 2001) it requires establishment of specialised units because of the amount of resources and specialised knowledge required (Alderman, 2001). Behaviour modification interventions, a key component in neurobehavioural rehabilitation, have also been criticised in that they fail to generalise to other environments (McGlynn, 1990). However, it may be the case that when cognitive impairment is the major contributing factor to maintenance of behaviour disorder, the highly structured environment acts as a prosthetic in that it facilitates the effective delivery of feedback through operation of behaviour modification interventions. When people are discharged and this prosthetic is no longer available, problems with monitoring return and behaviour deteriorates. It may be that when people are no longer within the specialised environment of the neurobehavioural unit, contingencies change in such a way that behaviour disorders are re-reinforced (Alderman, 2001). It may also be that when cognitive systems are severely damaged, people will be dependent for life on systems that are placed around them which circumvent the difficulties arising from their breakdown. If so, generalisation is an unrealistic expectation; instead, finding the least intrusive level

of support that enables the best quality of life becomes the goal rather than preoccupation with the idealistic aim of completely removing all structure, including behavioural programmes. When this proves to be the case, those environmental modifications necessary to achieve this aim must be implemented and maintained in order to support appropriate behaviour.

It is a reassuring reality that medical and rehabilitation expertise will continue to evolve. In the future it may be that progress in areas such as intracerebral and fetal brain cell implantation will have radical consequences for outcome after neurological insult (for example, see Elsayed, Hogan, Shaw, & Castro, 1996; Barami, Hao, Lotoczky, Diaz, & Lyman, 2001), and the blight of behaviour disorder becomes a thing of the past. In the meantime, the neurobehavioural paradigm gives clinicians a practical framework within which to work, and patients those opportunities required to maximise independence and ensure optimum quality of life.

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# Chapter 10

## REHABILITATION FOR PEOPLE WITH DEMENTIA

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Neuropsychological rehabilitation is just as relevant for people with progressive disorders affecting cognitive functioning as it is for people with non-progressive brain injury. If we define the goal of rehabilitation as enabling people to ‘achieve an optimal level of physical, psychological and social functioning’, given any limitations imposed by injury or illness (McLellan, 1991 p. 785), then it is clear that this is an appropriate goal at any stage of a progressive disorder. Improving well-being implies an enhancement in quality of life, not only for the person with dementia but also for his or her family or caregivers. Indeed, it has been suggested that the broad concept of rehabilitation provides a suitable unifying framework for conceptualising intervention in dementia (Cohen & Eisdorfer, 1986), and within this broad framework an understanding of neuropsychological functioning is an essential element in addressing the needs of the person and his or her caregivers.

In this chapter, following a brief overview of dementia, I will focus on four key questions:

- Why is neuropsychological rehabilitation relevant for people with dementia?
- Can people with dementia benefit from neuropsychological rehabilitation?
- What is the role of neuropsychological rehabilitation in clinical practice?
- The way forward: where do we go from here?



## **Dementia: a Brief Overview**

Dementia has been defined as ‘a clinical syndrome characterised by loss of function in multiple cognitive abilities in an individual with previously normal (or at least higher) intellectual abilities and occurring in clear consciousness’ (Whitehouse, Lerner, & Hedera, 1993). By implication, this decline in cognitive function will also impact on functioning in various domains of daily living and social interaction. There are numerous possible causes of dementia, but the most frequent dementia diagnosis is that of Alzheimer’s disease (Morris, 1996a; 1996b; McKhann et al., 1984), followed by vascular dementia or a mixture of the two types. Less frequently diagnosed sub-types of dementia include dementia with Lewy bodies and the frontal and temporal (semantic) variants of frontotemporal dementia; these have different neuropsychological profiles, particularly in the earlier stages, and consequently somewhat different implications for rehabilitation interventions (Brandt & Rich, 1995; Hodges et al., 1999; Graham, Patterson, Pratt, & Hodges, 2001). The main focus here will be on interventions for people with Alzheimer’s disease, vascular dementia or mixed dementia, reflecting the current evidence-base. Much of the work described will also be relevant for people with mild cognitive impairment or age-associated memory difficulties.

Even within a single sub-type of dementia such as Alzheimer’s disease, there is considerable heterogeneity in both initial presentation (Neary et al., 1986) and course (Wild & Kaye, 1998; Storandt, Morris, Rubin, Coben, & Berg, 1992). The rate of progression of dementia is very variable, with some individuals staying in the mild stages for a number of years and others progressing more rapidly to severe impairment (e.g. Bowen et al., 1997). Some individuals develop mild cognitive impairment, with significant difficulties in the domain of episodic memory, but do not show any progression to dementia. Therefore, needs will differ according to both the neuropsychological profile and the extent to which the cognitive impairments have progressed in severity. Individual assessment, formulation and goal planning is always necessary, and a diagnostic or staging label does not suffice as a basis for developing rehabilitation plans.

## **Why is Neuropsychological Rehabilitation Relevant for People with Dementia?**

In recent years a quiet revolution has been taking place in dementia care, and this has brought to the fore the concepts of personhood and person-centred care (Kitwood, 1997). The perspective of the person with dementia, hitherto largely neglected (Cotrell & Schulz, 1993), is now being explored and valued (Sabat, 2001; Allan, 2001; Harris, 2002) alongside that of the family member or caregiver. Psychosocial and social constructionist models of dementia (Sabat, Wiggs, & Pinizzotto, 1984; Kitwood, 1997) highlight the importance

of the unique set of life experiences and coping strategies that each individual brings to the challenge of living with dementia, and the impact of the social environment on the expression and course of neurological impairment. Social and psychological factors are understood to interact with the effects of neurological impairment in a dialectical process, so that a person surrounded by a 'malignant social psychology' is likely to show 'excess disability' (Reifler & Larson, 1990) and appear more disabled than the extent of any brain pathology would indicate ought to be the case. Reducing excess disability is therefore an important target for intervention. Rehabilitation has an important role to play in tackling excess disability and enhancing well-being and quality of life for the person with dementia and his or her family. Further, it has been argued that selfhood should not be thought of as lost in dementia (Sabat, 1995), and rehabilitation may help to maintain both sense of self for the person with dementia and the perception of selfhood by others (Romero & Eder, 1992).

The context in which rehabilitation occurs is therefore crucial. In developing a model for neuropsychological rehabilitation in dementia a range of factors need to be taken into account above and beyond the person's neuropsychological profile. I have argued elsewhere (Clare, 2000) that neuropsychological rehabilitation in dementia requires a psychotherapeutic framework, equivalent to the 'holistic' approach taken in brain injury rehabilitation by Prigatano (1999). It is essential to acknowledge the person's emotional responses and coping strategies, and to work with these (Clare, 2002). Equally, rehabilitation in dementia requires a systemic perspective, in which the person and the impact of dementia can be viewed in the context of the person's network of support and care. In many cases, caregivers will be essential allies if the rehabilitation process is to be effective. It is also vital to consider that dementia is typically – although not always – a problem of later life. Rehabilitation for older people with dementia should not be undertaken without an understanding of ageing and its psychological and social implications. Finally, it is necessary to be sensitive to differences in the way dementia is perceived across diverse cultural and religious groups, and to respect values and expectations that may diverge from the way in which dementia is typically viewed by western health professionals.

The essentially collaborative and individually-targeted nature of rehabilitation means that it sits easily within this contextual framework. In addition, there is a strong rationale for the specific relevance of neuropsychological rehabilitation for people with at least some forms of dementia. This derives from evidence regarding the neuropsychology and neuroanatomy of cognitive impairments, and the capacity of the person with dementia for new learning.

### Learning and Relearning: Possibilities for Intervention

Experimental studies of learning confirm that learning is possible in people with dementia. Both classical and operant conditioning of responses has been demonstrated (Camp et al., 1993; Burgess, Wearden, Cox, & Rae, 1992), as has retention of verbal information (Little, Volans, Hemsley, & Levy, 1986). However, explicit learning will be seen only where the conditions are favourable; Bäckman (1992) argues that appropriate support for memory must be provided both at encoding and at retrieval (termed 'dual cognitive support'), and notes that the level of support required will increase as the severity of dementia increases. A number of experimental studies demonstrate beneficial effects of different types of cognitive support. For example, memory performance is facilitated when multiple sensory modalities are involved at encoding (Karlsson et al., 1989) or where participants physically enact the target task at encoding (Bird & Kinsella, 1996). Similarly, in accordance with the encoding-specificity principle, provision of retrieval cues that are compatible with conditions at encoding assists recall (Herlitz & Viitanen, 1991); an example would be where a semantic orienting task is used at encoding (e.g. categorising 'apple' as 'fruit') followed by provision of category cues at retrieval (e.g. 'it's a kind of fruit') (Lipinska & Bäckman, 1997; Bird & Luszcz, 1991; Bird & Luszcz, 1993). Results presented by Lipinska and colleagues (Lipinska, Bäckman, Mantyla, & Viitanen, 1994) indicate that participants perform better with self-generated than with experimenter-provided cues. Perlmutter and Monty (1989) emphasise that personalising a task by allowing the participant to make choices about it increases perceived control and motivation, and consequently is likely to benefit performance.

A number of studies, then, demonstrate that elaboration and effortful processing can improve memory performance. At the same time, this needs to be balanced with the goal of reducing or eliminating errors during the learning process (Komatsu, Mimura, Kato, Wakamatsu, & Kashima, 2000), as the principle of errorless learning has also been shown to be useful in improving memory performance in early-stage Alzheimer's (Clare, Wilson, Breen, & Hodges, 1999; Clare et al., 2000; Clare, Wilson, Carter, Hodges, & Adams, 2001).

This growing body of evidence about the parameters that can help to facilitate successful learning or relearning for people with dementia provides important empirical support for the development of clinical rehabilitation practice. Before considering how neuropsychological rehabilitation can best be put into practice in dementia care, however, it is important to understand something of the history of psychological interventions in dementia, and to consider how neuropsychological rehabilitation relates to other approaches.

## Relationship of Neuropsychological Rehabilitation to Other Psychological Interventions

One of the earliest approaches to psychological intervention was the adaptation of reality orientation (RO) for use with people who have dementia (Woods, 1992). This represented a major breakthrough as it demonstrated the possibility that psychological approaches had something to offer. The concept of reality orientation attained widespread acceptance in long-term care settings, but its implementation was not always of a high standard, with interventions sometimes applied in a rather insensitive manner. Subsequently the approach was heavily criticised for overlooking the emotional needs of the person with dementia, and alternative methods emerged in the form of practices such as validation therapy (Feil, 1992). More recent work has demonstrated that interventions based on the principles of reality orientation can have positive effects on cognition and behaviour in people with dementia (Spector, Orrell, Davies, & Woods, 1998), and has attempted to 'rehabilitate' reality orientation through the development of group interventions for people with severe dementia in residential settings (Spector, Orrell, Davies, & Woods, 2001). Similarly, evaluation of 'cognitive stimulation' group interventions for people with dementia shows positive results (Breuil et al., 1994; Vidal, Lavielle-Letan, Fleury, & de Rotrou, 1998; de Rotrou et al., 1999). Because interventions based on RO or cognitive stimulation typically incorporate a number of elements, however, it remains difficult to determine the relative contribution of different components to the positive outcomes observed, or to derive a theoretical understanding of the mechanisms by which the interventions exert their positive effects.

In the meantime, the reality orientation tradition was succeeded by a related body of work focused on 'memory training' or 'memory retraining' for people with dementia. Memory training is similar to cognitive stimulation approaches, in that the goals set and tasks used are general rather than individually-designed, but differs in that there is a more specific focus on one or more aspects of memory functioning. Memory training has been criticised in turn, firstly on the basis that gains are limited and maintenance is poor, and secondly because it is said to have negative effects on mood and well-being for people with dementia or their caregivers (Rabins, 1996; Small et al., 1997). It should be noted that these criticisms were made in the context of a strong emphasis on the value of pharmacological treatments, although the effectiveness of the pharmacological treatments currently available for people with dementia is modest (Royal College of Psychiatrists, 1997). Other reviews, in contrast, have argued that this kind of approach may be beneficial; for example, Gatz and colleagues (Gatz et al., 1998) classify 'memory retraining' as a 'probably efficacious' form of intervention which warrants more research. One reason for this divergence of views may be that increased understanding of the conditions required in order for people with dementia to learn effectively has resulted in more appropriate intervention protocols,

as indicated by Bäckman (1992). There is a continuing interest in ‘memory training’ for people with dementia, with a variety of methods in evidence. For example, a recent randomised controlled trial (Davis, Massman, & Doody, 2001) reported gains in performance on targeted areas, but no generalised improvements. There is also a growing interest in computerised cognitive training for people with dementia (e.g. Hofmann, Hock, Kuhler, & Muller-Spahn, 1996).

In the last few years, the focus has shifted once again and researchers have begun to apply the concepts of cognitive or neuropsychological rehabilitation to dementia care (Clare & Woods, 2001). This strand of research draws extensively on the concept and practice of neuropsychological rehabilitation with brain-injured people. Interventions are devised on the basis of theoretical principles derived from neuropsychology, cognitive psychology and learning theory, and are targeted specifically to the individual on the basis of the person’s neuropsychological profile. In addition, following Prigatano’s holistic model of neuropsychological rehabilitation (Prigatano, 1999), they should endeavour to take into account the person’s emotional and practical needs and social context, drawing on perspectives from psychotherapy and systems theory.

It is necessary to distinguish the work carried out in the tradition of reality orientation, encompassing memory training and cognitive stimulation, from attempts at implementing neuropsychological or cognitive rehabilitation. At the same time, it is important to acknowledge that there are some shared elements and that knowledge or evidence derived from one can sometimes be applicable to the other. The review that follows will focus primarily on neuropsychological rehabilitation rather than on memory training and cognitive stimulation.

### **What is the role of neuropsychological rehabilitation in clinical practice?**

Neuropsychological rehabilitation can provide both a general framework for intervention and a means of tackling specific issues. As a general framework, it allows for a biopsychosocial formulation within which an understanding and acknowledgement of the person’s cognitive impairments is central. This means, for example, that explanations and advice can be provided to the person and his or her carers, helping them to make sense of some of their difficult and distressing experiences. Specific difficulties can be addressed using methods devised for people with dementia or adapted from those reported to be useful for people with brain injury. The way in which these two aspects of neuropsychological rehabilitation are implemented in practice varies according to the needs of the individual, so that the emphasis is likely to be quite different in early- and later-stage dementia.

### **Interventions for people with early stage dementia**

In the early stages of dementia, the main focus for intervention is likely to be everyday problems arising from difficulties with long-term episodic memory

or executive function. The discussion here will concentrate on memory functioning.

The most appropriate approach will be determined through a careful assessment of the neuropsychological profile and the person's everyday functioning. This assessment should be made in the context of a broader evaluation encompassing the person's past experience and preferred ways of coping, psychological well-being, awareness of difficulties and readiness to address them, and any other possible blocks to successful outcome that may need to be overcome before the intervention begins. The way in which the person perceives his or her difficulties is likely to be particularly important here, as it has been demonstrated that expressed awareness of memory difficulties and their impact is associated with better outcome in cognitive rehabilitation interventions in the early stages of dementia (Clare, 2000; 2001; Koltai, Welsh-Bohmer, & Schmechel, 2001). The person's support systems also need to be considered, along with the willingness of family members or friends to be involved. The assessment should lead to a collaborative exercise in setting goals for intervention, in which the person with dementia plays a full part. Interventions are most likely to be effective when they address issues that are important to the person and family, and relevant to everyday life. Where the goals of the person with dementia and the family are markedly discrepant, careful and sensitive negotiation is required in order to try to reach a consensus that is acceptable to both parties, acknowledging the different emotional and practical needs of all involved.

Some people with early-stage dementia may already be engaging in self-help activities, for example those provided in books about improving memory. This can be facilitated through provision of appropriate material or suggestions. Information about memory problems and how these may be tackled (e.g. Clare & Wilson, 1997) can be helpful for the individual and for family members, empowering them to identify their own solutions to specific issues or problems.

Consistent with memory rehabilitation in brain injury, specific interventions for memory difficulties in early-stage dementia take two main forms (Franzen & Haut, 1991). Firstly, assistance can be given with learning or relearning information and skills, in order to enhance residual episodic or procedural memory performance. Secondly, strategies can be developed that enable the person to compensate for aspects of memory that are impaired and functioning poorly.

### **Facilitating Residual Memory Functioning**

Interventions aimed at facilitating residual memory performance need to incorporate the twin guiding principles of effortfulness and errorlessness in the learning process. This can be achieved in practice by using one or more of a number of methods.

Expanding rehearsal, or spaced retrieval, has been used extensively with people who have dementia. The act of retrieving an item of information is a powerful aid to subsequent retention under any conditions. In addition, the temporal sequencing of retrieval attempts affects the extent to which benefits are observed as a result of retrieval practice, with maximum benefit occurring when test trials are spaced at gradually expanding intervals (Landauer & Bjork, 1978). Experimental studies have demonstrated that expanding rehearsal can aid new learning in people with memory disorders following brain injury (Schacter, Rich, & Stamp, 1985). The method has been adapted for use in Alzheimer's disease (Camp, 1989; Camp, Bird, & Cherry, 2000), with very short retrieval intervals – typically the first interval is 15 or 30 seconds long, and the length is repeatedly doubled. A series of studies has demonstrated clear benefits in teaching face-name associations, object naming (Abrahams & Camp, 1993; Moffat, 1989), memory for object location, and prospective memory assignments (Camp, 1989). A further advantage of the expanding rehearsal method is that it can easily be used by caregivers, with back-up support from professionals as required (Camp et al., 2000; McKittrick & Camp, 1993). Expanding rehearsal does not rule out the possibility of errors occurring, but in practice, because the initial recall intervals are so short, errors are rare. It therefore approximates well to an errorless learning procedure, while also requiring the effort of retrieving the information.

Another method that can be applied is the use of cueing (Glisky, Schacter, & Tulving, 1986; Thoene & Glisky, 1995). This can take various forms. In one version, termed 'vanishing cues' or 'decreasing assistance' (Riley & Heaton, 2000), the number of cues is gradually reduced. When learning a name, for example, this would mean that at each presentation an additional letter was removed from the end of the name. Another version, termed 'forward cueing' or 'increasing assistance' begins by offering just the initial letter and adds a letter on each subsequent presentation until the word or name is correctly given, after which the cues may be faded again as in the vanishing cues method. Cueing methods were used by Clare and colleagues (Clare et al., 2000), and were directly compared in one single case study, where forward cueing was found to be more effective than vanishing cues.

Strategies such as visual imagery mnemonics, chunking of information, the method of loci, the story method and initial letter cueing have been described in relation to the cognitive rehabilitation of memory disorders following brain injury, although some of these strategies may prove too difficult or demanding for many brain injured patients (Wilson, 1995; Moffat, 1992). There is limited evidence for the success of strategies of this kind when used with people who have Alzheimer's disease, who are likely to have difficulty both in learning an explicit mnemonic strategy and in remembering to use it appropriately (Woods, 1996; Bäckman, 1992). In some cases, however, simple strategies may be remembered and implemented. It is important to distinguish between the use of mnemonic strategies as a way of facilitating learning in specific tasks and the aim of developing spontaneous and independent use of

the strategy in a wider sphere. The former is often a more appropriate goal in memory rehabilitation, and clinicians can draw on a number of strategies to facilitate learning for the person with dementia.

One report of successful use of a mnemonic strategy is provided by Hill and colleagues (Hill, Evankovich, Sheikh, & Yesavage, 1987). They describe a single case experiment in which a 66 year old man with Alzheimer's was taught to use visual imagery to extend his retention interval for names associated with photographs of faces. In an attempt to replicate the findings in a case series of eight participants, which included seven people with Alzheimer's (Bäckman, Josephsson, Herlitz, Stigsdotter, & Viitanen, 1991), only one of the participants with Alzheimer's showed training gains similar to those demonstrated by Hill et al. (1987). The remaining patients failed to benefit from training. The authors conclude that the generalisability of the approach appears limited, but comment that there might be a subgroup of people with Alzheimer's disease who respond well to this form of memory training.

This finding was supported by the results of a single case study (Clare et al., 1999) which demonstrated effective relearning of names that the participant wished to know. These were names of members of his club, and relearning them helped him to continue his engagement in this social activity. The names were relearnt from photographs, using a combination of mnemonic, vanishing cues and expanding rehearsal techniques which was intended to provide an optimal combination of errorless and effortful processes. One name was taught per session. The procedure began with a discussion leading to choice of a suitable mnemonic, linking some feature of the person's appearance with the sound of their name ('Caroline with the curly fringe'). Next, a vanishing cues process was used to encourage the participant to retrieve the name with less and less assistance; initially the name was presented minus the final letter for him to complete, and a further letter was removed on each presentation until he retrieved the name with no cues at all. After this, expanding rehearsal was used to increase the time intervals between successful attempts at retrieval, with the interval starting at 30 seconds and expanding each time the name was recalled, up to a maximum of 10 minutes. Between sessions, the participant practised the names following a carefully-devised practice procedure that he was able to undertake alone. Once all the names had been trained, generalisation to the club setting was undertaken. The participant was asked, at the club, to match each photograph to the relevant person and say the person's name. Using these methods, the participant was able to improve his recall of the names from 20% at initial baseline to 98% following the intervention. In follow up sessions conducted one, three, six and nine months after the intervention, the participant scored 100% on each occasion. He continued to practise the names during this follow up period. A further study evaluated forgetting in the absence of home practice over the subsequent two years and found that performance remained well above initial baseline levels three years after the end of the intervention (Clare et al., 2001a). He continued to enjoy attending his club and participating in activities there.



