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ACCOUNTING FOR EMPLOYMENT OUTCOMES FOLLOWING TRAUMATIC BRAIN INJURY (TBI) -THE IMPLICATIONS FOR DELIVERING TBI VOCATIONAL REHABILITATION IN THE UK 1

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Thesis submitted for the degree of Doctor of Philosophy

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Contents		3
Contents of	Annex	9
List of Table	S	10
List of Figur	es	14
Acknowledg	ements	16
Abstract		22
Glossary		18
Abbreviation	IS	22
Part 1	Introduction, Literature Review and Vocational Rehabilitation (VR) Practice.	23
1.0	Overview	24
1.1	Why This Research Needs To Be Undertaken: The Development of a Personal Interest in Traumatic Brain Injury	24
1.2	The Nature of the Problem	27
1.3	Aims and Objectives	28
Chapter 2	The Incidence and Nature of Traumatic Brain Injury	31
2.0	Overview	31
2.1	Epidemiological Incidence of Traumatic Brain Injury	32
2.2	Causes of Traumatic Brain Injury	33
2.3	Traumatic Brain Injury Defined by Periods of Post-Traumatic Amnesia (PTA) and Common Impairments	33
2.4	Residual Deficits of TBI Classified by Clinical Groupings	34
2.5	Summary and Main Points	41

Chapter 3	Literature Review: Return to Work Studies	43
3.0	Overview	43
3.1	Defining Employment	45
3.2	The Value of Understanding Employment Outcomes	46
3.3	Return to Work Studies: Studies Reporting Outcomes and Id	lentifying
	Factors Said to Influence or Predict Employment Outcomes	52
3.4	Studies Reporting the Effectiveness of Vocational Rehabilita	tion
	Programmes	73
3.5	Variables Associated and Not Associated with a Return to W	ork 85
3.5.1	Demographic Variables	87
3.5.2	Neurological and Other Injury Factors	91
3.5.3	Cognitive and Neuropsychological Deficits	95
3.5.4	Psychosocial Factors	99
3.5.5	Workplace Factors	101
3.6	Four Matters Arising from the Analysis of Variables:	103
	a) the significance of the family	103
	b) the use of neuropsychological tests	105
	c) severity of injury	107
	d) type and duration of post-injury rehabilitation	107
3.7	Summary and Main Points	109
Chapter 4	The Development of Vocational Rehabilitation Services f	or People
	with TBI	114
4.0	Overview	114
4.1	UK: Department for Works and Pensions (DWP) Jobcentre F	Plus 116
4.2	Other Associated TBI Vocational Rehabilitation Services	121
4.3	Approaches to Vocational Assessment in the UK	126

4.4	Supported Employment in the UK	130
4.5	Approaches to TBI Vocational Rehabilitation in the United States	133
4.6	Job Coaching	142
4.7	Summary and Main Points	149
Part 2	Methodology and Results	152
Chapter 5	Research Methodology and Practical Issues	153
5.0	Overview	153
5.1	The Choice of Methodology	154
5.3	Realistic Evaluation	161
5.4	Identification of the Study Sample	171
5.5	Summary and Main Points	173
Chapter 6	Questionnaire Construction, Data Collection and the Application	
	of the Methodology	176
6.0	Overview	176
6.1	Items for Inclusion in the Survey Questionnaire	176
6.2	Questionnaire Construction and Data Collecting	181
6.3	Problems in Recording the Data	182
	a) Classification of Occupations	183
	b) Clinical Data	183
	c) Validity of the Data	187
	d) Intervention Processes	187
	e) Outcome Measures	188
6.4	Applying the Methodology to the Data	188