A similar approach taken with other participants again targeted goals identified by the participants, but explored the feasibility of different techniques in isolation (Clare et al., 2000; Clare et al., 2001a). Good results were obtained for mnemonic, expanding rehearsal and forward cueing strategies, with vanishing cues proving less effective, as noted above. This is in accordance with the findings of Thoene & Glisky (1995), which showed that visual imagery was a more effective strategy than vanishing cues for the acquisition of face-name associations in memory-impaired participants (the sample included one man with dementia). Thoene & Glisky argued that this was because the mnemonic strategy was able to optimise the use of residual explicit memory, in addition to encouraging deep levels of processing and the development of associations with existing knowledge.

The ability to perform everyday skills is particularly important in maintaining independence. Zanetti and colleagues (Zanetti et al., 2001; Zanetti et al., 1997; Zanetti, Magni, Binetti, Bianchetti, & Trabucchi, 1994) used a training method based on preserved procedural memory for rehabilitation of ADL skills in people with mild-to-moderate Alzheimer's. Training involved comprehensive prompting, with subsequent fading out of prompts. Preliminary results suggested this approach could be effective and produced some generalisation of improvements to untrained tasks. Another study (Josephsson et al., 1993) used individualised training programmes for activities of daily living and showed improvements in three out of four participants, although only one maintained the gains two months later. An important feature of this study was the selection of tasks which were part of the patient's usual routine and which the patient was motivated to carry out; the value of considering motivational factors in designing interventions was emphasised.

### **Providing External Support for Remembering**

Providing external support for remembering in the form of compensatory memory aids can help to reduce the demands on memory. The selection and introduction of external memory aids requires careful consideration, and aids should be targeted as specifically as possible, rather than simply providing a generalised reminder, the reason for which may be unclear to the person with dementia (Woods, 1996). Many people who develop dementia will already be used to relying on external memory aids such as diaries and lists, and it is helpful to build on this and try to ensure that these aids are used to maximum effectiveness; for example, a diary with unstructured pages may be replaced by one that has times of day listed. People with memory impairments are unlikely to start to use new memory aids spontaneously and usually need training in their use, for example by means of prompting and fading of cues, or expanding rehearsal. Effective use of an errorless prompting and fading method to help a woman with dementia use a calendar to find out what day

it was instead of repeatedly questioning her husband was reported by Clare and colleagues (Clare et al., 2000). This was a relatively simple intervention which consisted of ensuring that a suitable day-per-view calendar was placed in a prominent position and then supporting the participant's husband in carrying out a schedule of prompting in which he reminded her three times a day to look at the calendar and find out what day it was. This was intended to enable her to establish a habit of looking at the calendar. Once this habit was established, the prompts were gradually faded out. Using this method, the frequency with which the participant repetitively questioned her husband decreased significantly, and this decrease was maintained at follow up three and six months later. Both the participant and her husband were very pleased with this result and, interestingly, the gains from this simple intervention did appear to generalise to other situations as similar problem-solving strategies were spontaneously applied.

Developing technology offers increasing opportunities for identification of ingenious aids to remembering. In an early example (Kurlychek, 1983), a digital watch was set to beep every hour as a cue to prompt engagement in a predetermined activity. Use of technology is now being extended beyond the realm of specific memory aids by developing computer and video equipment to monitor and control the environment of the person with dementia in order to support independent functioning (Marshall, 1999).

### **Practical Implementation in Early-Stage Dementia**

In clinical practice with people who have early-stage dementia, the methods and techniques of neuropsychological rehabilitation have been implemented in a variety of ways. As well as individual interventions such as those described above, a number of centres have developed group programmes aimed at helping people with early-stage dementia to cope with memory difficulties (e.g. Koltai et al., 2001). Some programmes offer parallel sessions for participants with dementia and caregivers, while in others couples attend sessions together (e.g. Sandman, 1993). Group programmes typically incorporate information and education about memory and cognitive problems as well as identification of individual goals, introduction of suitable strategies or aids, and practice in their use. When they work well, groups provide an opportunity for members to support and encourage one another, and perhaps develop friendships and social contacts. However, some people with early-stage dementia may be reluctant to attend a group, preferring one-to-one sessions, and individual preferences should be respected. Elements of cognitive rehabilitation have been incorporated in broad-based community rehabilitation programmes which also incorporate aspects such as partnered volunteering (Arkin, 1996), and in psychosocial early intervention programmes (e.g. Moniz-Cook, Agar, Gibson, Win, & Wang, 1998).

### **Interventions for people with later stage dementia**

As dementia progresses, the focus of neuropsychological rehabilitation is likely to change to some extent. There is likely to be more emphasis on addressing behavioural issues and on enhancing well-being through maintaining interaction and engagement.

An understanding of the neuropsychological profile and the possibilities for new learning can be coupled with a behavioural approach that views behaviour as having a meaning or function rather than as a 'symptom'. This provides a framework for generating creative but highly practical solutions where cognitive impairments appear to play a part in producing 'problem' behaviour. This framework has been used, for example, to teach patients to associate a cue with an adaptive behaviour as a means of reducing behaviours that are regarded as problematic (Bird, 2001; Bird, 2000).

In some situations, rehabilitation of basic skills is an important focus. Camp and colleagues (Camp et al., 1997) describe the application of Montessori activities, designed to build skills in a developmental sequence in young children, to dementia care. An example here might be reinstating the ability to feed oneself with a spoon through a sequence of tasks starting with scooping beads with a large scoop, and progressing through scooping rice, sand and eventually liquids with gradually smaller scoops, and so on until a spoon can be used to spoon up soup.

A number of studies have demonstrated improvements resulting from the use of various external memory aids or equivalent environmental support for people with later stage dementia. In some cases these improvements have been maintained after the support has been withdrawn, while in other cases ongoing support has been required. Hanley (1986) trained in-patients with moderately advanced Alzheimer's to use a diary, reality orientation board or personal notebook to find out important information, although it is unclear to what extent the improvement was maintained. Bourgeois (1990) evaluated the effectiveness of memory wallets in enhancing conversational ability in a small sample of people with moderately advanced Alzheimer's, and reported significant improvements, with evidence of generalisation to novel utterances. Benefits were maintained at six-week follow up, and for three individuals benefits were retained after 30 months (Bourgeois, 1992). This finding has recently been replicated with people who have severe dementia (McPherson et al., 2001). As well as helping the memory-impaired person, memory wallets or memory books offer care staff a means of learning about, and engaging with, the person (Woods, Portnoy, Head, & Jones, 1992), and can be especially helpful at times of transition, such as the move into residential care. Romero and Wenz (2001) emphasise the importance of helping the person with dementia to maintain a sense of self, using materials such as memory books in a structured way to facilitate engagement with, and processing of, those aspects of self that are currently most salient for the individual. In this approach, too, memory books can become the focus for constructive interaction between the person with dementia and family members or carers.

Implementing cognitive rehabilitation in later-stage dementia requires particular attention to, and skill in, working with systems. Camp has taken an important lead in addressing practical issues regarding the implementation of rehabilitation interventions in long-term care settings (Camp, 2001), including issues of cultural and linguistic difference.

### **The way forward: where do we go from here?**

This chapter has shown that neuropsychological rehabilitation can be applied in the context of progressive disorders such as dementia with beneficial results. The approach is relevant for both earlier and later stages of dementia, but the focus differs according to the needs of the individual and his or her carers at any given point. Comprehensive recent reviews of the literature support the relevance of this kind of approach in dementia care (De Vreese, Neri, Fioravanti, Belloi, & Zanetti, 2001), suggesting that further research is warranted, and a systematic review is in preparation (Clare, Woods, Moniz-Cook, Spector, & Orrell, 2001b).

The application of neuropsychological rehabilitation for people with progressive disorders such as dementia is a relatively recent development, and there are a number of issues that future research will need to address. At a conceptual level it will be important to ensure that cognitive rehabilitation is clearly distinguished from related, but different, approaches such as reality orientation or memory training. At a practical level, it will be necessary to continue refining our knowledge of methods and techniques that may assist in achieving specific goals. Equally, it will be important to further develop the 'holistic' framework for cognitive rehabilitation with people who have progressive disorders, ensuring that emotional needs and responses are attended to, and that the person is considered in the context of his or her social system. It will be vital to identify more clearly the factors that indicate whether or not this kind of approach is likely to be suitable for a given individual at a given time, or whether some other form of support or intervention would be more appropriate. Finally, it will be necessary to situate neuropsychological rehabilitation within a coherent approach to supporting people with progressive disorders that reflects a genuinely biopsychosocial model and espouses the aims and values of person-centred care.

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# Chapter 11

## OUTCOME AND MANAGEMENT OF TRAUMATIC BRAIN INJURY IN CHILDHOOD: THE NEUROPSYCHOLOGIST'S CONTRIBUTION

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### **Introduction**

Childhood traumatic brain injury (TBI) is a frequent cause of acquired disability in childhood. While most such injuries are mild, with few sequelae, children sustaining more severe TBI may suffer permanent cognitive and behavioural impairment. Neuropsychological studies now consistently report residual problems in a range of domains, including information processing, attention, memory and learning, and executive abilities. These deficits may limit the child's ability to function effectively in day-to-day life, resulting in lags in the acquisition of skills and knowledge, with common difficulties noted in areas such as educational proficiency and social interactions. Secondary deficits may also emerge, relating to family stress and adjustment difficulties. Treatment and management of the head-injured child and family requires long-term involvement. As for adults, the aim is to understand

the cognitive and behavioural consequences of the child's injuries, how they impact on the child's day-to-day life, to liaise with teachers and rehabilitation workers, to design academic interventions and behaviour management programs, and to provide counseling with respect to adjustment issues for the child and family.

This chapter aims to review current knowledge with respect to recovery trajectories and residual sequelae following childhood TBI, and to discuss the nature and process of providing rehabilitation and management within the context of the child and family. While there is a large body of knowledge addressing these issues within the adult literature, as is evident from the various chapters in the current text, paediatric rehabilitation theory and practice has received much less attention. Many rehabilitation practices employed in adult TBI can be translated into work with children, however, there are important developmental issues, which need to be considered when designing intervention models in a paediatric context.

### **Epidemiology**

While epidemiological data on childhood TBI is scarce, findings from research in the U.S.A. has found that approximately 250 : 100,000 children suffer TBI each year. Of these, half will not seek medical attention, between 5 and 10 percent will suffer temporary and/or permanent neuropsychological impairment, and 5 to 10 percent will sustain fatal injuries (Goldstein & Levin, 1987). Examination of data specific to severe TBI shows that the mortality rate is approximately one third, with another third of children making a good recovery. The last third will exhibit residual disability (Michaud, Rivara, Grady, & Reay, 1992), and will benefit from ongoing management and rehabilitation.

The nature of childhood TBI varies with age. Infants are more likely to present due to falls or child abuse (Holloway, Bye, & Moran, 1994). The preschool stage is a high risk period, with the majority of injuries caused by falls and pedestrian accidents, consistent with increased mobility and lack of awareness of danger in this age group (Anderson, Morse et al., 1997; Lehr, 1990). Older children and adolescents tend to be victims of sporting, cycling or pedestrian accidents. Boys and girls are not equally at risk of injury. In preschool children, the male to female ratio is approximately 1.5 : 1 (Hayes & Jackson, 1989; Horowitz et. al., 1983), and by school-age males are more than twice as likely to suffer TBI (Kraus, 1995). The incidence of TBI increases in males through childhood and adolescence, with a contrasting decline for females over this period (Kraus, Fife, Ramstein, & Conroy, 1986).

TBI in childhood is more likely to occur on weekends, afternoons, and holidays, when children are involved in leisure pursuits or travelling to and from school, suggesting that many injuries may result from reckless behaviours, in poorly supervised environments (Chadwick, Rutter, Brown, Shaffer, & Traub, 1981b; Dalby & Obrzut, 1991). Some research has suggested that TBI is more common in socially disadvantaged families (Anderson, Morse, et

al., 1997; Brown, Chadwick, Shaffer, Rutter, & Traub, 1981; Klonoff, 1971; Rivara et al., 1993; Taylor et al., 1995) and in children with pre-existing learning and behavioural deficits (Asarnow, Satz, Light, Lewis, & Neumann, 1991; Brown et al., 1981; Craft, Shaw, & Cartlidge, 1972), however, recent research has failed to support such findings, arguing that children who sustain injury cannot be differentiated from the general population (Perrot, Taylor, & Montes, 1991; Prior, Kinsella, Sawyer, Bryan, & Anderson, 1994).

### **Pathophysiology**

Traumatic brain injury refers to a traumatic insult to the brain, usually due to a blow or wound to the head, and causing altered consciousness (Begali, 1992). TBI may be classified as penetrating (or open) head injury or closed head injury. Penetrating injuries account for approximately 10 percent of all childhood TBI. Primary cerebral pathology tends to be localized, while secondary damage may occur due to cerebral infection, swelling, bleeding, and raised intra-cranial pressure. Loss of consciousness is relatively uncommon, however neurologic deficits and post-traumatic epilepsy are frequently observed. Neurobehavioral sequelae tend to reflect the focal nature of the insult, and children often exhibit specific deficits consistent with the localization of the lesion, with other skills intact. Closed head injury refers to an insult where the skull is not penetrated, but rather the brain is shaken within the skull cavity, resulting in multiple injury sites, as well as diffuse axonal damage. The primary pathology includes contusion, or bruising, at point of impact of the blow and at other cerebral sites. Specific areas of the brain are particularly vulnerable to such damage, including the temporal lobes and basal frontal regions (Amacher, 1988; Courville, 1945). Secondary mechanisms, including neurochemical imbalance, haematoma, cerebral oedema, and raised intra-cranial pressure, may also occur, and are predictive of poor outcome in children (Baker, Moulton, MacMillan, & Sheddon, 1993; Quattrocchi, Prasad, Willits, & Wagner, 1991). Delayed complications may develop in the sub-acute stages post-injury, including communicating hydrocephalus, infections and there is an increased risk of epilepsy (Jennett, 1979; Pang, 1985; Ponsford, Sloan, & Snow, 1995; Raimondi & Hirschauer, 1984). Secondary injuries are more amenable to appropriate and timely medical interventions.

### **Mechanics, pathophysiology and age at insult**

A variety of mechanisms may be acting, depending upon the maturity of the CNS at the time of injury. The skull and brain develop through childhood, resulting in different injury consequences at different developmental stages. For example, during infancy neck muscles are relatively weak, and do not adequately support a proportionately large head, leading to less resistance to force of impact. Further, the infant and toddler possess a relatively thin skull, easily deformed by a direct blow, and resulting in more frequent skull fractures. Over one third of young children who sustain TBI will have skull

fractures. In contrast, contusions, lacerations and haematomas are rare (Berney, Favier, & Froidevaux, 1994; Choux, 1986; Sharma & Sharma, 1994). For older children and adolescents, intra-cranial mass lesions (haematomas, contusions) are more common, although not as common as in adult samples (Berger, Pitts, Lovely, Edwards, & Bartkowsky, 1985; Bruce, Schut, Bruno, Wood, & Sutton, 1978). Contrecoup lesions are relatively rare in all age groups (Berney et al., 1994).

The relative lack of myelination present in the immature CNS causes the cerebral hemispheres to be soft and pliable, allowing absorption of the force of impact best during infancy and early childhood. However, unmyelinated fibres are vulnerable to shearing effects, rendering the younger child at greater risk for diffuse axonal injury (Zimmerman & Bilaniuk, 1994). Reports suggest that TBI in children is more likely to result in diffuse cerebral swelling associated with vascular disruptions, with such pathology identified in one-third of the children examined by Bruce and colleagues (Bruce et al., 1978; Jennett et al., 1977). Outcomes are also different. Babies and toddlers lose consciousness less frequently than other age groups, however post-traumatic epilepsy is more common following early TBI (Berney et al., 1994; Raimondi & Hirschauer, 1984). The implications of these age-related differences are important, and suggest that pathophysiology, sequelae, recovery and outcome from childhood TBI cannot be readily extrapolated from adult findings.

### **Recovery from childhood TBI**

The consequences of brain insult sustained early in life have long been regarded as both qualitatively and quantitatively distinct from those documented in adulthood. Pathological conditions that would almost certainly lead to severe cognitive dysfunction in an adult, such as severe unilateral brain disease or localised cerebrovascular accidents, can have quite different consequences for children. Children with focal brain injuries, for example, may go on to acquire many age appropriate abilities, free from deficits observed following similar insults in adulthood (Taylor & Alden, 1997). In contrast, children sustaining generalized cerebral insult, such as TBI, have been shown to have slower recovery and poorer outcomes than adults with similar insults (Anderson & Moore, 1995; Anderson & Taylor, 1999; Gronwall, Wrightson, & McGinn, 1997; Taylor & Alden, 1997). The timing of CNS insult is particularly important within the immature brain. The consequences of trauma are dependent upon the developmental processes underway in the CNS at time of insult. It is generally accepted that early trauma has greater potential influence, impacting on the basic structure of the brain. Further, if insult occurs at a sensitive or critical developmental period specific structures or functions may be disrupted. As the child moves through later childhood and adolescence, the nature of impairment comes to resemble the adult picture more closely, reflecting the more mature CNS, and the associated reduction in plasticity/flexibility for recovery and reorganization.

There has been much research directed to establishing a fuller understanding of the recovery process, both in children and adults. Today, we are aware of many of the physiological consequences of brain insult and the underlying aspects of recovery. There is some dispute regarding the relative efficiency of these processes in the immature child's brain versus the fully developed adult brain, with some evidence for greater recovery following early brain insult. Brain damage results in a number of changes to brain tissue, depending on the type of damage incurred. Once a lesion occurs, be it vascular, traumatic, or aplastic, a number of degenerative events follow. These events involve the death and shrinkage of axons and associated neural structures, and the consequent actions of glial cells in repairing the damage as much as possible. While these degenerative processes may occur primarily in the acute phases post-injury, there is some evidence for ongoing degeneration and cumulative pathology in children following cerebral insult (Anderson et al., 2001; Anderson & Pentland, 1998; Paakko et al., 1992; Stein & Spettell, 1995). These mechanisms are well demonstrated in the case of 'Thomas', a toddler who sustained a severe traumatic brain injury, with focal frontal damage at age three years, as a result of motor vehicle accident. The brain scans illustrated in Figure 1 were obtained immediately post-injury, and ten years later. The initial CT scan (A) shows the extent of the initial injury, particularly within the right frontal lobe. MR scans conducted ten years later clearly demonstrate the original frontal lobe injury, and subcortical pathology (B). In addition, the right hemisphere now shows evidence of generalized atrophy (C), suggestive of abnormal development post-injury.



Fig. 1. Brain scans depicting pathology following severe TBI in a 3 year old child. (A) Acute CT scan, demonstrating extent of initial injury, which includes extensive right frontal damage. (B) and (C) MRI scans seven years post-injury, illustrating the initial pathology, as well as generalized right hemisphere atrophy.



Despite these various pathologic processes, some recovery of function is evident, both biologically and functionally. The proposed mechanisms of recovery can be grouped into two general classes – restitution theories and substitution theories (Kolb & Gibb, 1999; Laurence & Stein, 1978; Rothi & Horner, 1983). Restitution of function suggests that spontaneous physiological recovery occurs after brain damage. As damaged brain tissue heals, neural pathways are reactivated and so functions are restored. In contrast, substitution theories refer to restoration via transfer of functions from damaged brain tissue to healthy sites.

### **Restitution of function**

Following injury, an initial period of diaschisis occurs, a kind of general inertia which temporarily suppresses cerebral activity in regions far from injury site, because of widespread effects on processes such as blood flow, intracranial pressure, and neurotransmitter release. A number of additional recovery processes have been described. Regeneration, the process by which damaged neurons, axons, and terminals regrow and re-establish previous of neuronal connections, is the best documented, and has been demonstrated to be functionally advantageous in the peripheral nervous system, as well as in the CNS in animal studies (Kolb & Gibbs, 1999). The possibilities for such regrowth in the CNS in humans are less clear (Bjorkland & Stenevi, 1971; Finger & Stein, 1982; Rothi & Horner, 1983), although it has been demonstrated that the hippocampus and the olfactory bulb may generate neurons during adulthood (Altman & Bayer, 1993; Lois & Alvarez-Buylla, 1994). A second recovery process is that of sprouting, where intact neurons develop branches that occupy regions left empty by damaged neurons, thus re-innervating unoccupied areas. Sprouting occurs quite early in the recovery process, being complete in a matter of weeks, with some evidence that it leads to associated behavioural improvement (Kolb & Wishaw, 1996). Denervation supersensitivity (Cannon & Rosenbleuth, 1949) provides another possible mechanism for restoration of function, suggesting that, in areas of damage, post-synaptic processes may become supersensitive to neurotransmitter substance leaking from pre-lesion neurons, thus allowing activation of post-lesion pathways and restitution of normal functioning. Currently much research effort is focussed on application of pharmacological treatments which may enhance these physiological recovery processes.