Chapter 7	Results: The Relationship between Commonly Found Variables	
	Reported in the Literature and a Return to Work Amongst the	
	Study Sample	191
7.0	Overview	191
7.1	Reporting of Description and Association Statistics	191
	• age	192
	• gender	192
	domestic circumstances	193
	pre-injury level of education	193
	<ul> <li>socio-economic status at the time of injury</li> </ul>	194
	<ul> <li>history of regular employment</li> </ul>	194
	nature of a return to work	195
	<ul> <li>clinical and vocational rehabilitation</li> </ul>	196
	injury severity	198
	Frequency of Clinical Symptoms	199
7.2	Discussion of the Findings from the Study Sample	201
	• demography	201
	domestic circumstances	203
	<ul> <li>pre and post-injury qualifications and occupational status</li> </ul>	204
	job retention	207
	<ul> <li>regularity of pre-injury employment</li> </ul>	209
	<ul> <li>return to work by injury severity</li> </ul>	209
	full-time or part-time work	211
	rehabilitation	211
7.3	Study Sample Experience of Jobcentre Plus	215

7.4	Summary and Main Points	217
Chapter 8	Three Case Studies from the Study Sample and	
	an Evaluation of Working Out's Vocational Rehabilitation Strategy	221
8.0	Overview	221
8.1	Developing CMO configurations	222
	Case Study 1: KW	222
	Case Study 2 : G	239
	Case Study 3 : V	244
8.2	Working Out	249
8.3	Drawing together the Findings: What Produces Changes in the Status	
	of a Subject with TBI?	258
8.4	Summary and Main Points	263
Chapter 9	Revisiting Back to Work	266
9.0	Overview	266
9.1	Identification, Engagement, Recruitment, Compliance and Retention	267
9.2	Summary and Main Points	275
Chapter 10	Addressing Job Retention Issues and a Framework for Mapping	
	Employment Paths Following TBI	276
10	Overview	276
10.1	The Nature of the Retention Problem	278
10.2	Summary and Main Points	295
Part 3	Conclusion and Recommendations	297
Chapter 11	Main Findings and a Return to the Hypotheses	298
11.0	Overview	298
11.1	Discussion of the Main Findings	298
11.2	Revisiting the Hypotheses (Chapter 5)	304

11.3	Structural Issues Affecting Outcomes	310
11.4	Summary and Main Points	312
Chapter 12	Meeting the Aims of the Study	314
12.0	Overview	314
12.1	Lessons Learned, Methodological Issues, Findings and Limitations	314
12.2	Variables Influencing Employment Outcomes, Barriers to Work and	
	the Recognition of Suitable Employment	317
12.3	Developing a Theoretical Model TBI Vocational Rehabilitation Programme	322
	Programming for Vocational Outcome	
	<ul> <li>age and adjustment</li> </ul>	322
	<ul> <li>severity of injury and timing a return to work</li> </ul>	324
	Recommendation for a UK TBI Vocational Rehabilitation Programme	
	Based on the Literature and the Experience of the Study Sample	326
12.4	Summary and Main Points	339
Chapter 13	Research Issues	340
13.0	Overview	340
13.1	Research Methodology and Variables	342
13.2	Summary and Concluding Points	347
References		349

# **Contents of Annex**

1	Commonly Used Neuropsychological Tests	375
2	Valpar Work Samples	381
3	Study Sample Questionnaire	383
4	Statistical Package for the Social Sciences (SPSS) Categorisations	401
5	Work Personality Profile	406
6	The British Standard Occupational Classification (SOC) System	411
7	Constructing an Index of Employability following TBI	414
8	The Job Analysis Process	417

Table 2.1	Numbers and Percentages of Persons Reporting Various Problems National Traumatic Brain Injury Study (1998)	41
Table 2.2	Overview of Residual Deficits by Clinical Groupings	42
Table 3.1	Study Sample Characteristics Gilchrist and Wilkinson (1979)	57
Table 3.2	Study Sample Demographic Data Kay, Ezrachi, Cavello and Newman (1988)	61
Table 3.3	Work Status at Five Years Post Trauma Kay, Ezrachi, Cavalo and Newman (1988)	61
Table 3.4	Study Sample Characteristics Stambrook et al (1990)	62
Table 3.5	Pre- and Post-Closed Head Injury Employment Status Stambrook et al (1990)	62
Table 3.6	Predictors to be Analysed, How Treated and Direction of Association Ruff et al (1993)	65
Table 3.7	Disability Rating Scale Rappaport et al (1992)	72
Table 3.8	Study Sample Characteristics Ben-Yishay et al (1987)	76