The underlying mechanisms described in restitution theories may be argued to be equally efficacious in the mature and the developing brain, with no clear neurophysiological evidence to support better physiological recovery in the developing brain. Finger and Stein (1982), in their work on age and recovery, argue that anomalous neural growth following CNS insult, via restitution mechanisms, is more likely in the immature brain, due to the less rigid organisation present. One of the possible mechanisms acting in the recovery process, that of neural competition, provides a basis for this vulnerability position. This competition hypothesis predicts that, following cerebral

insult to the developing brain, there is a relocation of function, resulting in a decrease in synaptic sites available for mediating behaviours. The number of available synaptic sites is reduced, due to neuronal damage, and functional systems must work with a smaller number of synaptic connections, leading to reduced levels of functioning and the 'crowding' phenomenon. In the longer term, there remains less synaptic sites available to be taken up by new, emerging skills, leading to a picture of cumulative deficits and increasing problems with each developmental transition. (Aram & Eisele, 1994; Vargha-Khadem, Isaacs, Papaleoudi, Polkey, & Wilson, 1992).

### **Substitution of function**

Substitution theories, arguing for either anatomical reorganisation or functional adaptation, provide some evidence for plasticity, based on the assumption that the relatively unspecialised state of the immature CNS allows for transfer or re-routing of behavioural functions, with little evidence of impairment. The first group of substitution theories, those supporting anatomical reorganisation, have a long history. Theorists such as Munk (1881), Lashley (1929) and Luria (1963) put forward arguments that there are large areas of the brain that are 'unoccupied' or equipotential, with the capacity to subsume functions previously the responsibility of damaged tissue. The advantages of reorganization theories are generally thought to reduce with age, with young children having more 'uncommitted' brain tissue, leading to a greater potential for reorganization of function. Recent research showing that the most dramatic effect of cerebral insult may be as a result of pre-natal pathology is not consistent with these theories, suggesting that the relationship between age at injury and outcome may not be a linear one (Anderson, Northam, Hendy, & Wrennall, 2001; Duchowny et al., 1996; Jacobs, Anderson, & Harvey, 2001).

Behavioural compensation (Kolb & Wishaw, 1996; Rothi & Horner, 1983) is a second possible mechanism for substitution of function. This model suggests that the patient develops new strategies or routes for cognitive functions which were previously dependent on damaged tissue. For example, a child with right parietal damage, resulting in visual analytic impairment, may develop a range of verbal mediation strategies to implement when faced with visually-based tasks. Alternatively, external strategies may be employed to minimise residual deficits. A child with memory deficits may employ a diary or note system to compensate for poor learning. This perspective underpins the philosophy for rehabilitation intervention following CNS insult, aiming to maximise behavioural compensation and recovery by suggesting strategies and modifying the individual's environment to their needs. As with restitution theories, while this model suggests that it may be beneficial for children following brain insult, there is no indication that children will benefit more than do adults (Anderson, 1988; Anderson et al., 2001; Taylor & Alden, 1997).

### Neuropsychological consequences of paediatric TBI

Initially, research into paediatric TBI was directed towards identification of long-term sequelae from injuries. Today, this research is substantial and has established a knowledge base regarding the expectations for impairment following childhood TBI. In many respects, the characteristic impairments of childhood TBI mimic those seen in adults. However, where skills are undeveloped or immature at time of injury, research shows that these deficits may be more global and devastating for children.

### Domain specific outcome studies

#### *IQ*

Patterns of intellectual function following childhood TBI are now well documented (Anderson & Moore, 1995; Brown et al., 1981; Chadwick et al., 1981a; Chadwick et al., 1981b; Ewing-Cobbs et al., 1997; Ponsford et al., 1997; Prior et al., 1994; Rutter, Chadwick, & Shaffer, 1983). In the absence of any pre-injury problems, mild TBI has little impact on intellectual skills, even in the acute recovery phase. In contrast, lowered intellectual quotients are frequently reported following moderate and severe TBI, with lowest scores immediately post-injury, and continued improvement in the first 6 to 12 months post-injury, followed by a plateauing effect thereafter. Long-term follow-up does indicate that intellectual growth may be differentially impacted in children with severe injuries, and for those injured in the preschool years, with intellectual quotients reducing with time since injury in these groups

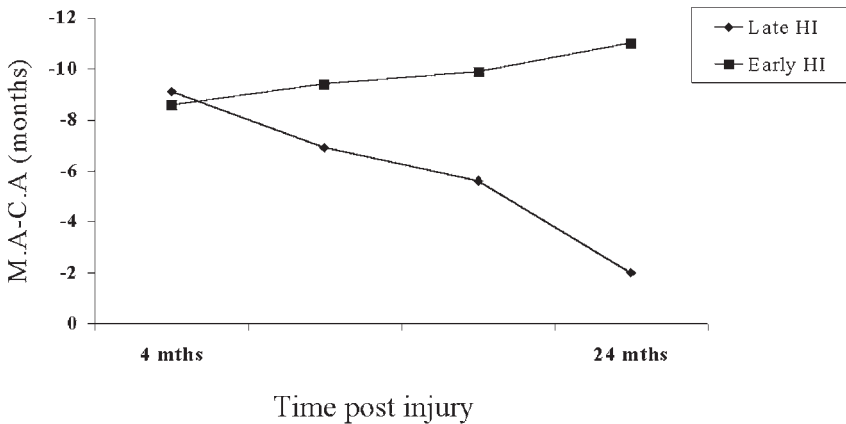


Fig. 2. Comparison of recovery trajectories for children injured before and after 7 years, represented by mental age (M.A) – chronological age (C.A) at 4 months and 24 months post head injury (HI). These findings suggest that earlier age at injury is related to poorer recovery post-injury.

(Anderson, Catroppa, Morse, Haritou, & Rosenfeld, 2000a; Jaffe, Polissar, Faye, & Liao, 1995). Figure 2 illustrates this finding, with expected results over time for older children, and those with mild to moderate injuries, but lack of recovery and/or development in the younger, severely injured children (Anderson & Moore, 1995). These results emphasize the importance of continued review and intervention in these children.

### *Language skills*

Aphasias are rare following childhood TBI. However, clinical reports and research findings describe functional communication impairments, including slowed speech, dysfluency, poor logical sequencing of ideas and word finding difficulties (Dennis, 1989; Morse et al., 2000). Residual deficits in expressive language skills and writing abilities have also been documented (Campbell & Dolloghan, 1990; Chapman, 1995; Chapman, Levin, Wanek, Weyrauch, & Kufera, 1998; Dennis & Barnes, 1990; Didus, Anderson, & Catroppa., 2000; Ewing-Cobbs, Brookshire, Fletcher, & Scott, 1998; Ewing-Cobbs, Levin, Eisenberg, & Fletcher, 1987; Ewing-Cobbs et al., 1997; Haritou et al., 1997), with recent studies reporting high level problems with functional communication skills (Turkstra, McDonald, & DePompei, 2001). Not surprisingly, greater deficits are associated with more severe injuries. Further, younger children appear to exhibit more global language difficulties, with additional deficiencies in language comprehension observed when injuries occur in the pre-school period (Anderson et al., 1997).

### *Visual and motor skills*

Debilitating motor and visual deficits (e.g. hemiparesis, impaired balance and steadiness, visual field defects) are common in the acute recovery stages, with rapid improvement occurring in the first few months post-injury, and systematic, but non-linear recovery up to 5 years post-injury (Thompson et al., 1994). It is only where children sustain very severe injuries, or injuries early in life, that significant motor deficits persist (Thompson et al., 1994). However, more subtle deficits, such as visuo-motor incoordination and reduced eye-hand co-ordination may be ongoing, and may occur even following relatively mild injury (Winogron, Knights, & Bawden, 1984). Such problems may limit the child's capacity for day-to-day activities such as sport and other physical pursuits and school-based skills including writing, drawing, and copying, with possible secondary implications for self-esteem, socialization, and academic development. Further, as speed requirements increase in daily life, children with significant TBI have been found to demonstrate increasing difficulties (Ewing-Cobbs, Miner, Fletcher, & Levin, 1989; Ewing-Cobbs et al., 1997).

### *Memory and learning*

Early studies identified memory function as the most likely cognitive domain to show impairment following childhood TBI (Levin & Eisenberg, 1979;

Levin Eisenberg, Wigg, & Kobayashi, 1982; Levin et al., 1988), with greatest deficits and poorest recovery occurring following severe TBI. More recent literature has extended these findings, documenting a consistent trend for children with severe TBI to exhibit generalized deficits in learning, storage and retrieval. For children with mild/moderate injuries, consequences are less clear, but indicate that these children perform closer to normal, with perhaps some mild retrieval problems evident (Anderson, Catroppa, Morse, Haritou, & Rosenfeld, 2000b; 2001; Catroppa & Anderson, in press; Jaffe et al., 1992, 1993, 1995; Levin et al., 1993; 1994; Ong, Chandran, Zaslmani, & Lye, 1999; Yeates, Blumstein, Patterson, & Delis, 1995). The implications of memory impairment in the child are likely to be substantial, given that the day-to-day tasks of childhood largely revolve around acquiring knowledge and learning and perfecting new skills. Memory problems may interfere with this process, resulting in a failure to develop at an age appropriate rate in domains such as education and social skills (Kinsella et al., 1997).

#### *Attention skills*

In contrast to the specific psychomotor slowing seen following moderate to severe adult TBI, children present with global attention deficits, with many of these problems persisting beyond the acute recovery stage (Bakker et al., 2000; Catroppa, Anderson, & Stargatt, 1999; Catroppa & Anderson, 1998; Anderson, Fenwick, Manly, & Robertson, 1998; Anderson & Pentland, 1998; Dennis et al., 1995; Ewing-Cobbs et al., 1998; Fenwick & Anderson, 1999; Kaufmann, Fletcher, Levin, Miner, & Ewing-Cobbs, 1993). These more generalized problems may reflect the relatively immature state of the attention system at the time of injury. The injury, and its associated pathology, may interrupt ongoing development, so that components of attention which usually emerge and differentiate post-injury, will fail to do so, leading to delayed or deficient performance, as for memory impairments. These problems may lead to increasing lags in the efficient acquisition of knowledge and skills, and a failure in the development and differentiation of cognitive and attentional abilities (Anderson & Moore, 1995; Dennis, Wilkinson, Koski, & Humphreys, 1995; Fletcher, Miner, & Ewing-Cobbs, 1987).

#### *Executive functions*

Deficits in executive functions, such as planning, reasoning, and self-regulation, are commonly reported in children who have suffered TBI, in keeping with the vulnerability of the pre-frontal regions in head trauma (Courville, 1945; Walsh, 1978). Despite these observations, there have been few formal studies of executive abilities, though some case descriptions do exist (Dennis, Barnes, Donnelly, Wilkinson, & Humphreys, 1996; Mateer & Williams, 1991, Passler, Isaac, & Hynd, 1985; Williams & Mateer, 1992). Neuropsychological studies have examined outcomes on traditional executive function tests, showing that performance is consistently related to injury severity, and with a trend for younger age at injury to be implicated in poorer perform-

ances (Anderson, Levin, & Jacobs, 2002; Garth, Anderson, & Wrennall, 1997; Levin et al., 1997; Levin et al., 1994; Pentland, Todd & Anderson, 1998). Children with TBI exhibit poorer reasoning skills, make more errors and use less efficient strategies, and provide ineffective or unworkable planning strategies as a result.

### Functional Outcome Following TBI in Childhood

Survivors of childhood TBI frequently make a good physical recovery, and appear outwardly normal. The expectations of their abilities and behaviours are often determined by this relatively healthy presentation, despite ongoing significant cognitive and behavioural disabilities (Johnson, 1992).

#### *Educational abilities*

Academic failure has been argued to be one of the most serious consequences of paediatric TBI (Catroppa & Anderson, 2000b; Goldstein & Levin, 1985; Greenspan & MacKenzie, 1994; Levin et al., 1987). Early studies identified a relationship between injury severity and educational achievement, with Klonoff and associates (Klonoff et al., 1977) reporting that one quarter of their sample required remedial classes by five years post-injury. More recently, Kinsella et al. (1995; 1997) have found that, by two years post injury, 70 percent of children with severe injuries, and 40 percent of those with moderate injuries, were receiving special educational assistance. Socioeconomic status, male gender, maladaptive behaviours, reduced verbal learning skills and slowed psychomotor processing have been identified as predictors of poorer academic achievement post-injury (Donders, 1994; Kinsella et al., 1997; Stalings, Ewing-Cobbs, Francis, & Fletcher, 1996; Taylor et al., 2002).

Qualitative analysis of data from these studies suggests that reading accuracy skills appear to be relatively resilient in school-aged children, with arithmetic and comprehension more vulnerable (Catroppa & Anderson, 2000; Barnes, Dennis, & Wilkinson, 1999; Berger-Gross & Shackelford, 1985; Kinsella et al., 1997). Injuries sustained in the preschool period, even those of mild severity, have been associated with school failure. Despite appearing to be fully recovered immediately post-injury, these children are more likely to have reading difficulties, and require special education input as they move through the school system (Gronwall, et al., 1997; Wrightson, McGinn, & Gronwall, 1995). One possible explanation for these somewhat unexpected consequences following mild TBI, may relate to the observation that these skills must develop from scratch following a preschool injury. Thus even a mild impairment of attention and/or memory may cause disruption to this acquisition process.

#### *Behaviour and social skills*

Debate continues with respect to the aetiology of behavioural and social difficulties post-TBI. Some authors claim that these problems reflect pre-

morbid behavioural and family problems, while others support an important impact of brain injury (Donders, 1992; Farmer et al., 1996; Fletcher, Ewing-Cobbs, Miner, Levin, & Eisenberg, 1990; Max, Castillo et al., 1997a; Max, Smith et al., 1997b; Perrott, Taylor, & Montes, 1991; Prior et al., 1994; Wade, Taylor, Drotar, Stancin, & Yeates, 1996). Clinical reports frequently describe behavioural change post-TBI, even in the absence of physical disability or cognitive impairment. Problems range from initial symptoms of fatigue and irritability, to more persisting deficits such as aggression, poor impulse control, hyperactivity, distractibility, depression, and anxiety (Asarnow et al., 1991; Black, Jeffries, Blumer, Wellner, & Walker, 1969; Bohnert, Parker, & Warschausky, 1997; Brink, Imbus, & Woo-Sam, 1980; Brown et al., 1981; Butler, Rourke, Fuerst, & Fisk, 1997; Cattalani, Lombardi, Brianti, & Mazzuchi, 1998; Klonoff, Clark, & Klonoff, 1995; Max, Smith et al., 1997). Reduced self-esteem and social difficulties may accompany these problems (Bohnert et al., 1997; Turkstra et al., 2001). Andrews and colleagues (Andrews, Rose, & Johnson, 1998) have identified low levels of self-esteem and adaptive behaviour and high levels of loneliness and aggression in children with TBI.

These post-injury behavioural difficulties are closely linked to injury severity. Children with severe injuries have been found to show a marked increase in psychiatric disturbance, both acutely and in the long-term post-injury. Brink and coworkers (Brink et al., 1980) report that while only 10% of their sample of severely head-injured children had any persisting neurologic impairment, 46% had severe emotional/behavioural disturbances requiring professional counselling. Brown and colleagues (Brown et al., 1981) noted that the rate of new psychiatric disorder was more than doubled in the severely injured group in comparison to controls. Within this severely injured group, history of pre-injury behavioural deficits was predictive of later psychiatric disturbance, with over half of these children developing a disturbance in the 12 months post-injury, in contrast to a figure of 29% for children with no premorbid problems.

A number of studies report increasing problems in behaviour, and increased incidence of psychiatric disturbance post-TBI (Brink et al., 1980; Brown et al., 1981; Cattalani et al., 1998; Perrot et al., 1991). This pattern may be due to the direct effects of TBI (e.g. increased impulsivity, hyperactivity associated with right frontal damage), or related to secondary factors such as family dysfunction or depression and adjustment difficulties occurring in the process of coming to terms with long-term implications of injury.

In summary, children who sustain significant TBI are at risk for cognitive, educational and behavioural problems. These problems may not be evident initially post-injury. Rather, they may develop secondary to problems of adjustment or, alternatively, they may emerge as the child fails to meet expected developmental milestones. As a consequence, rehabilitation resources need to be available to children and families throughout childhood, to ensure early identification and treatment.

## Injury Related Predictors of Outcome

Variability in outcome following childhood TBI has been well documented (Fletcher, Ewing-Cobbs, Francis, & Levin, 1995). Even with our increasing understanding of the consequences of TBI in children, it remains difficult to predict which children will show good recovery, and who will require ongoing support and rehabilitation. Researchers are now beginning to address this issue, by identifying and studying potential predictors of outcome.

*Injury-related factors* have received most attention to date, with a clear dose-response relationship identified for injury severity and outcome at all stages of recovery. The nature of injury is also relevant, with more focal injuries generally thought to lead to better outcome than generalized insults (Anderson et al., 2001). A number of specific injury characteristics have been found to be associated with poorer prognosis in children, including depth of lesion (Ommaya & Gennarelli, 1974), presence of secondary damage due to intracranial haematomas (Berger et al., 1985; Walker, Mayer, Storrs, & Hylton, 1985), diffuse axonal injury (Filley, Cranberg, Alexander, & Hart, 1987), oedema, hypoxia, haemorrhage and herniation (Gentry, Godersky, & Thompson, 1988). Severity of total injuries and post-traumatic seizures have also been identified as predictive factors (Michaud et al., 1992).

*Developmental and psychosocial factors* may also contribute to long-term function. Younger age at injury has been noted to be associated with poorer recovery initially, and a failure to maintain developmental progress in the years post-injury (Anderson, 1988; Anderson et al., 2000a, 2000b; Anderson & Moore, 1995; Ewing-Cobbs et al., 1997; Gronwall et al., 1997). Psychosocial parameters, including reduced access to rehabilitation services and special education, degree of family burden and significant family dysfunction and psychiatric problems have all been found to impact on long-term recovery (Rivara et al., 1993, 1994; Taylor et al., 2002; Wade et al., 1996). Recently, gender has also been identified as a factor contributing to recovery, with females demonstrating better recovery from early childhood insult (Kolb, 1995; Raz et al., 1994, 1995).

It is probable that specific factors are predictive of recovery at different stages post-TBI. For example, injury severity is a crucial predictor of function in the acute stages of recovery, but may become less important in the long term. Longitudinal studies are underway (Anderson et al., 1997; Ewing-Cobbs et al., 1997; Jaffe et al., 1995; Kinsella et al., 1997; Taylor et al., 1995) which build on the knowledge of functional impairment gained from past research, but currently there is minimal information regarding outcome after two years post-injury.

In a recently completed study within our laboratory (Newitt, 2002), the long-term contribution of injury severity was investigated in a sample of 59 young adults who had sustained TBI in childhood. Results from the study showed that, while participants who had sustained mild or moderate TBI during childhood appeared to be functioning as independent members of the



community, those with severe injuries had made a less successful transition to adulthood. Poor educational attainment, high rates of unemployment, difficulties with relationships, limited leisure activities and social isolation were commonly documented. Within this group, most participants lived with their families, and changes in family structure and function (e.g. family breakdown, marital difficulties) were common. Substance abuse and criminal behaviours, as well as psychiatric disorders, were also over-represented in this group. Greatest impairments were found for survivors who had sustained other serious injuries in addition to TBI. Similar patterns of disability have been reported in other studies (Klonoff, Clark, & Klonoff, 1995; Koshiniemi, Timo, Taina, & Leo, 1995).

Knowledge of the importance and relative contribution of injury-related, developmental and psychosocial variables is important to ensure early identification and appropriate follow-up of 'at-risk' children and families. Research suggests that additional resources may need to be directed to children with severe TBI, to younger children, who may appear to have made a good recovery acutely, but may develop problems over time since injury, and to those with multiple injuries, where physical, cognitive and emotional stressors may be present. Families experiencing high levels of stress, perhaps due to death of another family member in the accident, or to pre-existing family difficulties, may also need careful follow-up, as they may have less personal resources available to identify and act upon problems arising post-injury. Careful documentation of these potential risk factors at time of hospitalization may minimize unnecessary secondary complications of TBI.

### **Paediatric Rehabilitation: Theoretical Considerations**

As with adult models, paediatric rehabilitation is a multidisciplinary endeavor, incorporating rehabilitation physicians, physical therapists, occupational therapists, speech therapists, play therapists, special educators, and social workers, as well as neuropsychologists, and families, in the acute stages, and providing a range of specialist interventions. Later, educational specialists and counselors may also become involved. The goals of the rehabilitation process are to promote recovery and work with the injured child and his/her family to compensate for residual deficits, to understand and treat cognitive and behavioural impairments, to recognize the role of these impairments in functional disabilities, and to monitor family and other social factors (Rourke et al., 1983; Wilson, 1997; Ylvisaker, 1998). The broad aim is to enable the child to do what he/she would like to do, or needs to do, in order to cope with life demands, but finds difficult because of the various consequences of brain injury (Ylvisaker, 1998). Thus, the emphasis of rehabilitation may vary, depending on the nature of the difficulties experienced by the individual.

### **Models of intervention**

As for adults, approaches to paediatric rehabilitation may be divided according to the aim of the intervention. Internally focussed methods stress improving the individual's capacities, by either restoration of function via re-establishment of impaired functions, or functional adaptation, where intact abilities are utilized to 're-route' skills which have been disrupted via behavioural training. Externally focussed approaches are directed towards altering the environment to meet the child's new needs, with no intention for changing the child's actual abilities (Mateer, 1999). This environmental modification is particularly relevant once the child has returned home, and must recommend activities of daily living (Anderson et al., 2001; Park & Ingles, 2001; Ponsford et al., 1995).

For injured children additional rehabilitation options are often present. One approach focuses on acceleration of the acquisition of new skills, as well as restoration of established abilities (Ylvisaker, 1998). Such ongoing acquisition of knowledge and skills is a critical task of childhood. Unfortunately, it is the dynamic skills required for these important learning processes (e.g. attention, memory, processing speed, executive function) that are often impacted by TBI, placing children at risk for cumulative problems (Anderson et al., 2000). Thus, the treatment and optimization of these 'processing' skills is a central focus of rehabilitation. In addition, developing functional abilities, such as academic and social skills, requires particular support in the paediatric context. In many child rehabilitation centres, a combination of these intervention approaches is employed simultaneously. Currently, there is little research available on the relative efficacy of each of these models within the paediatric context. However, a recent study conducted by Selznick and Savage (2000) provides some support for such an approach. These researchers report the outcome of three single case studies where they employed behavioural methods to treat self-monitoring difficulties, which are commonly identified in children with TBI. They found that their intervention led to greater on-task behaviour and higher accuracy levels on their training tasks. Unfortunately, as with many intervention evaluations, there was no indication whether these improvements translated into day-to-day activities.

In children with TBI, a further critical intervention avenue is provided by the family unit. Parents may play a key role in the rehabilitation process, especially as early discharge to the familiarity of the home environment from acute settings is generally considered optimal in paediatric settings. Often children will return home while still suffering from the acute effects of injury (e.g. irritability, fatigue, poor attention), which are difficult to understand and manage. Detailed and realistic education for parents is an essential element of the rehabilitation program. Further, parents and families need to be informed regarding the likely physical, cognitive and emotional consequences of TBI, their impact on the child's day-to-day life, and the likely time lines for recovery. They will benefit from counseling regarding best methods for managing their child's impairments and for negotiating

access of resources for their child with schools and other agencies (Holster, 1999).

### *Restoration of function*

Restorative interventions are designed to treat the cognitive impairments, which have resulted from injury (Cicerone & Tupper, 1990; Sohlberg & Mateer, 1989). Usually, this method of intervention requires an initial neuropsychological evaluation to identify impaired cognitive abilities. The child is then trained, using specific exercises focussing on those cognitive abilities or processes, in an attempt to improve these skills, as well as to impact more generally on all cognitive functions. This method of intervention, while controversial, is probably the best evaluated rehabilitation modality. Adult results suggest that such approaches may be more effective in certain cognitive domains (e.g. attention), with small, non-significant improvements reported in other domains (Diller & Gordon, 1981; Gray, Robertson, Pentlan, & Anderson, 1992; Mateer, Kerns, & Eso, 1996; Robertson, 1990). As might be expected, there is little evidence that these approaches generalize to other cognitive domains (Miller, 1992; Park & Ingles, 2001; Ponsford et al., 1995; Wilson, 1997; Wood, 1988) or to daily functions. Further, the critical emotional, behavioural and social sequelae that often follow from brain injury are not incorporated in such approaches, despite their potential influence on the patient's capacity to benefit from treatment.

### *Functional adaptation*

Perhaps the most popular approach to rehabilitation is to attempt to train individuals with head injury to perform various activities and tasks using alternative strategies, enabling the person to compensate for their cognitive deficits. Such intervention procedures are designed to improve or restore cognitive capacity or lessen the functional impact of the impairment (Mateer, 1996). This approach is in keeping with an emphasis on maximizing identified cognitive strengths to ensure optimal performance in everyday life. As with restorative interventions, rehabilitation needs to be preceded by a thorough evaluation of cognitive strengths and weaknesses to provide a baseline for developing appropriate compensatory strategies. Compensatory approaches are well known within the child context, and are regularly utilized in educational programs for children with developmental disorders including language delay and specific learning difficulties. For example, for children with language difficulties, teaching strategies which employ visual imagery or visual memory will provide an optional 'route' for learning skills traditionally acquired via language-based teaching strategies. Or for older children, where complex cognition may be required, training in breaking down tasks (e.g. essays, projects) into a series of steps may provide a strategy for adequate performance, which can gradually be generalized into the child/adolescent's approach to complex or novel tasks. Importantly, and as emphasized by Rourke (1989) in his treatment-orientated approach, such methods are most

effective when less severe impairment is present. The more global the deficits due to TBI, the more difficult it is to identify an intact modality to employ in the design and implementation of compensatory strategies.

In addition to behavioural approaches, which emphasize changing cognitive strategies, there is also the alternative of provision of external aids or cues, such as lists, diaries or alarms. There are a number of studies within the adult literature which have suggested that application of these techniques is related to significant improvement in skills (Berg, Koning-Haanstra, & Deelman, 1991; Schmitter-Edgecombe, Fahy, Whelan, & Long, 1995; Wilson & Moffat, 1992). Until recently, external cueing has not been found to be a particularly successful approach for younger children, but becomes of increasing benefit as children reach adolescence and develop the skills necessary to use these methods to enhance memory and retention. A recent study by Wilson and colleagues (Wilson, Emslie, Quirk, & Evans, 2001) has challenged this view, showing that children as young as 8 years of age were able to benefit from a computerized reminder intervention program ('Neuropage'), showing increased ability to recall important events and information when accessing this system.

#### *Environmental modification*

Where restoration or compensation approaches are unhelpful, therapists frequently employ more external measures to minimize the functional impact of cognitive impairments. To a great extent, the emphasis of paediatric rehabilitation is on modifying the child's environment to ensure that the context is conducive to best level of function (e.g., changing school curriculum, limiting class size, ensuring low noise levels). One of the major criticisms of this method in isolation is that it makes an assumption that the child will show little 'internal improvement' post-injury (Mateer, 1996). As a result, such interventions become more important once recovery processes have stabilized and the residual deficits are apparent. To implement such environmental modifications, a thorough understanding of the individual child's cognitive strengths and weaknesses is essential. On the basis of such information, physical, contextual and educational issues can then be implemented. Such interventions rely heavily on the availability of resources, and the full support of the child's family, school and community.

#### *Accelerating developing skills*

As previously noted, the acquisition of new skills may be delayed following TBI, due to a combination of factors, including the presence of attention and memory difficulties, missed educational and social experiences, and poor self-esteem. One emphasis of rehabilitation or educational intervention, is aimed at speeding up these processes. Educational skills provide an excellent example of this. In general, with children with TBI, traditional intervention approaches are employed to help the child acquire basic academic skills of reading, spelling and mathematics, with these areas noted to be areas of

deficiency post-injury. In particular, methods which utilize individual or small group tuition, where children's processing capacities can be closely monitored, have been shown to be particularly effective (Anderson, Smibert, Godber, Ekert, & Weiskop, 2000).

### *Education*

There is some debate regarding the efficacy of educating children with respect to the consequences of head injury, and its possible impact on their lives, with current research findings in this area being inconclusive. In a recent study by Beardmore, Tate and Liddle (1998), findings demonstrated that, while children did not show any benefit of an educational program, parents did appear to show improved understanding of their child's difficulty. These results emphasize the importance of provision of detailed and appropriate information to families. Our own experience would suggest that this information needs to be in written form, as families, affected by the stress of their child's injury and hospitalization, often have difficulty absorbing and retaining the verbal material provided by rehabilitation teams during individual consultations and family meetings. At the level of the school and community, much of the intervention effort is also focussed on providing an understanding of the child's likely deficits, those which may be explained by TBI or secondary influences, and how these may limit the child's ability to cope with routine expectations. As is the case with many aspects of intervention within the paediatric context, the educational process needs to continue over time, as children recover, and pass through various developmental stages.

Education regarding the pattern of recovery and the residual nature of deficits is of critical importance for children and families. For example, contrary to expectations for recovery post-injury, behavioural difficulties have been reported to increase with time since injury (Brink et al., 1980; Cattalani et al., 1998), associated with adjustment difficulties, or perhaps family dysfunction. Further, as children with TBI move through normal developmental transitions new cognitive problems may emerge, particularly in areas such as organization, reasoning, and problem solving. It is critical that families and survivors are aware that such problems may be head injury-based, and so seek appropriate intervention. While these difficulties may be successfully treated, specific treatment approaches need to be implemented, which account for TBI-specific effects.

### *Psychological treatments*

Effective rehabilitation models take an holistic view of the injured child, and his/her unique profile of disabilities, taking into account behavioural and emotional functioning. Despite this, management approaches addressing the emotional, social and behavioural consequences of childhood TBI are poorly documented and evaluated. Children with TBI may exhibit such problems as a result of primary brain injury (e.g. impulsivity, inattention, hyperactivity), or secondary to hospitalization, family separation and adjustment to residual

disabilities (e.g. anxiety, depression, social isolation). An understanding of the likelihood of these problems, and their bases, need to be incorporated into rehabilitation plans, with potential for assessment and management integrated into treatment models (Anderson et al., 2001; Ponsford et al., 1995; Wilson, 1997)

### **Developmental issues**

Approaches to paediatric rehabilitation are directed, to some extent, by the unique needs of the young child and family. Most importantly, the young child is in a state of rapid development. As a consequence, intervention strategies need to account for possible disruptions to ongoing brain development, as well as potentially cumulative cognitive and psychosocial deficits. Following TBI, children may never reach their pre-injury potential. Children with significant impairments will require long-term management and rehabilitation, with particular emphasis on developmental transitions (e.g. pre-school to school-aged, middle childhood to adolescence), where strategic shifts in approach to treatment may be required, due to changes in both contextual and cognitive demands. Further, as new skills are programmed to come 'on-line' through childhood (e.g. reasoning, planning), children with TBI may experience delayed acquisition, in association with impairments in attention, learning and processing skills. The potential for such 'emerging' deficits suggests the need for active and long-term monitoring for this group.

Assessing recovery in children is a particularly complex task. In contrast to expectations following adult TBI, simple improvement in performance is not sufficient to imply 'recovery', as developmental expectations assume ongoing improvement in abilities through childhood. Thus, when determining if a child has demonstrated recovery, or benefited from rehabilitation, developmental factors need to be carefully considered.

At a more practical level, the common practice following injury in childhood is for early discharge from hospital, usually once symptoms of post-traumatic amnesia (PTA) have subsided. The accepted view is that return to the familiar home environment will be beneficial for recovery. As a result, intensive, structured rehabilitation programs are often impractical within the paediatric context, after the acute recovery stage. Rather, the emphasis is on outpatient care, and supporting the family to cope with the child's needs. Thus, a heavy burden of care falls upon the family unit, and there is much evidence that the healthy functioning of the family is critical to good outcome for survivors of childhood TBI (Perrott et al., 1991; Wade et al., 1996).

The educational context is also important to consider. Children are encouraged to return to school, at least on a fractional basis, as early as possible, thus re-establishing a social network, and a normal daily routine, as quickly as possible. This transition is often difficult and fraught with stress for the child, family and school. For many schools, the return of the child with TBI will be their first experience of working with a brain-injured child. There is a need for close liaison between rehabilitation team, school staff and

family during this gradual process, to ensure that appropriate knowledge is available regarding expectations and treatment. Often, the head-injured child appears quite normal superficially, despite significant cognitive deficits, and it is important that those within the school context comprehend and act upon the child's need for special assistance. Classroom discussions may also be beneficial, providing the child's classmates with an understanding of the child's needs and problems in a manner that is readily understood, and minimizes fears associated with the child's possible disabilities.

## **Management and Intervention: the Process**

### **Recovery**

Assessment and management of the child who has sustained a TBI commences at the scene of the injury, where conscious state and neurological status are evaluated. By the time the child reaches hospital he/she will have sustained permanent primary impact-related brain injury, which is thought to be relatively insensitive to medical treatment. Secondary effects will also be developing, and these have been shown to be more amenable to medical intervention. Early treatment is directed towards the accurate identification of these secondary complications and their rapid treatment (Miller, 1992). A number of parameters are particularly informative for determining injury severity at this early stage: level of consciousness, duration of altered consciousness, duration of post-traumatic amnesia, clinical evidence of skull fracture or cerebral pathology, and neurological and mental status.

In paediatric patients a combination of measures is usually employed to determine the severity of the injury, as no single indicator has proven to have sufficient predictive power in isolation (Fletcher et al., 1995). The poor reliability of traditional indices may reflect the relatively recent development of tools, such as the paediatric versions of the Glasgow Coma Score, PTA scales, the range of mechanisms of injury, the developmental level of the child at time of injury, as well as pre-injury factors including environment and premorbid ability.

### **The recovery process**

The stages of recovery following childhood TBI follow a relatively predictable path, depending on the nature and severity of injury. As for adults, there are substantial differences between the rapid and uncomplicated recovery following mild TBI, and the more protracted process associated with moderate and severe TBI.

#### *Mild injuries*

After mild TBI, there may be a brief period of altered consciousness, and perhaps a period of post-traumatic amnesia, characterized by confusion and disorientation. Children are routinely observed for a short time and dis-

charged home without hospital admission. Clinically, children may exhibit symptoms of fatigue and irritability. Transient cognitive problems may also occur, including reduced attention, psychomotor slowing, poor memory and behavioral symptoms (Beers, 1992; Boll, 1983). More significant motor and language deficits are uncommon. Over time, these deficits reduce and, while there is ongoing debate with respect to outcome, a good recovery is common, particularly in school-aged children, and where no premorbid problems were present (Asarnow et al., 1995; Polissar et al., 1994; Ponsford et al., 1997).

#### *Moderate and severe injuries*

Recovery from moderate and severe TBI is more protracted and may be seen as a multi-phase process, where there is an interaction between the child's physical recovery and developmental level, the family response and the reintegration of the child back into the wider community. Waaland and Kreutzer (1988) describe a series of stages which families commonly experience post-TBI, beginning with shock, optimism, and denial during the early stages of recovery, followed by more realistic anger, guilt and blame, and later grief and adjustment. These phases are summarized in Table 1.

#### *Acute phase*

During this phase progress is monitored for evidence of deterioration, due to raised intra-cranial pressure or haematoma, which may require surgery. Physical rehabilitation commences at this early stage, focussing on maintaining the child's physical strength. This is a time of intense anxiety for families, where the major focus is their child's survival. Further stressors may include injuries/fatalities of other family members, financial or employment pressures, family separation, and the need to care for other siblings. Feelings may fluctuate from hope and optimism to devastation and despair. Grief, guilt and blame can also be central issues for parents and siblings during this period (Waaland & Kreutzer, 1988).

#### *Early rehabilitation*

As the child emerges from coma more active rehabilitation begins. Some children are difficult to manage at this time, when features may include restlessness, agitation, confusion and disorientation. Nursing care and therapies during this period are often limited to containing such behavioural challenges. On emergence from PTA, functional impairments may be evident, and more intensive rehabilitation, including occupational and speech therapy may be instituted. The goal is to work towards an early return home to a familiar environment. Return to school is generally a gradual process, with the child initially attending for short periods, primarily for social contact, with involvement increasing as he/she gains physical strength.

This phase of recovery tends to involve a degree of balancing between rehabilitation goals, social adjustment needs of the child, and school and family resources. It is a stressful time for the family, who must negotiate



Table 1. Issues facing children and families following TBI.

Recovery stage	Child issues & responses	Family issues & responses
<i>Acute: survival</i> hospitalisation	survival early rehabilitation separation from parents coping with medical procedures	hope/fear re child's survival helplessness guilt/blame over injury family separation practical pressures: child care for other siblings, financial and employment concerns
<i>Sub-acute: recovery/adjustment</i> discharge and rehabilitation	intensive rehabilitation adjustment of acute disability fatigue and irritability social isolation	adjusting to changes in child denial of child's disability balancing needs of injured child and other family members practical issues: ongoing financial and employment concerns
<i>Chronic: acceptance</i> reintegration into community	adjustment to residual physical & cognitive disability social rejection and isolation feelings of loss and frustration depression	stress of attending and following through on rehabilitation procedures practical issues: organising educational resources managing family changes accepting residual disabilities of the child & adjusting expectations managing behavioural and physical problems

and organize the various resources required for the child, as well as adjust to the child's physical and behavioral limitations. Families react in different ways to these stresses, depending upon their own strategies and coping styles (Waaland & Kreutzer, 1988). While family intervention may appear warranted, often parents are unable to take advantage of psychological resources at this early stage. Practical difficulties (e.g. limited time, lack of child care, employment responsibilities), intense focus on the rehabilitation demands of the child, and denial of the difficulties and stressors may each limit the success of such interventions.

### *Assessment*

Evaluation of cognitive function is critical to efficacious treatment. Standardized intellectual assessment may be useful in determining global levels of function in the child, however, IQ tests alone are insufficient to demonstrate the range of impairments experienced post-injury. Research suggests that there may be specific neurobehavioural domains, which are particularly vulnerable to the impact of TBI, for example, attention, executive function, speed of processing, memory and learning (Anderson et al., 2001). The effect of deficiencies in these abilities may not be apparent on IQ testing until some time post-injury. Evaluation of functional abilities, such as academic achievement, behavioural and social skills, via direct testing, parent and teacher questionnaires or observations, may supplement test-based information regarding impairments of day to day function. Such data are critical to the accurate diagnosis of cognitive strengths and weaknesses, their impact on day-to-day functions and the subsequent design of individual treatment plans.

### *Return to school*

Initial return to school is often on a part-time basis, and focussed on re-establishing social contacts for the child. Fatigue and poor attention frequently preclude children from full involvement in the curriculum. Glang, Singer and Todis (1997) note that during this process accommodations for the child need to be considered at a number of levels: (1) physical: incorporation of adaptive equipment, including wheelchairs, special desks, computers, communication devices; (2) environmental: provision of extra time, quiet, well structured classroom, opportunity for repetition, revision; and (3) instructional: specific educational programming, individual tuition, social skills retraining. These modifications need to be negotiated prior to school return preferably, to make the transition as smooth as possible for child, family, teachers and peers. Careful consultation and liaison is critical to the success of this process. Further, the development of a special program is frequently required, even in the case of less severe injuries. As Rourke (1989) states, the goals of such programs need to be realistic, and the process for achieving them operationalized carefully, rather than left at an abstract level.

As for the neuropsychological assessment process, educational planning and environmental modifications within the school context need to focus

on the areas of neurobehavioural function which are commonly impaired as a result of TBI. Motor skills, fine motor skills and processing speed, attention and memory are important targets, with executive skills becoming more important as the young child moves through childhood into adolescence. Common examples of environmental modification include use of a personal computer for writing tasks, provision of extra time for task completion to compensate for slowed processing speed. Attentional difficulties may be supported by provision of an 'aide' who is able to work one-on-one with a child and help direct and maintain attention to task. Short days, or school weeks may be beneficial for a child suffering from fatigue, while modification to the school curriculum may also be required. For example, for a child suffering from visual and motor deficits, subjects such as graphics or art may be particularly frustrating. For the more mildly injured child, who suffers from fatigue and mild processing difficulties, reducing the curriculum, thus allowing for more time to be committed to each subject, may be all that is required to enable adequate performance. Where memory and learning problems are present, access to individual tuition which can provide repetition and revision of classwork may be helpful. A number of recent texts provide a range of practical suggestions for school re-integration of children with TBI (e.g. Begali, 1992; Glang, Singer, & Todis, 1997; Johnson, Uttley, & Wyke, 1989; Ylvisaker, 1998).

### *Chronic phase*

Some children sustaining more severe TBI may enjoy a relatively full recovery, with little requirement for professional intervention or support. More commonly such injuries are associated with ongoing impairments necessitating life-long medical involvement and rehabilitation. Problems are often most apparent at each developmental transition. At such times the child and family may need support and professional input to negotiate new challenges, and enhance the understanding of those working with the child. School entry may emphasize the child's limitations, for example, motor incoordination may be apparent in poor sporting ability or writing and drawing difficulties. Communication and attentional difficulties may limit the child's capacity to participate fully in many academic and social activities. Children experiencing these problems may require support additional to that provided within regular school resources. Perhaps the most stressful transition of all is into adolescence, where peer pressure and issues of identity are paramount. Adolescents may refuse to accept extra therapy or intervention, which identifies them as different. They may become depressed as they begin to fully appreciate the impact that their deficits will have on their future. This pattern of recovery, with its developmental implications, argues that children sustaining moderate and severe TBI require ongoing professional support into adulthood, particularly as they and their families gradually adjust to residual physical, cognitive and behavioral sequelae, and then at critical developmental transitions.