Table 3.9	Employability Rating Scale	77
	Ben-Yishay et al (1987)	
Table 3 10	Distribution of Employability Ratings	77
	Ben-Yishay et al (1987)	,,
Table 3.11	Study Sample Characteristics	81
	Haffey and Abrams (1991)	
<b>T</b>     0 40		0.4
Table 3.12	Rodney - Case study from Literature	84
Table 3.13	Rodney - From Clinical Deficits to Adaptive Mechanisms	85
Table 3.14	Organisation of Variables and Relationship to Employment Outcomes	86
Table 4.1	Functional Assessment Inventory	124
	Crewe and Atheistan (1984)	
Table 4.2	Work Personality Profile	124
	Bolton and Roessler (1986a and b)	
Table 4.3	Job Coach Functions	144
	Deal and James-Brown (1997)	
Table 4.4	Into Job Copphing	145
	Morrit and Clark (1997)	145
Table 4.5	Categories of Compensatory Strategies Used in Vocational Settings	148

Table 4.6	Community Employment Support Options	149
	Nisbet and Hagner (1988)	
Table 6.1	Summary of the Research Variables	177
Table 6.2	The Categorisation of Variables	178
Table 7.1	Domestic Circumstances on Follow-Up	193
Table 7.2	Highest Level of Qualification of Study Sample	193
Table 7.3	Socio-Economic Status of Study Sample	194
Table 7.4	Final Return to Work Figures	196
Table 7.5	Return to Work (Any Time) Following Rehabilitation	196
Table 7.6	Return to Work Position Following Rehabilitation (When Follow-up Data Collected)	197
Table 7.7	Return to Work (Any Time) Following VR	197
Table 7.8	Return to Work Following Vocational Rehabilitation (When Follow-up Data Collected)	197
Table 7.9	Frequencies of PTA Severity	198
Table 7.10	Return to Work (Any Time) by Severity of Injury	198
Table 7.11	Return to Work by Severity of Injury (When Follow-up Data Collected)	198

Table 7.12	Clinical Frequency of Injuries of the Study Sample	199
Table 7.13	Ranking of Reported Study Sample Symptoms	201
Table 8.1	An Overview of Contexts, Mechanisms and Outcomes (CMOs) following TBI	227
Table 8.2	Overview of CMOs. Case Study KW.	233
Table 8.3	Contrasting Study Sample/Working Out Data	250
Table 8.4	Overview of CMOs. Working Out.	252
Table 8.5	Contexts and Mechanisms: Working Out	256
Table 9.1	Final Source of Referrals Back to Work 2003/04	270
Table 9.2	BtW Course Completion by Referral Source	272
Table 9.3	Summary of Engagement Issues	273
Table 9.4	Summary of Compliance Issues	274
Table 11.1	Summary of Post-Injury History of the Study Sample	307
Table 12.1	Barriers to Employment Following TBI	318

# List of Figures

Figure 1	Working Out Programme	127
Figure 2	Overview of Employment Activity Not in the Open Labour Market	133
Figure 3	The Realist Evaluation Cycle Pawson and Tilley (1997)	163
Figure 4	An Overview of Realistic Evaluation Pawson and Tilley (1997)	165
Figure 5	Basic Framework for Researching TBI Vocational Outcomes	168
Figure 6	Steps in Questionnaire Design	182
Figure 7	Contexts of Injury Bearing on the Self	258
Figure 8	Contexts, Mechanisms and Regularity	259
Figure 9	How Working Out Produces Changes in Regularity	261
Figure 10	Programmes, Changes and Contexts	263
Figure 11	Cycles of Vulnerability James, Cunningham and Dibben (2003)	280

Figure 12	Contexts of Decision Making Process	288
Figure 13	Options Available to TBI Subjects	289
Figure 14	Role of Stakeholders	290
Figure 15	Framework Mapping Employment Outcomes Following TBI	293
Figure 16	Recommended TBI Vocational Rehabilitation Process	327
Figure 17	Delivery of TBI VR within Jobcentre Plus/NHS Framework	330

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## ABSTRACT

This thesis arises out of personal experience of the employment problems faced by people sustaining traumatic brain injury (TBI). Through tracking the post-injury experience of 54 subjects it aims to test the opinion that, generally, there is a lack of expert support to facilitate a return to work and, for young people, inadequate mechanisms to facilitate a transition from education into employment. In particular, it is maintained that generic vocational rehabilitation (VR) services provided by Jobcentre Plus fail to meet the needs of many TBI *customers* ( to use their terminology). In the circumstances it is contested that a return to work following TBI may follow a random pattern, but that an appropriate programme of VR, objectively identified within the thesis and based upon best practice and research based evidence, should improve resettlement rates.