## The Neuropsychologist and Paediatric Rehabilitation

In the context of a multidisciplinary rehabilitation team, the neuropsychologist may be minimally involved with the injured child during the acute stage of recovery. Input may be sought regarding issues such as emergence from post-traumatic amnesia or the appropriate environment for optimal recovery, but by-and-large these tasks are incorporated into other therapy programs. The neuropsychologist becomes more central once the child is able to cope with assessment procedures, and an initial evaluation may be conducted to determine early impairment. Neuropsychological findings may then be integrated into the rehabilitation and school re-integration processes. Once full re-integration has occurred, the need for extra educational support may become evident. Teaching aides, to provide individual instruction or tailoring of educational programs, are frequently employed to encourage ongoing development and recovery. The child may continue to receive therapies during this period, either at a rehabilitation facility, or via the school. Regular liaison may be established with school staff, parents and involved professionals, to ensure that programs are being implemented appropriately, and with expected impact. Ongoing neuropsychological assessment of recovery and current levels of functioning is important in order to inform those working with the child. Results will inform parents and teachers about any recovery that may have occurred, or of plateaus in recovery. Such data may provide much needed motivation, or help determine why the child is not progressing, despite enthusiastic input. In addition such reviews may alert the rehabilitation team to the need for extra therapeutic intervention.

Completion of education can also be a time of significant trauma for adolescents and families. Our own research has demonstrated that children who sustain severe TBI are more likely to leave school early, and to have difficulty finding paid employment (Newitt, 2002). This process may be supported via a range of vocational services, ranging from those which provide training for the individual to prepare curriculum vitae or to perform adequately in interviews, to liaison services where counselors discuss the individual's needs with potential employers or conduct site visits to determine any environmental modifications which may be required to enhance the individual's performance.

Depending on the resources of the rehabilitation team, the neuropsychologist may also be required to monitor family function and coping. The added demands of the child's injury, in terms of emotional, financial and physical resources may be great. Issues of blame, loss and grief may need to be addressed. Feelings of hopelessness, being trapped, and ambivalence to the child may also emerge. Even in families that cope well, behavioural difficulties exhibited by the child with TBI are often difficult to understand and manage. Treatment and education regarding these problems may be provided by the neuropsychologist, perhaps in consultation with a family therapist or individual counselor.

## Conclusions

Consequences of childhood TBI are varied and difficult to predict. Research suggests that mild TBI may result in few, if any, residual impairments. In contrast, for moderate-to-severe injuries residual neurobehavioural deficits are common. Crystallized skills (e.g. well learned skills and knowledge) appear less vulnerable than fluid skills (e.g. planning, reasoning, problem solving), with greatest deficits in attention, memory speed of processing and high level language and non-verbal abilities. The common sequelae of childhood TBI appear to be qualitatively different from those described following adult TBI. While adult injury may result in immediate and devastating consequences in terms of brain injury, cognitive disability and behavioural impairment, for the child there is an ongoing interaction among these domains, potentially resulting in cumulative, and global disability. Thus, recovery is less complete, with additional deficits often 'emerging' as the child passes through each developmental stage.

Recent longitudinal research has shown that recovery and ultimate outcome are dependent on a number of biological, developmental and psychosocial factors, including nature and severity of injury, premorbid abilities, developmental level at time of injury, time since injury, stability of family unit, and access to resources. The relative importance of each of these parameters in determining outcome, the possibility that their impact may be greatest at different stages in the recovery process, and their mechanisms of interaction, are still to be determined.

Rehabilitation in the paediatric context, aimed at treating these ongoing and substantial neurobehavioural problems, is a long-term commitment. Children and families will often require ongoing support and intervention, as the child and family pass through developmental transitions and family change. Regular monitoring is required to prevent the emergence of unnecessary secondary problems, particularly in the social and emotional domains. At present, within the paediatric context specifically, there is limited direction for clinicians, with few models for child rehabilitation described in the literature, and even less data describing evaluation and efficacy of child-based interventions. Reports from outcome studies of injured children who have reached adulthood, argue strongly for more intensive and long-term intervention and education following child TBI.

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# Chapter 12

## REHABILITATION OF PEOPLE IN STATES OF REDUCED AWARENESS

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### Background

‘No head injury is too severe to despair of, nor too trivial to ignore’

Hippocrates 4th Century B.C.

Survival after very severe head injury is a relatively new phenomenon. Numbers of survivors appear to be increasing although this has not been formally evaluated. Recent advances such as the introduction of paramedics and better roadside care, improved neurosurgical techniques, development of Intensive Therapy Unit (ITU) care and greater understanding and prevention of secondary complications have contributed to this increase. These measures, while preventing or minimising some head injuries, may also have the unanticipated consequence of increasing survival among very severely injured people. Therefore a relatively new area of rehabilitation has been developing in the past ten years – the rehabilitation of people who are considered to be in a reduced state of consciousness.

Four distinct groups can be described as being in reduced states of consciousness after head injury – those in coma, those in the Vegetative State (VS), those in the Minimally Conscious State (MCS) and those who are in Post Traumatic Amnesia (PTA). Although these are four distinct groups, many of the approaches to assessment with the first three groups are similar



although the treatment and the goals set may be completely different. Because of this it is essential that the diagnosis is accurate.

## Coma

The word coma comes from the Greek 'Koma' meaning state of sleep. The best known definition is that of Jennett and Teasdale (1977) who describe coma as 'giving no verbal response, not obeying commands and not opening the eyes spontaneously or to stimulation' (p. 878). Other features of coma include: no arousal and no awareness; no eye opening; reflex movements only; no language comprehension and no purposeful response. Traumatic coma per se is short lived and within 2–4 weeks the patient will have progressed either to the vegetative state, the minimally conscious state or to PTA.

## The Vegetative State

The vegetative state is the description most commonly used to describe the state of complete unresponsiveness observed where the patient is not in coma – i.e. eye opening is present. Jennett and Plum (1972) coined the term 'persistent vegetative state' but the term of choice in the UK and the USA at present is either 'vegetative state' or 'chronic vegetative state'. This is because the term 'persistent' implies that there will be no change. While this is undoubtedly true for the majority of patients who are vegetative after a significant period of time, a small minority may recover to some extent.

Two reports on the vegetative state are those produced by the Royal College of Physicians (RCP) (1996) and by Andrews et al. (1996). The report by the RCP state three criteria which must be met if a patient is to be diagnosed as being in VS: first, that patients show no evidence of awareness, no volitional response and no evidence of language comprehension; second that a cycle of eye opening and closure is present and third that hypothalamic and brain stem function is intact. Further behavioural features, include incontinence, spontaneous blinking, occasional movements of eyes or head, aimless movement of limbs or trunk and facial grimacing.

In contrast to this clinical description of the syndrome, Andrews et al (1996) suggest behavioural description of patients rather than distinguishing between coma, vegetative presentation and an 'undecided' category. They recommended that the most appropriate method of assessment was to describe the level of responsiveness in behavioural terms and to describe but not to interpret any movements or behaviours observed.

## The Minimally Conscious state

The minimally conscious state is defined by Giacino et al. (2002) as “evidence of limited but clearly discernible self or environmental awareness on a reproducible or sustained basis by one or more of the following – simple command following; yes/no responses; intelligible verbalisation; purposeful behaviour and inconsistent but meaningful interaction” (Giacino et al. 2002). The presentation includes arousal and sustained tracking but the patient’s behavioural repertoire is severely compromised. It is reported that there is limited self awareness but that patients do feel pain. As with the vegetative state, sleep wake cycles are established and many patients have severely limited movements.

## Post Traumatic Amnesia (PTA)

PTA is defined as ‘a period of variable length following closed head trauma when the patient is confused, disorientated, suffers from retrograde amnesia and seems to lack the capacity to store and retrieve new memories’ (Schacter & Crovitz, 1977, p. 150). Although termed ‘amnesia’ PTA involves impairment of a number of cognitive processes. Amongst the features of PTA are disorientation, impaired day to day memory, slowed retrieval from semantic memory, slowed reaction time, slowed speed of information processing and difficulty with abstract thought (Wilson et al., 1999).

## Recovery and Rehabilitation

The underlying mechanisms of recovery and response to rehabilitation after traumatic brain injury are not entirely clear but rehabilitation should not be confused with recovery. It is probable that recovery of the ‘vegetative’ functions such as eye opening occur purely as a result of biological recovery. On the other hand, improvements in day to day ability to function in the community are more likely to occur as a result of as a result of new learning, relearning and compensation. It is less clear how recovery and rehabilitation interact in the interim stages and it is for this reason that a number of ‘theories’ or models have been proposed. It is probable that a combination of factors is involved, more heavily loaded towards biological recovery in the initial stages and towards learning and compensation at the end.

Ponsford et al, (1995) identifies the following as a basis for rehabilitation after brain injury:

- restorative – theories relating to restoration of function.
- compensatory – theories of behavioural compensation and functional adaptation.
- environmental – manipulation of the environment to facilitate independence.

## Restoration

The basis of restoration is that the intervention can restore or repair the lost function. This aim of restoration is to maximise the biological recovery by focusing therapy at the specific function which is impaired. The goal of treatment is for the patient to perform the activity in the same way and using the same functions (motor, cognitive, perceptual) as before. The intention is to isolate the impairment and treat using highly structured and repeated practice focusing on the impairment rather than on the disability caused by it. Examples of restorative approaches are the 'Bobath' approach to restoration of physical function (where the goal is for patients to move 'normally' rather than functionally) or computer training to restore impaired attentional skills. The theoretical basis of restorative treatment is that recovery of damaged functions may be facilitated if treatment begins early enough, but there is little evidence as to efficacy. Such approaches may bear little relationship to daily life as intervention is focused solely on impairment with little or no input at the level of disability or handicap. At present, the main restorative intervention for patients who are in coma in the vegetative state or who are minimally responsive is coma stimulation programmes.

## Studies of Coma Stimulation

The concept of stimulating patients who are unresponsive after a brain injury is not a new one. Hippocrates recommended that 'the patient in a state of coma should be spoken to in a loud voice, splashed with cold water and exposed to bright light'.

Giacino (1996) reviewed studies of coma stimulation in treating patients in coma and evaluated them using a classification system developed by Woolf (1993). Experimental evidence was categorised as class I, II or III. Class I evidence was described as the 'gold standard' and comprises evidence based on randomised, prospective controlled clinical trials. Class II evidence includes descriptive studies, retrospective studies and prevalence studies as well as retrospective and cohort studies. Class III evidence includes uncontrolled studies and case reports. One study met the criteria for class I evidence (Johnson et al., 1993), three studies met the criteria for class II evidence. (Mitchell et al., 1990, Pierce et al., 1990 and Wood et al., 1993) and three others met the criteria for Class III evidence. Of the latter, two were case study series [Hall et al., (1992) and Talbot & Whitaker, (1994)] and one was a descriptive study of a clinical series (Rader et al., 1989). The only study to meet the criteria for Class I evidence evaluated the effect of a programme of multisensory stimulation to a group of patients admitted to a neurosurgical unit. Patients were randomly allocated to a treatment or non treatment group. However, no significant differences between the groups were found although this may have been because of the small sample size ( $n = 14$ ).

In fact, the numbers of patients included in all studies were small. The study meeting class I criteria included only 14 patients (Johnson et al., 1993) and the studies meeting class II criteria included 24 (Mitchell et al, 1990), 30 (Pierce et al., 1990) and 8 (Wood et al., 1993) patients respectively. Emergence from coma was used as a measure of outcome in all studies and the studies by Pierce et al. (1990) and Wood et al. (1993) also examined length of hospital stay. Although the results of all studies except that of Johnson et al. appeared to suggest that the patients undergoing intervention – sensory stimulation or in the case of Wood et al. – (1993), sensory regulation – spent less time in hospital, the small numbers make such a conclusion debatable. The results also appear contradictory; in the study by Wood et al. (1993) patients were not stimulated; in contrast, the amount of stimulation was regulated. Hence, when the combined results of these studies are considered, in each case the group that improved most rapidly was the intervention group. This raises the question of whether the interventions (ie stimulation or regulation) were in fact effective or whether the increased time and attention given to the intervention groups was in fact more important than either of the interventions tested.

### **Compensation**

Recovery is defined in terms of reduction of disability and handicap. In using compensation the emphasis of treatment is changed from focusing on impairment (as in restorative approaches) to focusing on intact skills and using these to compensate for limitations caused by the impairments. Patients are taught to use compensatory devices and learn to develop new strategies and skills. For example, if a patient has memory problem internal strategies such as mnemonics or imagery and external aids such as notebooks, diaries and checklists may be used. Previous research (Wilson & Hughes, 1997) demonstrated that some brain-injured patients could learn compensatory strategies. Such techniques are also acceptable to patients. Use of external aids such as notebooks and diaries is in many cases an extension of previously learned behaviour rather than introduction of new behaviour. Where it is a new behaviour it is socially acceptable in that it is an extension of everyday behaviour. However, to succeed in using compensation, patients must have some ability to learn as it involves learning new skills or applying previously learned skills to new areas. Therefore, the approach is not appropriate for patients with severe cognitive impairment or severely impaired learning skills.

### **Environmental Modification**

An alternative compensatory approach is to modify the environment rather than the patient. Using this approach, tasks are altered and components of the environment changed to facilitate independence. This approach is particularly

appropriate for patients with severe cognitive impairment or severe dysexecutive syndrome with poor motivation and who are incapable of adapting to changed circumstances. The benefit of such an approach is that it maximises residual abilities but the major disadvantage is that the success or failure of the environmental manipulation is dependent on others.

A second aspect of the environment to be considered is the effect of a stimulating environment. Results from animal studies suggest that the environment of the patient can moderate survival and growth of nerve cells. When rats placed in enriched or impoverished environments after brain injury were examined it was shown that not only did the rats in the enriched environment show evidence of improved cognitive and behavioural recovery but also that the effect was permanent (Stein et al., 1995).

A further environmental variable often not considered is the effect of the behaviour of other people in the patient's environment. Studies with other patient groups e.g. people with schizophrenia have shown that changing the behaviour of others in the patient's environment can affect the person's own behaviour (Falloon et al. 1984), although this is an area which has not yet been formally investigated in patients with traumatic brain injury.

Although these models of rehabilitation differ, none is used to the exclusion of the others. In fact, different approaches to rehabilitation at different stages is probably most appropriate. Animal studies suggest that the most rapid recovery of damaged structures occurs in the days and weeks immediately after the insult. Thus, rehabilitation programmes using a restorative approach would be most likely to affect outcome in the early recovery period. Compensatory approaches may be more appropriate as time passes. However, as achievement of the target goals(s) is the aim of rehabilitation, it is rarely possible to differentiate the exact processes whereby this is achieved.

## Pharmacology

The literature on pharmacological intervention for people in states of reduced consciousness is surprisingly sparse and, as yet, there is little evidence of efficacy. Theoretically, drugs acting on neurotransmitters could increase arousal thereby facilitating responsiveness. However, increased arousal (e.g. increased frequency and duration of eye opening) does not necessarily result in increased awareness. In a recent review, Giacino (2001) commented that the dearth of literature on this topic suggests that recovery from states of reduced consciousness mediated by drug therapy is rare.

## Assessment

Once a head injured patient is medically stable, more attention turns to assessment of the consequences of the injury. A head injury may cause a variety

of physical, cognitive, social and behavioural impairments. Emergence from coma in severely injured patients may be gradual but the difficulties involved in assessing these patients (whether they are in coma, in a vegetative state or in a minimally conscious state) are similar. Unless accurate assessment takes place, small gains may be missed or misinterpreted. With such patients, it is not unusual to believe mistakenly that nothing is happening even though slow but subtle progress is being made over weeks or months. Therefore both monitoring progress and setting appropriate and achievable goals can present a challenge for the rehabilitation team working with these patients. Patients may have a very limited behavioural repertoire and these behaviours may occur at infrequent and unpredictable intervals. Furthermore, as level of consciousness fluctuates, different degrees of stimulation may be required to elicit responses at different times. For the therapist dealing with these severely compromised patients, goal setting particularly in the area of cognition may be difficult when the baseline level of functioning is not clear.

Among the scales available to assess this population are the Rancho Los Amigos Scale (Hagen et al., 1987) and the Glasgow Coma Scale (Jennett & Teasdale 1977), (GCS) (See Appendix). There are limitations to the use of these scales however, when the period of unresponsiveness continues for an extended period. Subtle changes in behaviour may not be enough to record a change – as for example with patients where there is general agreement among those caring for him/her that the patient is ‘lighter’ (i.e. more responsive but in an undefined manner) but the change is not enough to move categories on the GCS or the Rancho scales.

In response to the need for an assessment to fill this gap, the Wessex Head Injury Matrix (WHIM) (Shiel et al., 2000a, 2000b) was developed. The scale was developed by observing recovery after brain injury in 88 patients and dividing this into small steps or behaviours. In all, there are 62 behaviours or steps on the scale and these items can be used to monitor change from the point of admission to emergence from PTA. The scale has behaviours relating to social behaviour, cognition, attention and communication. The items on the scale are in hierarchical order – i.e. the order in which they are most likely to recover. Thus, the items on this scale can also be used to formulate short term goals for rehabilitation. The scale is designed to be used by the multidisciplinary team and is administered by observation and by presenting patients with meaningful stimuli e.g. photographs and relevant questions (identified by the patients’ families) and by observing and recording their responses to these.

The scale divides clinical recovery into small steps which can be used to evaluate progress from the point of admission to emergence from PTA. It includes items of communication, social behaviour, cognition, attention and communication. All items require ability to make some kind of response but do not require any assumption to be made about the purpose of the response or the patient’s level of awareness. The items on the scale are assessed by observation and items are fine grained enough to show small increments. The

items on the scale also have the potential to be used to formulate short term goals for rehabilitation.

In the next section, rehabilitation programmes incorporating the approaches to assessment and rehabilitation described above will be considered in the context of specific case studies.

## Coma

Many of the techniques used in rehabilitation with patients who are in coma, minimally conscious or in the vegetative state overlap. However, the goals of treatment will be very different in each of these cases. These differences will be illustrated by using a number of case descriptions. Initially, it may not be possible to elicit any meaningful response from the patient – however, changes of position or environment may alter this giving the team a focus for intervention. An example of this is given in the first case.

### Case Study 1

JX, a 20 year old man was involved in a RTA and sustained a severe head injury. CT/MR showed diffuse brain injury with focal frontal and temporal lesions. GCS at the scene of the accident was 3 and increased to 4 after resuscitation. JX also had a fractured pelvis, fractured right femur and tibia, fractured ribs and a fractured clavicle. He was electively sedated, paralysed and ventilated. A bilateral frontal craniotomy was carried out to reduce intercranial pressure, and his orthopaedic injuries were fixed. 14 days after the accident, sedation was withdrawn but JX made poor respiratory efforts and GCS remained at 3. Over the next week he was gradually weaned off the ventilator but his GCS still remained at 3.

Rehabilitation commenced with JX as soon as sedation was withdrawn. In addition to the GCS he was assessed daily using the WHIM. Physiotherapy treatment commenced aiming at preventing deformity such as contractures and maintaining respiratory independence. By the 23rd day after injury JX had begun to open his eyes and was extending his limbs to painful stimuli (GCS motor score 2).

He was otherwise unresponsive while lying in bed. However, when he was seated over the side of the bed his eye gaze became more purposeful and he also tried to push the physiotherapist away from him. At this point his respiratory system was compromised so he was only able to tolerate sitting for about 4 minutes before his oxygen saturation level decreased. As his responsiveness while sitting suggested that this was crucial for his early rehabilitation, a multidisciplinary programme of rehabilitation involving nursing, OT and physiotherapy staff was commenced. The aims of the programme were as follows

- to increase sitting (and ultimately standing) tolerance.
- to monitor change in levels of arousal and determine whether this was related to posture.
- to use this information to monitor level of cognitive function during times of high and low arousal.

It transpired that JX's levels of arousal and responsiveness were consistently better while sitting upright. Furthermore, the increase in arousal was maintained for up to an hour after treatment. Although, levels of arousal at rest gradually began to 'catch up' JX continued to be more responsive when sitting and standing than when lying.

Goals for his early rehabilitation were now extended and the WHIM was used to identify the following common goals (i.e. to be addressed by all disciplines):

- 1) to track for 3 seconds
- 2) to maintain eye contact for 5 seconds
- 3) to make eye contact for 3 seconds
- 4) to look at the person giving attention

Each of the goals was time dated based on the rate of recovery which had already been observed. As the rate of recovery over the previous fortnight had been slow but steady a timespan of two weeks to achieve the goals was aimed for. In the event, JX's recovery began to speed up and all goals had been achieved a week later. At this stage also JX's condition was considered to be stable so he was moved from the ITU onto the ward. The rehabilitation procedure continued in the same manner i.e. interdisciplinary. Rehabilitation should begin in coma. As can be seen from the example above the principles are the same as in any other stage after brain injury – goal driven and multidisciplinary. However, rehabilitation during coma differs from that at a later stage in one main way – it is not possible to carry out a rehabilitation programme successfully as in a single discipline. In the example above, arousal levels only improved when the patient was seated out of bed initially. Had this observation not been made, staff motivation to continue with such an intensive programme may have been less. Later, behaviour occurred at infrequent and unpredictable intervals. The team involved worked together with the patient, thus allowing him have more intensive treatment (because a minimum of 3 disciplines were present each session). As the nursing staff monitored his progress on the WHIM on a 24 hour basis this facilitated an accurate picture of JX's cognitive level to be established making goal setting more realistic and achievable. The salient point is that none of the rehabilitation disciplines could have achieved what they did alone but as they did work in a multidisciplinary manner JX's rehabilitation programme was well underway by the time he moved to an acute neurosurgical ward. The programme provided for JX utilised the skills of all members of the team and, because the team used joint sessions,



several issues were addressed in fewer interventions – for example, changes in position from lying to sitting and standing affected not only arousal levels but also benefited respiratory and urinary systems, and helped prevent development of secondary complications such as contractures. Prevention of such secondary complications is an essential part of early intervention with these patients. If such problems are allowed to develop, valuable rehabilitation resources may need to be directed towards reversing these rather than towards promoting improvement in other areas.

### The Vegetative State

On the surface, it may seem as though a patient in the vegetative state is unlikely to benefit from neuropsychological rehabilitation. However, there are two main areas where input is extremely valuable – in assessment and in using observation to answer questions. These two points are illustrated in the following case description.

### Case Study 2

YZ, a 41 year old man was admitted to hospital with a severe respiratory tract infection. He was homeless and had a long history of alcoholism. Following admission to hospital his condition deteriorated and he had a cardiac arrest. He was resuscitated but did not regain consciousness. A CT scan taken at the time did not identify significant abnormality but mild atrophy was noted.

YZ was nursed on an acute medical ward. Seven days after the arrest he was recorded as having his ‘eyes open and looking around’. He was not referred to the rehabilitation team for another 4 months, for physical and cognitive assessment and rehabilitation. He was assessed using the WHIM and his level of function is shown below.

- eyes open
- eyes open and move
- attention held by dominant stimulus

These behaviours are consistent with a diagnosis of vegetative state. In addition, YZ had severe contractures of all 4 limbs and both hands were contracted so that spontaneous or purposeful motor activity was to all intents and purposes impossible. The rehabilitation programme designed for YZ was based on principles of environmental manipulation. As his injury was anoxic and no change had been observed for 4 months it was considered that his potential for change was low. However, this did not mean that rehabilitation was inappropriate – just that appropriate techniques and models were selected and used. The main goals of rehabilitation were to:

- identify any evidence of independent cognitive function
- identify any potential behaviours which could be exploited to set up a communication system

Again as in the previous case described, a multidisciplinary approach was required. As the patient was so severely physically compromised, the first area to be addressed was that of seating and positioning. As YZ groaned and grimaced occasionally it was difficult to determine whether he was comfortable or uncomfortable in different positions and types of seating. Therefore a series of behavioural observations using time sampling was used at rest, before changing position, after being seated and again when at rest in an attempt to find a seating system which would place him in a good posture to facilitate any purposeful movement possible and maximise arousal while causing no distress or discomfort. The results of this exercise were ambiguous – in the case of one seating position groaning and grimacing increased on two occasions out of three. In the cases of the other two systems tried no change was observed. It was concluded that the position where it was possible that he could be uncomfortable would be avoided and the other system was chosen.

Once seating had been satisfactorily addressed the next goal was to assess the level of cognitive function. Staff on the ward had reported that YZ enjoyed sitting at the ward window watching the traffic on the road below. As he had worked as a mechanic at one stage, this was of interest in that it could potentially have been an appropriate response to a meaningful stimulus. Consequently a series of behavioural observations using event sampling was undertaken. The behaviour of interest was eye movement and this was counted looking out the window, sitting in the ward, sitting in the hospital restaurant and lying in bed. The results were unequivocal – eye movement in all four conditions was the same.

During this time, observations of behaviour using the WHIM were taken weekly. No new behaviours had been recorded during his admission to rehabilitation although his posture and contractures had responded to treatment. While the assessment and treatment had been taking place a search had also been underway to find a suitable placement for the patient. He was discharged to a nursing home but the aims of rehabilitation (to set up a seating system such that any voluntary motor skills were facilitated and to identify if there were any signs of independent cognition) were achieved. Although no major gains in function were achieved by rehabilitation in this case, the benefits of intervention are clear. The patient's diagnosis was confirmed, a seating system was organised and based on the diagnosis, an appropriate placement was found.

### **The Minimally Conscious State**

Patients who are initially in the vegetative state may improve some considerable time after the injury. This fact draws attention to the importance of

reassessment of such patients as a change in awareness may allow significant progress to be made at a later stage. The third case description highlights this.

### Case Study 3

GA is a 23 year old man who incurred a very severe head injury in a RTA where he was the driver. Two passengers in the car were killed in the accident and GA was admitted to hospital with GCS of 3. It was also noted that he was hypoxic in A&E. He remained in coma for 26 days when his GCS reached 9 (E4,VR M3). After 3 months his total number of behaviours on the WHIM was 3 (eyes open briefly, eyes open for an extended period and eyes open and moving). He was transferred to a rehabilitation unit and after 10 months was discharged to a nursing home. He was diagnosed as being in a vegetative state. Four years later, his family were contacted as a follow-up study of all patients admitted to a previous study was being undertaken. A health professional who was in contact with the patient wrote to the researcher with the following information 'he is in a vegetative state and will probably refuse to co-operate with your assessment'. Before seeing the patient for follow up, several members of staff were interviewed about his communicative behaviour using an adapted version of the Pragmatics Scale of Early Communication Skills. Amongst the behaviours reported were 'stiffening his limbs when being dressed by a member of staff he disliked'; 'moving his head to facilitate being shaved' and 'getting agitated when he heard his family's voices when they came to visit'.

Assessment on the WHIM demonstrated that while this man was very severely brain injured he was no longer in a vegetative state and could be more accurately described as being in the minimally conscious state (Giacino et al 2002). The behaviours observed are shown in Table 1.

Table 1. Whim Behaviours.

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#### WHIM Behaviours

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- obeying simple commands
  - moving body and limbs to facilitate washing, shaving etc
  - tracking source of sound
  - nod/shake head
  - volitional vocalization to express feelings
  - silent mouthing
  - selective response to preferred people
  - turn head/eyes to look at when someone is talking
  - watches person moving in line of vision
-

In this case, the change in 'label' had major consequences for the patient. He was seen by a speech and language therapist and after a number of sessions learned to indicate 'yes' and 'no' reliably. Although very dysarthric he became able to indicate preferences. He was also reassessed by OTs and physiotherapists and began attending a Day Centre for people with Head Injuries where daily therapy was provided. Reassessment some time later showed that his attention and socialisation had improved significantly.

### **Post Traumatic Amnesia**

Another stage of recovery where the patient can be said to be in a reduced state of consciousness is the period of PTA. Patients in PTA have poor memory and are disoriented but studies by Wilson et al. (1992 and 1999) have shown that a number of other cognitive deficits are also present during this period. Behaviours observed during PTA may include any or all of the following: aggression (both verbally and physically), disinhibition, swearing, limited awareness of personal safety, no initiation of movement, passivity, lack of motivation or general lack of co-operation. Although patients in PTA manifest a large number of impairments it is not usually appropriate to assess using standard neuropsychological instruments. They have such poor attention that it is frequently difficult to test for longer than 10-15 minutes and in addition they may change so rapidly that the results of the tests are worthless by the time that testing is complete. There are a number of assessments of PTA. The best known are the Galveston Orientation and amnesia test (GOAT) (Levin et al., 1975) and the Westmead Test (Shores et al., 1986). However, both of these assessments concentrate on aspects of memory and orientation and do not address the other deficits found in patients in PTA. Thus in common with assessment of patients in the other states of reduced consciousness observation of behaviour is a valuable tool.

Although the goals and interventions used with patients in PTA will be very different, again the underlying principles will be the same. Not infrequently, referrals for patients in PTA will be prompted by difficulties in managing their behaviour in the ward environment. Many of these difficulties are caused by impaired memory, disorientation to time and place, impaired language skills, reduced reasoning, insight and judgement which leads to misperceptions causing problem behaviour. Although rehabilitation should be well underway by this stage, a large part of the intervention available here involves managing the problem, frequently by altering the environment and the behaviour of the people within it.

Many management approaches are potentially useful. Amongst the alterations, which can be made, are the following:

- Limit number of visitors – overarousal may exacerbate behaviour problems
- Treatment and assessment sessions should be for short periods

- Consistency of staff as far as possible to give a feeling of familiarity
- Therapy sessions to be carried out on the ward if possible on ward
- Simple instructions

It may also be helpful if the patient is nursed in a single room as this can decrease stimulation. However, if this is the case, care must be taken not to isolate them as this can create a whole new set of difficulties if the patient is deprived of all social contact. In those cases where physical aggression is present, simple precautions such as not treating the patient in a room alone and being aware of issues such as personal space are important.

#### Case Study 4

A 33-year old male jockey was racing when he was involved in an accident. The horse fell and he was kicked on the head. He sustained a severe head injury, a fractured left clavicle and scapula, a fractured pelvis, bilateral fractured femurs and a fractured right tibia and fibula. His GCS after resuscitation was 6 (E2, V1, M3). He was sedated and ventilated and the fractures were treated using external fixation among other procedures. 28 days after injury he was out of coma and in post traumatic amnesia. He believed he was on holiday in a hotel and persisted in trying to get out of bed. He was verbally and physically disinhibited and aggressive on occasion. He had removed part of the external fixation on his pelvis and had to return to theatre to have it refixed. He had an attention span of less than 30 seconds and became upset and aggressive when more than one person was present.

The main aim for this patient was to manage the behaviour in the short term by modifying the environment and modifying the behaviour of the people around the patient. He was moved to a single room but was checked every 15 minutes. His family and friends were requested to visit one at a time and for no longer than 15 minutes at a time. His family provided a television so he could watch sports programmes. Therapy sessions had already been held on the ward as he was supposed to be on complete bedrest and this was continued. Another important aspect of the intervention was to explain what was happening to the patient's family and friends who were very concerned that he had had a 'personality change'. Post traumatic amnesia was explained to them and the management regime was also described.

In terms of rehabilitation, the following cognitive goals were set and as in all other cases were addressed by the interdisciplinary team

- to be oriented in time, place and person
- to comprehend short sentences
- to attend for short periods

Progress was recorded daily and in the next few week he gradually emerged from PTA.

## Conclusion

Rehabilitation of patients in reduced states of consciousness, particularly in coma, the vegetative state and the minimally conscious state is an emerging issue. Knowledge and skills in treating and assessing these groups could be considered to be in their infancy in comparison to rehabilitation of patients after head injury generally. Yet, there is enormous potential for development of the whole concept and the potential benefits are considerable if the time in hospital is reduced and the overall outcome improved. Working with relatively unresponsive patients demands particular skills but can be more rewarding than many other areas of rehabilitation. To quote a physiotherapy colleague

*'you can be verbally and physically abused at work; you never receive positive feedback from the patient; they may never remember you; it's frustrating – the patients can be slow to recover, if they ever do, ... and I love it!'*

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**Appendix – The Glasgow Coma Scale**

EYES	4 =	Open spontaneously
	3 =	To verbal command
	2 =	To pain
	1 =	No response
MOTOR	6 =	Obeys commands
	5 =	Localises to pain
	4 =	Flexion – withdrawal
	3 =	Flexion – abnormal
	2 =	Extension
Verbal	1 =	No response
	5 =	Oriented and converses
	4 =	Disoriented and converses
	3 =	Inappropriate words
	2 =	Incomprehensible sounds
	1 =	No response





# Chapter 13

## NEUROREHABILITATION SERVICES AND THEIR DELIVERY

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### Introduction

If you spend an hour leafing through this book, during that time there will have been almost 25 admissions to hospital as a result of traumatic brain injury (TBI) for every 60 million people living in a Western culture (200,000 people with TBI per year). Most of these will be people with 'minor' TBI; ie brief loss of consciousness and post-traumatic amnesia lasting less than a day. Some people with minor TBI are admitted to hospital for overnight observation and then discharged, often with little understanding of the possible impact of head injury on daily life. Many of these make a good recovery within 3 months and if then asked, many would report no persisting symptoms, but not all. For example in some urban areas, persisting disability has been reported in more than 40% of people with minor TBI, one year post-injury (Thornhill et al., 2000). Nevertheless they are not routinely offered follow-up, support, education or rehabilitation if needed. During this hour, another 4 people will have been admitted with cerebral damage (excluding stroke but including subarachnoid haemorrhage) from other causes (Langton-Hewer, 1993) and a further 2 or 3 people will have sustained a severe TBI. If they have severe physical injuries they are likely to receive rehabilitation. If not, they are likely to follow a similar path to people with minor TBI unless

becoming an obvious problem because of very severe and persisting cognitive impairment, aggression or are disruptive. Even if discharged from general hospital to a nursing home, it is likely that half will receive no specialist rehabilitation before admission and few after admission (Barodawala et al., 2001, McMillan & Laurie, submitted). In the UK, hospital records will not record 20-50% of cases as having had a TBI at all, and overall, less than 30% will receive follow-up, rehabilitation or social services support (Murphy et al., 1990; Moss & Wade, 1997; Thornhill et al., 2000).

These recent studies make clear that these problems continue. What is worse, is that in the UK we know about the absence of comprehensive and well organised neurorehabilitation services, and have been reminded of this repeatedly for more than half a century (Tomlinson, 1943; Piercy, 1956; McCorquodale, 1965; Tunbridge, 1972; Royal College of Physicians, 1986, 2000; Medical Disability Society, 1988; British Psychological Society, 1989; Royal College of Psychiatrists, 1991; British Society for Rehabilitation Medicine, 1998; Royal College of Surgeons, 2000). Perhaps during this time we have learned more about what a comprehensive service needs to include (McMillan & Oddy, 2001), more about the nature and consequences of traumatic brain injury on the person and their family (Oddy, 1993; Ponsford, 1995; Willer, 2001) and more about rehabilitation and its effectiveness (Chesnut et al., 1999, Cicerone et al., 2000, Wilson, 2002).

The NIH Consensus Development Panel (National Institutes of Health, 1999) noted a number of shortcomings of current rehabilitation in the USA which are also relevant elsewhere; these include (a) the narrow focus of medical restoration approaches and the need to emphasise environmental modification to create enabling conditions, (b) the needs of high risk groups are under-represented (eg infants, adolescents and the elderly), (c) the need for rehabilitation over a lifetime, (d) difficulties in accessing rehabilitation and (e) involvement of the person with TBI and their families in decision making. It seems worthwhile therefore, to establish principles that guide services and their development.

## General Principles in Developing a Comprehensive Service

### *1. A Comprehensive service*

This should be available to all people with acquired brain injury irrespective of age. It should include a range of professional staff together with cognitive and behavioural assessments and interventions. It should include or have access to assessment and interventions for related problems such as alcohol and drug abuse.

### *2. Identification of Cases*

It is known that many people with TBI are not identified as such and hence cannot be considered for rehabilitation (Moss & Wade, 1997; Thornhill et al.,

2000). Clearly it is important to have a system which not only allows proper diagnostic labelling, but that this information is easily transferred to services that provide post acute management, treatment and support. Early after injury, some people with TBI do not think that they have problems and will not take up offers of help. However in the early stages, they can be given information about how to access appropriate services should they later wish to seek help.

### *3. Quality of Life and Users Views*

The purpose of rehabilitation is to maximise quality of life and independence. Service development and rehabilitation programmes should take account of the views of clients and their carers.

For example, people with acquired brain injury can find it difficult to mix with other client groups such as people with learning difficulties, physical disability or those who they understand to be mentally ill. This is because they feel different from these groups—people with TBI have usually led an independent premorbid lifestyle, their problems usually stem from cognitive and emotional rather than physical problems and they themselves have organic brain injury and not mental illness.

### *4. Client Centred Approach*

It is widely accepted that rehabilitation of people with acquired brain damage should be client centred, and adopt whenever possible a ‘partnership’ model between client and clinician. The importance of taking account of the view of close relatives has also been long recognised (Brooks et al., 1987b). Systems exist which incorporate this approach into the backbone of rehabilitation processes, such as client centred goal planning (McMillan & Sparkes, 2001).

### *5. Appropriate discharge*

In most cases discharge planning should begin soon after admission. The principle is that people should be moved on to the next stage in rehabilitation when they are capable of benefiting from it, this includes discharge to home, or to specialist rehabilitation.

### *6. Flexibility of Approach*

A service for people with acquired brain injury must provide for an immense range of disability and handicap. This extends from people with minor TBI who might require information and advice for a short time, to people with severely brain injury who are dependent for all care. A heterogeneous population of this kind needs a seamless service that is responsive to changing needs over time and can detect these needs by offering follow-up. A poor service may provide intervention that is non-specialist and dependent on availability rather than the patient’s needs.

### *7. Community Integration*

Most people with acquired brain injury return to the community within days or weeks of injury. A small but significant number require longer periods of inpatient treatment. Some require treatment after return to the community. It is important that wherever possible treatment and support services are developed in areas of reasonable geographical proximity to the person's eventual destination. This allows flexibility in terms of gradual return to the community and allows relatives easier access during inpatient stay. Historically there has tended to be a focus in the UK on hospital based rehabilitation services. These are needed but it has to be remembered that most people with brain injury spend most of their lives in the community and there is a need to have a range of services for community residents. Local proximity of services, should not however be at the expense of the effectiveness of treatment.

### *8. Access*

Given that people with severe acquired brain injury are likely to have impairment and disability over the long term, it is important that services are accessible to them at those times in life when they are in need. It is not unusual for individuals to live in the community for some time even though their coping skills are reduced, but then cannot manage following a life event (e.g. death of a carer) when they require further help.

### *9. Liaison between Services*

In the UK it is acknowledged that services which exist for acquired brain injury do not always communicate well with each other, or with other relevant services such as Child and Adolescent, Mental Health, Forensic, Drug and Alcohol Abuse and Older Adult. The principle should be for provision of the appropriate service(s) at a time that the client needs it; systems need to be developed to allow closer interagency and within agency working.

### *10. Evaluation*

A key focus in Health Services now is the effectiveness of intervention. New services that are being created should have an evaluation system inbuilt at the outset and existing services need to develop such a system. Although this system should include activity (e.g. numbers and types of cases seen), it should also go beyond this to other key result areas. There should be objective indicators of change in disability or handicap for treatment services and outcome in terms of maintaining or enhancing quality of life for other services that are not treatment focussed.

## **Issues in Service Planning**

These are considered under five main headings, which are service need, component services, liaison and communication, staffing and funding.

### *1) Service need*

A recent study reported findings on a cohort of people with TBI admitted to Glasgow hospitals over a period of one year (Thornhill et al., 2000). The study was unusual because it included all people 14 years and over and did not exclude cases on the basis of previous history or other concurrent problems. It therefore represents the clinical load and case-mix that a service would have to deal with in practice. They found that 3,000 people with TBI were admitted in the year (approximately 330/100,000 population). About 500 remained in hospital for 48 hours or more. Of these more than half were discharged in a week or less, about 80 were admitted for more than 4 weeks and 45 were aged over 70. The admission rate found by Thornhill et al. (2000) is a little higher but not dissimilar to earlier studies (270-310) in Scotland (Jennett & MacMillan, 1981) and in England and Wales (Field, 1976), with 5-7% of people with TBI sustaining a severe injury or worse (Glasgow Coma Scale score < 8), (Lewin, 1968, Miller & Jones, 1985). Thornhill et al found more than 40 percent of their representative sample were disabled at one year follow-up of a representative sample, including more than 40% of those classified as minor brain injuries. At one year only 47% of the disabled survivors had received hospital follow-up, only 28% rehabilitation and only 15% contact from social services (see also Kay et al., 2001).

It seems that there has been a threefold decline in death/serious injury resulting from road traffic accidents between 1973 and 1993 (Broughton 1997). This is probably as a result of improved safety (such as seat belts and cycle helmets), developments in medical care and treatment-for example published guidelines for trauma care, the availability of CT scanners in local hospitals, early transfer to neurosurgery and the continuing development of pharmacological treatments (Teasdale, 1995). Nevertheless the persisting high incidence and one year prevalence of TBI reported in Thornhill et al's cohort study, means it remains the most common cause of acquired brain damage in young adults and is one of the top five most common neurological conditions overall. However caution should be applied when considering the size of service components locally, given the wide range of incidence reported in one study in the North West Region of England. Although the overall incidence of admissions of people with TBI was similar to reports from other studies (295/100,000) there was a huge range within its 19 component districts (88-885/100,000), and less than a quarter had an incidence within the range normally quoted for the UK (Tennant et al., 1995). A wide range of incidence has also been reported in the US (Kraus & McArthur, 1996).