Following a review of research methodologies commonly found in employment and disability studies the thesis relies upon a combined methodological strategy to test the above opinions. The literature review, and the experience of the study sample, are used to identify a) significant demographic and clinical variables to be taken into account when planning vocational intervention, b) difficulties in accessing appropriate VR programmes. A non-experimental survey research design relied on a fixed format questionnaire to collect study sample data, evaluated through the use of description and association statistics. Three case studies are further analysed through a realist approach identifying the circumstances in which measures taken to resume employment contributed to the final outcomes.

The thesis identifies an inaccurate recording of the brain-injured population within the DWP and a significant job retention problem amongst the study sample. It establishes why generic vocational rehabilitation services are failing this population and why many potentially employable people find themselves receiving long-term incapacity benefits.

The conclusion presents a theoretical model VR programme, deliverable within the context of current developments for joint NHS/Jobcentre Plus condition management (VR) programmes. It argues the case for TBI VR programmes in the UK moving away from a focus on pre-placement treatment and job-search activity towards one incorporating lengthy occupational trials and on-site support for both the employee *and employer*. It establishes the need for both 'joined-up' services, from hospital to employment, and trained job coaches. Finally there are recommendations for enhancing future research in the employment and disability sector.

# Glossary

#### Acquired Brain Injury (ABI)

An injury to the brain that has occurred since birth. The term acquired brain injury includes traumatic brain injuries and non-traumatic brain injuries. It does not include brain injuries that are congenital or produced by birth trauma.

#### Amnesia

Partial or total loss of the ability to remember things which have been done or experienced. (See post-traumatic amnesia and retrograde amnesia).

#### Anosmia

Failure to smell.

#### Aphasia

Reduction of the ability to communicate with others through the use of language. Receptive aphasia is not understanding the language of others. Expressive aphasia is a reduction in the ability to use language, for example naming and making mistakes in word usage.

#### Apraxia

Inability to plan and perform purposeful movements, while still having the ability to move and be aware of the movement.

#### Ataxia

Unsteadiness of movement, lack of co-ordination when voluntary movements are attempted.

#### Behaviour Modification

A form of therapy using the principle of learning, aimed at changing behaviour by altering the rewards and consequences of that behaviour.

#### Closed Head Injury

An injury where there is no penetration of the skull.

#### Coma

State of unconsciousness, the depth of which can be measured by the Glasgow Coma Scale, allowing a grading of coma by observation of eye opening, limb movements and speech. Whether it is for a few seconds or a few weeks, the immediate effect of a head injury is the loss of consciousness. Coma can be defined as a state of depressed consciousness in which the person does not respond to the outside world.

The Glasgow Coma Scale is universally used to rate the severity of coma through the patient's ability to open his eyes, move and speak. A patient is assigned a number in each of three categories; eye opening, motor response and verbal response. The minimal possible score is 3 and the maximum possible score is 15. The more severe the injury, the lower the performance and the lower number assigned.

The length of coma is one of the most accurate predictors of the severity of residual symptoms. The longer coma, the greater the likelihood of residual symptoms, particularly physical disabilities.

#### Concrete Thinking

A style of thinking in which the individual sees each situation as unique and is unable to generalise from the similarities between situations.

#### Confabulation

Verbalisations about people, places or events with no basis in reality.

Contralateral

Opposite side.

Contracoup

Bruising of brain tissue on the opposite side to where the blow was struck.

Contusion

A bruise caused by a blow with a blunt object.

Diffuse Axonal Injury (DAI)

Widespread tearing of nerve fibres across the whole of the brain.

Diplopia

Double vision.

Dysarthria

Difficulty with articulation and pronunciation of words, due to slowness, weakness or unco-ordination of tone of muscles.