### *2) Component services*

In principle these are the easiest to determine, and are discussed later in this chapter. A key issue is to what extent should a planner make use of existing services-or develop these, and to what extent should new services be planned. The overall model will obviously be influenced by services already present. TBI results in disabilities which can be of relatively short duration, or which

can be lifelong, which may require inpatient or residential stay or return home, which can result in difficulty with basic daily living skills ranging from minimal to complete dependence, which can end with return to previous employment or make return to work impossible. Given that outcome is so wide ranging, no single unit is likely to cater for all needs and instead a multi component system is more appropriate if a goal of providing the right input at the right time for the client is to be achieved.

### *3) Communication and Liaison*

A system is needed for identification that distinguishes between those who have facial/head lacerations and cerebral injury, which records the fact of TBI even when there are more acute somatic issues to deal with at the time, and which routinely refers for specialist assessment or to the next stage in rehabilitation. People with brain injury may have co-existing problems that bring them into contact with other services such as drug and alcohol abuse, mental health, learning disabilities and forensic. Inter-agency liaison is needed to properly deal with these issues, and clearly worked referral pathways are required to achieve this. People may fall through a 'therapeutic net' not only between hospital and community, but also when they cross age barriers between adolescent-adult and adult-older adult. Most neurorehabilitation services are for the younger adult. Traditionally younger adult refers to people aged 16–64, the former to allow for developmental and educational considerations and the latter retirement and frailty. However given the trend for earlier retirement, and physical good health into the 70s and beyond it may be worth giving careful consideration to upper age restrictions for neurorehabilitation services. Continuity requires good liaison with child and adolescent and older adult services.

Long term needs need to be considered and account taken of vulnerability to life events that the TBI causes. Someone may do well in rehabilitation and return to the community to a good quality of life but may not be able to cope with life stresses following a bereavement, relationship difficulties, moving house or a change of job. At these times they may need further help which should not only be available but should be readily accessible and within a reasonable period of time. Hence people with acquired brain injury and their relatives have to have been told how to get help and this should be available without barriers (e.g. by self referral).

### *4) Staffing*

Reviews of workforce planning for brain injury rehabilitation services in Scotland make clear that there is in fact little co-ordination between planning workforce numbers and service developments. Commonly services are planned locally with little consideration of where the staff might come from and this can result in problems with recruitment or retention, the latter resulting from a finite pool of trained staff circulating around services. Workforce planning is obviously a long-term issue, where the numbers of professionals

needed has to be projected several years ahead of the implementation of service plans. For example, in the UK there is a shortage of clinical psychologists generally. Training psychology graduates in clinical psychology takes three years, with a further six years before they would be considered to be sufficiently experienced to take charge of a rehabilitation facility. What is needed is central co-ordination of workforce planning, informed by the professions, by training courses and by local planning initiatives and government policy for health. Difficulties caused by poor co-ordination of workforce and service planning are often greatly underestimated.

Services can founder if dependent on a charismatic and experienced individual leader who leaves. A critical staff mass reduces this possibility. It means that sufficient experienced and senior staff are available to allow for random variations in recruitment and retention without the service deteriorating catastrophically. Having a critical staff mass at key points in the Service means that less skilled staff can be given professional support and training to enable them to work effectively in parts of the Service where they may be the only professional in that discipline.

### *5) Funding*

Obviously many initiatives have foundered here. Insurance claims can fund rehabilitation packages. Health insurance may provide funding but this is often strictly time limited. In the UK insurance funding tends to operate in the independent sector, and surprisingly is found rarely in the National Health Service; the NHS funds both NHS operated rehabilitation facilities and those in the independent sector. In Australia, the no fault compensation scheme provides rehabilitation for people with TBI resulting from accidents. In the USA rehabilitation tends to be funded by health insurance, and is often more strictly time limited for this reason. Clearly there is a political dimension to planning if funding is to become available to the extent required to provide a comprehensive service. In an era of cost constraints for health and social services, it is worth noting estimates of the financial cost to the community of people hospitalised because of TBI over their lifetime. In the mid 1980s, Max et al. (1991) estimated this to be over 115,000 US dollars per person, providing an unambiguous argument for reducing this cost, by effective neurorehabilitation.

Purchasers must be encouraged to achieve a balance between financial cost and impact of a service on disability/handicap or quality of life. This requires meaningful audit of clinical input as well as measurement of outcome. Other non-specific activities such as information giving and staff training must also be accounted for. Clearly research should be part of health planning, (e.g. the development/effectiveness of new treatment techniques).

Purchasing priorities can be altered by public policy. Legislation can provide a mandate for the development of services. For example allowing the development of state co-ordinated services in Minnesota (Murrey et al., 1998). In 1996 the US Congress passed the TBI Act, to improve access



to services and enhance prevention, surveillance and research and funded government departments in order to do this; States can apply for grants and have to match funding. In some states in the USA, a proportion of fines from road traffic offences are put towards trust funds for brain injury and spinal cord injury rehabilitation (Vaughn & King, 2000). Nevertheless in the USA there remains a view that access to rehabilitation is dependent on the ability to pay, that services are patchy, may not be available for the length of time needed by the client and that the concept of a seamless service is a distant hope (Eazell, 2001). In Australia most people with brain injury receive rehabilitation automatically under the Transport Accident Commission and Work Cover schemes together with no-fault compensation; this seems to allow a more comprehensive and less time limited service than currently found in the UK or USA (Ponsford, 2001). The ratio of cost to outcome (cost-effectiveness) has been reported, although well controlled studies on brain injury rehabilitation are rare (see Cardenas et al., 2001). They could be used to argue for changes in funding priorities; however it is more likely that pressure from large and well organised voluntary groups supported by professionals and research evidence, will lead to root changes in legislation that will have a more substantial and widespread effect.

### **The Components of a Service (see Fig. 1)**

These numbers are based on numbers of people requiring a service per one million of the population.

#### *Early Management and Rehabilitation*

Soon after trauma, a decision has to be made about whether there is a TBI and if so whether it may be severe. Given the association between TBI and alcohol drinking it may not be clear whether an individual is intoxicated, in PTA or both. In other cases there may be concern over developing intracranial complications. Hence there is a need for a short-term observation facility, for up to 48 hours in Accident and Emergency (Royal College of Surgeons, 2000). Although formal rehabilitation is usually not practical, staff require skills in managing patients who may be difficult because of being confused and disorientated, and as a result are difficult to manage.

People with multiple injuries are likely to be admitted to surgical, orthopaedic or general medical wards. In the UK, people without severe physical trauma who remain in coma, may be admitted to any ward where a bed is available. This includes young people with TBI admitted to wards for the elderly, oncology wards and so on. Ward staff often have little experience in dealing with these cases, who can be disruptive to other patients because of post traumatic amnesia (eg getting into the wrong bed, wandering, shouting and swearing, being over familiar). Discharge can be miss-timed because of poor understanding of the likely time course of recovery, rehabilitation

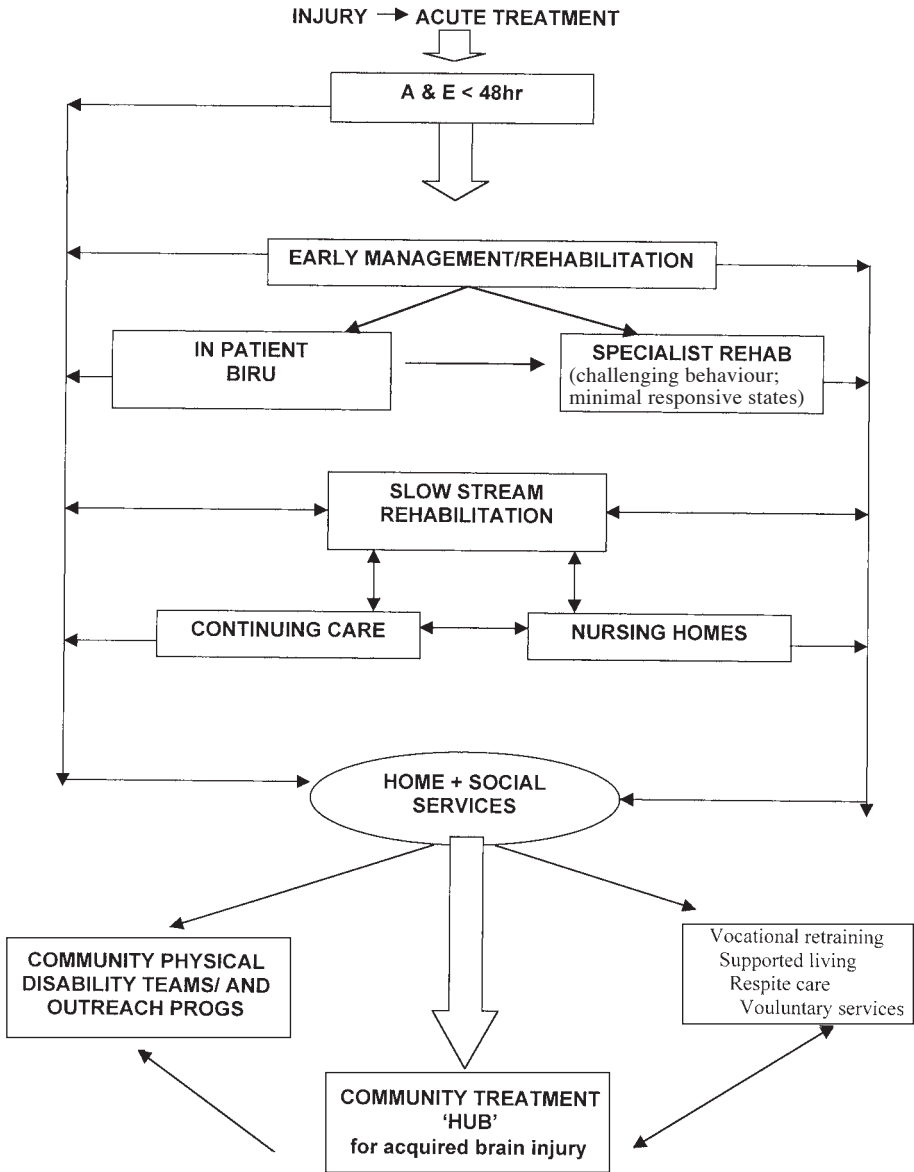


Fig. 1. A model for neurorehabilitation services for acquired brain injury.

needs and available resources. Some people are admitted to specific wards for specific interventions (eg orthopaedic) and are discharged without record or referral regarding the TBI.

For those people with TBI admitted for more than 48 hours, an early management and rehabilitation ward is needed. Staff would be experienced in dealing with these cases and the ward would have clear referral links with inpatient rehabilitation and community services. They would have an understanding of key concepts of help in managing these patients and promoting best outcome, including sensory regulation (Wood, 1991), capacity to learn even in post traumatic amnesia (Wilson et al., 1992), forestall unnecessary emergence of persisting challenging behaviour (Johnson & Balleny, 1996), appropriately use psychotropic medications and provide measured early education to relatives about brain injury. Patients would be admitted once medically stable/after surgery. The main goals would be to actively encourage referrals of all people with TBI admitted for more than 48 hours; monitor prolonged coma and gauge signs of recovery; provide an environment which is safe; prevent contractures and sores developing and maintain posture; offer active rehabilitation for those who are able, taking account of likely fatigue, poor stamina and need for rest; discharge to the next appropriate step in rehabilitation having initiated this process at an early stage in concert with social services as appropriate.

Ideally there should be one ward of this kind in each hospital where there is a major Accident and Emergency receiving unit. Hence, in a city with a population of a million there may be several such sites. One study reported over 550 people with TBI/million /annum admitted for longer than 48 hours; length of stay will vary but more than half will be discharged in 3–7 days, and 84% within a month hours (Kay et al., 2001). To prevent bed blockages, services for people who are slow to recover or in prolonged coma are needed in addition to intensive inpatient rehabilitation and community resources.

### *Inpatient rehabilitation*

A small proportion of people with acquired brain injury require traditional residential, specialist physical therapy. Sixty-eighty beds per million are needed for rehabilitation of young adults with physical disability from all causes (Royal College of Physicians, 2000); about six would be needed for people with TBI. The treatment team consists of nurses, physiotherapists, occupational therapists, speech and language therapists, clinical psychologists, social workers and leadership by medical staff. Rehabilitation is usually intensive (eg 5 hrs/day) and may last for up to 12 months, but in the UK lasts more commonly for 2–3 months. Trends towards reducing the intensity and duration have been noted in the USA (Eazell, 2001), but there is danger that outcome will become less effective in reducing disability and handicap.

Psychosocial rehabilitation is geared towards minimising the impact of cognitive and emotional impairments prior to discharge into the community. The team would be as above, with less emphasis on physical therapy. Leadership is usually non-medical and there may be greater emphasis on generic

workers. This reflects the model, which is geared towards psychological approaches to reducing dependency (Wood & Worthington, 2001). Units of this kind can usually manage challenging behaviour that is mild or moderate (ie does not involve danger to self or others). Residential units more specifically orientated towards psychosocial interventions are often based on the milieu approach, where the environment itself is devised as a therapeutic medium, in concert with specific individual and group-based programmes sometimes including psychotherapy; admission is often for 6-12 months and there is some evidence for effectiveness from controlled trials (Willer et al., 1999, Wood et al., 1999).

### *Severe Challenging Behaviour*

About 1 person per million per annum will develop severe and persisting challenging behaviour, where the person is a danger to themselves or others or their behaviour leads to significant social disadvantage. Almost ten times this number might have persisting behaviour problems that are less severe and affect daily life adversely (Johnson & Balleny, 1996), but may not need inpatient treatment. Such behaviour has traditionally been treated in specialist units, which adopt a therapeutic milieu in addition to specific behaviour modification programmes tailored to each individual. Few such units are needed, but they require high staffing ratios and high quality of intervention to be safe and effective. These units are usually staffed by clinical psychologists who commonly lead the clinical team that includes medics, occupational therapists, speech and language therapists, social workers, generic workers. They treat chronic, severe behaviour problems by designing a programme which manipulates reinforcers of behaviour and gives immediate and consistent response to inappropriate behaviour in an environment which itself operates as a therapeutic milieu. This is required especially when an individual has little or no insight into the inappropriateness of the behaviour. There is clear evidence for the effectiveness of interventions of this kind (see Alderman, 2001) although treatment can be lengthy and is often 6-12 months in duration (Eames & Wood, 1985).

Neurorehabilitation units that do not specialise in behaviour treatment might manage difficult behaviour during its natural course by providing a safe and understanding environment and a programme of care geared towards this end. Occasional cases have been reported where treatment has been successful in non-specialist inpatient units that have clinical psychology support. They often employ additional nurses to reduce disruption and who are trained to apply the behaviour programme for that client (McMillan et al., 1990, Johnston et al., 1991). Nevertheless, this can prove difficult (see Alderman, 2001), often causing tensions within these units because of the disruption to other patients and staff and the common expectations of ward staff that unless behavioural treatments show immediate effects it is inappropriate for violent patients to remain with them.

*Minimally Conscious or Responsive Cases*

This refers to people who are or may be in a low awareness state or where cognitive ability is unknown because of severe physical impairment. There may be a question of whether the individual is in a vegetative state. Less than one percent of hospital admissions will pass into a persisting vegetative state (Kraus & McArthur, 1996) and only a small proportion of these survive beyond 12 months, but a few survive for many years (Jennett, 2002). They tend to block acute beds in general wards for many months and are then discharged to nursing homes where they receive neither rehabilitation nor further specialist assessment. Usually there is little expert advice available with regard to whether the person is progressing and is moving out of the vegetative state, whether they would be able to communicate if the appropriate response medium was found and the person was trained to use it or whether they are not recovering. Clearly there are very different implications in terms of management for someone who is 'locked in' with relatively intact cognitive functioning and an inability to express this and someone who is in a vegetative state with absence of cognitive function. This is also a key issue for relatives who may be unable to process their grief because they maintain hope that their loved one can understand them.

A specialist unit with 3–4 beds/million is required, which will carry out repeat assessments, will give appropriate nursing care, can provide any treatments that might possibly be considered effective (such as sensory stimulation), will liaise with and counsel relatives and will give an informed opinion about prognosis and needs. This could be a part of another inpatient unit such as the Early Management Unit, or an inpatient rehabilitation unit. The effectiveness of sensory stimulation treatments is not proven (McMillan & Wilson, 1993), but in the least, can allow relatives to feel they are making a contribution to care.

*Community 'Hub' for Treatment of Psychosocial Problems*

Traditionally, neurorehabilitation facilities have concentrated on physical rehabilitation. Over the past twenty years the need for rehabilitation of problems associated with cognitive and emotional problems has become increasingly apparent, as has awareness that most disabled people with TBI do not have debilitating physical problems and few have access to rehabilitation treatments. The problems that they have are nevertheless significant and stem from combinations of cognitive deficits, reduced motivation, impaired insight, irritability and other changes in personality. Community based treatment is needed given that these people will spend most of their lives after injury in the community. Furthermore such services may be needed intermittently over many years, because this group tends to be young, with a near normal lifespan but with reduced ability to cope with life stress. Day units specifically orientated towards psychosocial interventions are often based on a 'holistic' approach, where the individual is considered as a whole, in concert with specific individual and group-based educational and treatment

programmes sometimes including psychotherapy. Admission is often for 6–12 months, and there is some evidence for overall effectiveness (Prigatano & Fordyce, 1986; Teasdale et al., 1993; Ben Yishay, 1996; Klonoff et al., 2000; Wilson et al., 2000).

A community treatment unit can act as a ‘hub’ for local community services. It requires a day centre base, allowing clients the option of being seen at home or at the Centre, and in this way making the most efficient use of clinical time. It also allows for group based programmes to be established and ease of access to several members of the multidisciplinary team at once. Ideally everyone admitted with TBI would be automatically referred and followed-up, (including people with minor TBI admitted to Accident and Emergency). It would act as a ‘hub’ for less specialised community based ‘spokes’. Its six major roles are discussed below. These roles may apply to other service components, or given a different configuration of services but are given here to emphasise the way in which a unit of this kind can serve as a ‘hub’ for community rehabilitation.

### *1. Follow-up*

The establishment of routine or automatic referral pathways of all people admitted to hospital after TBI is crucial. All people hospitalised after TBI would be actively followed up. This facilitates early hospital discharge as well as preventing people with TBI falling through the therapeutic net. However, to ensure this, a reliable and valid system for coding traumatic intracerebral damage is needed (Jennett, 1996).

### *2. Treatment*

The service would offer time limited treatment interventions. These would involve support and advice to relatives. Included would be people hospitalised with minor TBI; the provision of limited/brief intervention for people admitted to hospital with less severe TBIs, can lead to fewer symptom complaints and reduced social disability at follow-up (Wade et al., 1998). Group and individual based programmes would be available to people with more severe disabilities. Physical therapy would not be offered but would be found in the community elsewhere. Deterioration of function and the development of new problems might be reduced by proactive follow-up and successful treatments are more likely to generalise to the environment in which the individual normally lives, than they would in an artificial hospital or ‘hotel’ based setting.

The service would offer clinical interventions designed not only to monitor and maintain function (including managing changes in circumstance), but also, where realistic, to reduce disability using rehabilitation techniques embedded in a client centred goal planning system (McMillan & Sparkes, 2001). In this way deterioration in function and the development of new problems might be minimised and successful treatments should be best placed to generalise to the actual environment in which the individual normally lives rather than an artificial hospital or ‘hotel’ based setting. Interventions would

include functional changes in the environment to prevent problems arising, strategies to circumvent problems, treatments which might reduce cognitive impairments and psychological effects (eg depression, anxiety, PTSD) and the development of greater insight through education and role play.

### *3. Critical staff mass*

As described above this would reduce dependency on any individual in the team and makes the effectiveness and viability of the team less vulnerable to problems resulting from acute staff retention.

### *4. Inter-agency liaison*

People with traumatic brain injury can be involved with a number of other health provisions including mental health, drug and alcohol abuse, learning difficulties and forensic services. There is a clear need for liaison to ensure continuity of input and that the right input is provided at the right time; a key feature of the case management role of the centre. A community unit of this type is also key in liaising with adolescent services to ensure continuity of care as the individual passes in to adulthood. The same is true of older people in the adult service who become the responsibility of the older adult services.

### *5. Staff training*

Professional training usually contains a large generic component and there is often limited training in neurorehabilitation. There is a need for training some of which has to take place locally including for staff at the 'spokes'. Training is at three levels; for local professionals who specialise in neurorehabilitation but need to keep apace of new developments; for local professionals who see people with brain injury infrequently; for care assistants/ carers who may be involved intensively with an individual with brain injury but have had no training.

### *6. Evaluation*

Purchasers of services must be encouraged to consider costs in terms of value. This requires audit of clinical input as well as measurement of outcome. The other non-specific activities such as information giving and staff training must also be accounted for. Specific research issues should be addressed, such as the effectiveness of new treatment techniques.

### *Community Based Outreach and Rehabilitation*

There has been a rapid expansion of community based physical therapy teams in the past decade. These are typically multidisciplinary (but are under-resourced in terms of clinical psychology), see people in their homes (but do not have opportunity to see people as groups in Centres, reducing efficiency), their main client groups are stroke and multiple sclerosis (about 5% of caseload is those with brain injury). In the UK intervention is time limited, a minority are offered routine follow-up and the intensity of input routinely

offered is limited (McMillan & Ledder, 2001; Enderby & Wade, 2001). Although this resource is used only by a small number of people with TBI it is valuable and needs to be linked not only to hospital discharge but also with the Community 'Hub' for acquired brain damage. Recent randomised control trial evidence suggests that a community based team, seeing clients usually in their own homes for 7 months can improve self-organisation and well being, with no differences found for socialising, employment or mood (Powell et al., 2002).

### *Vocational Re-entry*

Return to competitive employment is greatly reduced following severe brain injury, with less than a third working 2–7 years after injury (Brooks et al., 1987a; McMordie et al., 1990). In addition to obvious financial implications for the person with brain injury and their family, loss of work is often associated with reduced self-esteem and feelings of lack of worth. In addition to formal rehabilitation schemes, a range of other options that include work retraining and supported work is required. Key to this is assessment of capacity and guidance about feasible options.

Supported employment schemes have been advocated in the USA, which incorporate client assessment, client advocacy, matching of client capacity to job needs, training at the job-site by a job coach, developing job retention strategies and follow-up which includes assessment of work performance (Kreutzer et al., 1988). Support may be required for 10 months, reducing in intensity during that time and with relative independence being achieved after about 5 months. Overall an average of about 300 hours of intervention is needed, but with input of this kind and for this length of time, return to work can be increased dramatically from 36% to 75%, with an average time in work of 10 months at follow-up (Wehman et al., 1993). Wall et al (1998) found greater return to work (from 32% *pre-injury* to 59%) after a 10-week community based, work retraining programme (work adjustment training and supported employment), with continued employment at 18 month follow-up. In these studies, return to work is often in a lower capacity (and with lower salaries) than pre-injury, which may lead to dissatisfaction in the longer term as suggested by one 5 year follow-up (Ashley et al., 1997).

### *Case Management*

Where the community is geographically dispersed over a wide area, or where there are few specialists in head injury, or where an individual requires a care regime, a case management system may be effective in monitoring and maintaining the individual in the community. This is the model where the case manager acts as a co-ordinator of (community) service provision and advocate of the patient. If there is a limited rehabilitation system to refer people to Case Management may be ineffective in changing outcome (Greenwood et al., 1994) except for severely dependent cases. Nor is there compelling evidence



from studies on other patient groups, for effectiveness of case management in improving service provision or reducing costs of care and time off work (Leavitt et al., 1972; Perlmann et al., 1985; Wasylenski et al., 1985; Chalis & Davies, 1986). If there is a comprehensive system as suggested here, then brain injury case management may be redundant. This may not be true where case managers are financially empowered and can initiate an end to rehabilitation provision, such as in the USA (Dixon et al., 1988; Deutsch & Fralish, 1988).

### *Social Support*

Social care is a key service component. The purpose is to enhance and maintain quality of life, as distinct from treatment (designed to reduce disability of handicap). Included are social services care support, day centres, sheltered work, respite care, legal advice including advice and help about benefits. In addition the voluntary sector provide services that are relevant to leisure, education and care. There are few day centres specifically for people with brain injury in the UK; Headway Houses (organised via the National Head Injuries Association) are an important exception. Day centres can at a minimum provide a routine and some sense of variety in day to day life and prevent the person with brain injury becoming effectively housebound, lonely and feeling stigmatised because they find it difficult to fit in to activities run by the able bodied and are not always well received by them. When suitable, opportunities designed to integrate people with brain injury into support systems and activities for use by the general population can be taken advantage of. However, by nature of the brain injury, these people differ from some other disabled groups. Personality and behaviour changes can cause difficulty with social integration and to avoid them withdrawing and become isolated, specific support services for people with brain injury can be a solution and are needed.

Included here must be support for relatives. Many studies attest to the strain associated with living with people whose personality has changed as a result of TBI, often accompanied by financial stringencies and social isolation (Oddy et al., 1985; Brooks et al., 1987b).

### *Residential Care*

There is little published about people with brain injury in nursing homes. A recent study surveyed all nursing homes in Glasgow and found 100 young adults with acquired brain damage per million. Documentation provided to the nursing homes was poor. This meant that reason for placement and rationale for medication were unclear. Proactive review of needs was uncommon. Many were taking several medications prescribed preadmission and not reviewed. A minority had rehabilitation before or after admission. Many were in mixed units with older adults and people with learning disabilities. Specialist residential homes with regular Consultant review and access to rehabilitation are recommended (McMillan & Laurie, submitted).

### *Supported Living*

A small proportion of people with TBI cannot live independently and are unable to live with relatives. In this case placement will often be in group homes or residential nursing homes. Even if suitable in principle, the latter most commonly have a mixture of residents, most of whom are elderly and some are learning disabled, and hence in practice are not ideal for young people with TBI. Group homes are more commonly found for ex-drug and alcohol abusers and people with mental health problems and less commonly for people with brain injury people specifically; this echoes disadvantages stated previously in terms of care staff not building expertise with this client group.

### *Respite Care*

There is a need not only to provide services to allow people with brain injury and their relatives to live apart for short periods. These facilities need to be available not only for planned breaks, but for periods of family crisis. This can be difficult to achieve given the unpredictable nature of crises and the tendency for holidays to be popular at specific times of year. Included would be (traditional) residential accommodation near to the locality, sporting schemes for disabled people, which ideally specialises in brain injury and holiday centres providing breaks for people with brain injury. Short breaks can make use of day centres, sheltered or voluntary employment, sporting and leisure facilities. Social services care support or 'buddy' systems can allow people with brain injury access to leisure and shopping facilities independently from their family.

### **Children, adolescents and older adults**

It is tragic that that most discussions about services for people with acquired brain injury focus on sub-populations, most usually young adults with TBI and older adults with stroke. This may reflect the poor service available generally. However the notion of a comprehensive service should not be that it starts at 16 and ends at the age of 65. It is not suggested that service components serve all ages, but that services are designed to be seamless across age barriers, and that artificial barriers are not maintained (e.g. excluding an active 65 year old from intensive rehabilitation with younger people). Although the incidence of TBI is greatest in young adults, there are also peaks under the age of 5 and over 75 (Kraus & McArthur, 1996).

Arguments for strictly compartmentalising these services are in part historical and based upon numbers (e.g. that there are several fold more disabled older than younger adults and limited services for the latter), outdated views of age (e.g. that people aged 65 and older are necessarily less active). It might be more equitable to work towards a system where people are included on the basis that they can benefit from the programme that has been developed for their needs. Education has to be accounted for with children, although a greater degree of flexibility, allowing access to adult services and routine

referral pathways across the adolescent-adult barrier would help until a comprehensive rehabilitation service is available to children and adolescents.

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# Chapter 14

## THE FUTURE OF NEUROPSYCHOLOGICAL REHABILITATION

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### Introduction

Neuropsychological rehabilitation is coming of age. In a recent book on neuropsychological interventions, Eslinger (2002) said ‘Professionals who reported psychometric testing data in relationship to a particular lesion location or disease process were somehow perceived as more experimental and scientific, while rehabilitators were perceived as seeking a therapeutic effect from a theoretical and non-experimental approach’ (e.g. how can we make this person better?) (p. 4). Although this attitude still prevails in some quarters, there is increasing recognition of the value and effectiveness of rehabilitation to improve the quality of life for people with brain injury and enable them to survive in their most appropriate environments. The contributors to this book demonstrate how theory and practice inform each other and can result in the successful remediation of real life problems.

Since I started working in the field of brain injury rehabilitation twenty three years ago, I have noticed several changes and these are almost certainly changes for the better. I cannot say that all these changes are new developments as Poppelreuter, for one was describing some of them as long ago as 1917 (Poppelreuter). Indeed, the rehabilitation programmes set up for the German soldiers who survived gun shot wounds to the head in the first world war are better than many rehabilitation programmes in existence today. Nev-



ertheless, the early twenty first century is an exciting time to be working in rehabilitation and the future looks promising. To my mind, recent changes that I feel will be most influential in neuropsychological rehabilitation for the next decade or two are:

1. Rehabilitation is now seen as a partnership between people with brain injury, their families and health service staff.
2. Goal planning is becoming increasingly established as one of the major methods for designing rehabilitation programmes.
3. Cognitive, emotional and psychosocial deficits are interlinked and all should be addressed in neuropsychological treatment programmes.
4. Technology is playing (and will continue to play) an increasing part in the understanding of brain injury and in enabling brain injured people to compensate for their difficulties.
5. Rehabilitation is beginning to take place in intensive care, it is not solely for those people who are medically stable and
6. There is a growing belief that neuropsychological rehabilitation is a field that needs a broad theoretical base incorporating frameworks, models and methodologies from a number of different fields.

Let us now consider each of these six points in turn.

### **Rehabilitation as a Partnership between Clients, Families and Health Care Staff**

In 1991, McLellan (1991) defined rehabilitation as a two way process between people disabled by injury or disease, health care staff and members of the wider community. He believed that, unlike surgery or drugs, rehabilitation is not something we 'do' to people or 'give' to people. Instead, the disabled person is part of a two way interactive process. This represented a move forward. For many years the person with disability was told what to expect in and from rehabilitation, the rehabilitation staff determined what areas to work on, what goals to set, what was achievable and what was not. Sometime in the 1980's, the philosophy began to change – at least in some centres – so that in many rehabilitation programmes today, clients and families are asked about their expectations, rehabilitation goals are discussed and negotiated between all parties involved. The focus of treatment is on improving aspects of everyday life and, as Ylvisaker and Feeney (2000) say, rehabilitation needs to involve personally meaningful themes, activities, settings and interactions. Evans, this volume Chapter 4 illustrates this approach in his case description of David, a man with attention and planning problems following a stroke. Tate, Strettles and Oseteo, this volume Chapter 8 also imply the importance of partnership in the descriptions of their service for people with brain injury and Clare, this volume Chapter 8, describes how people with dementia select their own targets for treatments. McMillan, too, in Chapter 13 states that cli-

ent centred approaches are desirable in the delivery of rehabilitation services. This is a much healthier state of affairs than providing clients with experimental or artificial material to work on. Motivation is likely to be increased because all are working on real life problems and generalisation difficulties are avoided.

### **Goal Planning as a Means of Designing Rehabilitation Programmes**

One of the ways of ensuring a client centred approach and achieving a genuine partnership is to use goal planning to devise treatment programmes. Goal planning allows treatment to be tailored to the individual needs of people with brain injuries and their families. Although this approach is not new and has been used in rehabilitation settings for a number of years and with a number of diagnostic groups, including people with brain injury, in the last 10 years more and more centres have adopted this method to plan rehabilitation. Goal planning makes sense to staff, to clients and to families.

Houts and Scott (1975) suggest there are five principles involved in goal planning. First, involve the patient. Second, set reasonable goals. Third, describe the patient's behaviour when the goal is reached. Fourth, set a deadline. Fifth, spell out the method so that anyone reading it would know what to do. McMillan and Sparks (1999) add to this list. They say that goals should be client centred, they should be realistic and potentially attainable during admission, they should be clear and specific, have a definite time deadline and be measurable. They also say that long term and short term goals are required. Long term goals usually refer to disabilities and handicaps as the purpose of rehabilitation is to improve everyday functioning and these goals should be achieved by the time of discharge from the centre. Short term goals are the steps required to achieve the long term goals.

The process of goal planning involves allocation of a chairperson, formulation of a plan of assessment, having goal planning meetings, the drawing up of a problem list and plans of action, and the recording of whether or not the goals are achieved (or, if not achieved why not). The main advantages of this system are first, the aims of admission are made clear and explicitly documented; second, patients or clients, their families and carers are all involved; third, some outcome measures are incorporated into the treatment programmes and fourth, the artificial distinctions between outcomes and patient/ client activities are removed. Although, in principle, it is possible to make the goals too easy, there are ways round this. McMillan and Sparks (1999) believe one can avoid making goals too easy through staff training and experience while Malec (1999) describes goal attainment scaling to allow a measure of comparability between different goals. It is probably true to say that goal planning is one of the most sensible outcome measures but should be used alongside other more standardised measures such as measures of handicap, mood, psychosocial functioning and demographics. Wilson, Evans and

Keohane (2002) provide a fairly detailed description of goal planning used in the successful treatment of a man who sustained both a head injury and a stroke. Manly, this volume chapter 3, discusses the targeting of functional goals in treatment; Evans, chapter 4 and Wilson, chapter 5 both refer to goal planning in their descriptions of treatments. Williams, chapter 6 says goal setting procedures are one of the main components of programmes dealing with cognitive and emotional disorders and the recognition of the importance of goal planning is directly or indirectly addressed in almost every chapter in this volume.

### **Cognitive, Emotional and Psychosocial Deficits are Interlinked**

Although cognitive deficits are, perhaps, the major focus of neuropsychological rehabilitation, there is a growing awareness that the emotional and psychosocial consequences of brain injury need to be addressed in rehabilitation programmes. Furthermore, it is not always easy to separate these out from one another. Not only does emotion affect how we think and how we behave, cognitive deficits can be exacerbated by emotional distress and can cause apparent behaviour problems. Psychosocial difficulties can also result in increased emotional and behavioural problems and anxiety can reduce the effectiveness of our intervention programmes. There is clearly an interaction between all these aspects of human functioning as recognised by those who argue for the holistic approach to brain injury rehabilitation. This approach, pioneered by Diller (1976), Ben-Yishay (1978) and Prigatano (1986) is committed to the belief that the cognitive, psychiatric and functional aspects of brain injury should not be separated from emotions, feelings and self-esteem. Holistic programmes include group and individual therapy in which patients are encouraged to more aware of their strengths and weaknesses, helped to understand and accept these, given strategies to compensate for cognitive difficulties and offered vocational guidance and support. Prigatano (1994) suggests that such programmes appear to result in less emotional distress, increased self-esteem and greater productivity. Prigatano (1999) and Sohlberg and Mateer (2001) both describe the importance of dealing with the cognitive, emotional and psychosocial consequences of brain injury. Wilson et al. (2000) present a British holistic programme based on the principles of Ben-Yishay (1978) and Prigatano (1986). This is the Oliver Zangwill Centre for Neuropsychological Rehabilitation in Ely, Cambridgeshire. Although, these programmes appear to be expensive in the short term, they are probably cost effective in the long term (see Wilson & Evans, 2003) and Prigatano (2003).

In this volume, several chapters are concerned with cognitive difficulties (e.g. Chapters 3,4,5, 6 and 10). Williams, Chapter 7, is concerned with the rehabilitation of emotional disorders following brain injury; he says that survivors are at particular risk of developing mood disorders. He goes on

to say that this area is one of the key areas for development in neurological services. Social aspects of rehabilitation are the concern of Tate et al in Chapter 8. They describe a service in Australia that many countries must envy. Behaviour disorders are targeted by Alderman, Chapter 9. He works at The Kemsley Unit, St Andrews Hospital, Northampton – a unit that treats some of the most severely disturbed brain injured people in the United Kingdom. Anderson, Chapter 11 discusses cognitive, social and behavioural problems in children who have survived brain injury; she says that it is rare to find holistic programmes for children and McMillan Chapter 13 addresses several aspects of holistic treatment approaches.

### **Technology in Rehabilitation**

The increasing use of sophisticated technology such as Positron Emission Tomography and Functional Magnetic Resonance Imaging is enhancing our understanding of brain damage (see for example Menon et al., 1998). To what extent these methods can improve our rehabilitation programmes remains to be seen. What is clear is the value of technology for reducing everyday problems of people with neurological damage. One of the major themes in rehabilitation is the adaptation of technology for the benefit of people with cognitive impairments. Computers, for example, may be used as cognitive prosthetics, as compensatory devices, as assessment tools or as a means for training. Given, the current expansion in information technology, this is likely to be an area of growth and increasing importance in the next decade. One of the earliest papers to use an electronic aid with a person with brain damage was Kurlychek (1983). This was important in that it tackled a real life problem as it was used to teach a man to check his timetable. In 1986 Glisky, Schacter and Tulving (1986) taught memory impaired people computer terminology and one of their participants was able to find employment as a computer operator. Kirsch and his colleagues (Kirsch, Levine, Fallon-Krueger, & Jaros, 1987) designed an interactive task guidance system to assist brain injured people perform functional tasks. Since then, there have been numerous papers reporting successful use of technology with brain injured people. A recent paper by Wilson, Emslie, Quirk and Evans (2001) used a randomised control crossover design to demonstrate that it is possible to reduce the everyday problems of neurologically impaired people with memory and/or planning difficulties with a paging system. Another area where technology is likely to play an increasing role in the future is Virtual Reality (VR). VR can be used to simulate real life situations and thus be beneficial for both assessment and treatment.

In this volume, Boake, chapter 2 includes discussion of some of the early computer based cognitive rehabilitation programmes; Manly, chapter 3, presents some discussion of technology in the remediation of attention disorders and unilateral neglect, while both Evans and Wilson also refer to technology in rehabilitation in their respective chapters.

## Rehabilitation Begins in Intensive Care

Perhaps one of the greatest changes in rehabilitation over the past few years has been in the assessment and management of people in reduced states of awareness i.e those who are in coma, or who are vegetative or who are minimally conscious (Jennett, 2002). Jennett and Teasdale (1977), the authors and developers of The Glasgow Coma Scale (GCS -1977) define coma as 'giving no verbal response, not obeying commands and not opening the eyes spontaneously or to stimulation ' (p. 878). The Royal College of Physicians report (1996) describes the characteristics of people in the vegetative state and Giacino et al. (2002) discusses the Minimally Conscious State. Since the GCS appeared over a quarter of a century ago, several other assessment tools have been developed to measure the behaviour of people in reduced states of awareness. One of the most recent is The Wessex Head Injury Matrix (WHIM – Shiel et al., 2000). The WHIM can also be used to set goals for treatment. The goal planning approach is followed here in much the same way as described earlier with the exception that the client will not be able to participate in goal selection. The goals of course will be different from those set for people in the later stages of recovery. Whereas a rehabilitation goal for someone in a rehabilitation centre a year or two post injury might be to do with work or driving or using a compensatory system, the goal for someone just emerging from coma might be to increase eye contact or to establish a method of communication. The goals for this group of people might well be focussed on reducing impairments where the goals for people in the later stages are more likely to be with reducing handicap or increasing participation in society.

In this volume, Shiel, chapter 12 discusses rehabilitation of people in states of reduced awareness and presents four case studies to illustrate some of the principles involved.

## Neuropsychological Rehabilitation is a Field that Needs a Broad Theoretical Base

Because people with brain injury are likely to face multiple difficulties including cognitive, social, emotional and behavioural problems, no one model or group of models is sufficient to deal with all these issues. In order to improve cognitive, social emotional and behavioural functioning in everyday life we should not be constrained by one theoretical framework. Of the many theories that impact on rehabilitation, four areas are perhaps, of particular importance namely theories of cognitive functioning, of emotion, of behaviour and of learning. Consideration should also be given to theories of assessment, recovery and compensation. All the contributors to this book have tried to make clear how their clinical practice has been shaped by different theoretical models. Wilson, Chapter 1, explicitly argues for a broad based model and

refers to a recently published comprehensive model of rehabilitation (Wilson, 2002). Boake, Chapter 2, describes the different methodologies that influenced some of the historical figures in the field. In Chapter 3, Manly refers to numerous theories of attention that have guided treatment approaches to this difficult area. The same is true of Evans in Chapter 4 and Wilson Chapter 5. Raymer and Maher, Chapter 6, carefully describe language frameworks that have been used to understand language disorders and to assess these disorders and finally to treat them. Of several models of emotion, Williams, Chapter 7, is particularly influenced by Cognitive Behaviour Therapy which is certainly one of the most carefully worked out and clinically useful models of emotion at this time. Tate and her colleagues, Chapter 8, are influenced, among other things, by the World Health Organisation's International Classification of Functioning framework to address social problems faced by people with brain injury. The neurobehavioural model of Wood (1987, 1990) is one that has influenced Alderman's work, Chapter 9, in his treatment of brain injured people with severe behaviour problems. Clare, Chapter 10, in her discussion of rehabilitation for people with dementia draws upon theories of memory, psychotherapy, emotion and other work. Anderson, Chapter 11 considers the outcome and management of children with traumatic brain injury so an understanding of development along with other frameworks and models is crucial in this field. Recent frameworks of levels of awareness and recovery are incorporated into Shiel's chapter (Chapter 12) about her work with people in states of reduced awareness. Finally, McMillan in Chapter 13 is concerned with the components and frameworks of service delivery for the rehabilitation of people with brain injury. Thus, it can be seen that ethical and effective neuropsychological rehabilitation requires a synthesis and integration of several frameworks, theories and methodologies to achieve its aims and ensure the best clinical practice.

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