Dysexecutive Syndrome

See Executive Functions.

Dysphasia

(Same as Aphasia).

Dyspraxia

(Same as Apraxia).

Emotional Lability

Rapid and drastic changes in emotional state (laughing, crying, anger) that are inappropriate.

**Executive Functions** 

Planning, organisation, problem solving, sequencing, prioritising, self-monitoring, self-correcting,

controlling or altering behaviour and judgement.

#### Frontal Lobe

The part of each cerebral hemisphere primarily concerned with planning and organising, attention and the control and regulation of behaviour and emotion.

#### Head Injury

Often used synonymously with Traumatic Brain Injury (TBI), as within this study. Strictly, not everyone who suffers a head injury will sustain a brain injury.

#### Job Coach

A person appointed to identify a suitable rehabilitation and/or employment placement and, for a period, provide in situ support.

#### Open Head Injury

An injury where there is a penetration of the scalp and skull through to brain tissue, also known as a penetrating head injury.

#### Parietal Lobe

The part of each cerebral hemisphere primarily concerned with the perception and interpretation of sensation and movement.

#### Perception

The ability to make sense out of what one sees, hears, feels, tastes or smells.

#### Perseveration

Involuntary prolonged repetition of words or actions.

#### Post-Concussion Syndrome

A group of symptoms occurring after mild head injury that may persist for days, weeks or months.

#### Post-Traumatic Amnesia (PTA)

Post-Traumatic Amnesia (PTA) is a state in which a patient is conscious, lucid and on the surface appearing to be aware of their surroundings but he/she is unable to remember everyday things and is disorientated in times and place. Behaviour during this period may also be restless, disinhibited and agitated and characteristic behaviour during this period, such as swearing and shouting and sexual disinhibition, is not unusual. Length of PTA is often used as the best indicator of the severity of a head injury. PTA is assessed by asking the patient a number of questions at regular, usually daily, intervals. The first group of questions is concerned with awareness of time, place and person. For example "What is your name?", "Where are you now?", "What time of the day is it?", "What day of the week is it?", "What month is it?", "What year is it?". A second group of questions relates to the person's awareness of the accident, "What was your last memory before the accident?", "What was your first memory after the accident?". A patient deep in PTA is unable to answer such questions correctly. It is only as they emerge from PTA that the answers become more accurate and sensible. Due to medication or the patient's pre-injury alcohol consumption, it is often difficult for clinicians to establish a definitive period of PTA

#### Retrograde Amnesia

Inability to remember events that happened for a period before a blow to the head.

#### Temporal Lobe

The part of each cerebral hemisphere concerned with sound and language interpretation, and important in memory function.

#### Traumatic Brain Injury (TBI)

Injury to the brain caused by trauma, eg. a blow to the head.

#### Vocational Assessment

A process addressing occupational and social skills and deficits for employment which may form a discreet part of the evaluation but should be viewed as a continuing process throughout a client's vocational rehabilitation as a part of monitoring the client's performance under changing conditions.

#### Vocational Evaluation

Can be defined by reference to six major elements of the process (Thomas, 1990).

- a) accumulation and review of background information in preparation for the intake interview;
- b) formulations of specific referral questions in co-operation with the referring agent;
- c) development of hypotheses that can be tested or addressed during the evaluation;
- d) initiation of the evaluation by starting in a controlled situation;
- e) vocational testing and situational assessment;
- f) documentation of the entire process in the vocational evaluation report.

#### Vocational Rehabilitation

The process of assessing and predicting the work behaviour and potential of individuals who are head injured for employment. It may be accompanied by a range of intervention strategies. A model vocational rehabilitation process may include vocational evaluation, vocational counselling and exploration, job trials, job coaching, job placement (with support) and long-term follow-up

#### Vocational Rehabilitation Counsellor

In the UK there is no recognised vocational rehabilitation profession and the person responsible for the vocational rehabilitation process may be from a number of disciplines such as occupational psychology, nursing, social work or occupational therapy. They may also be the holder of a specific post-graduate disability management qualification.

#### 22

# Abbreviations

- ABI Acquired brain injury
- BtW Back to Work (research programme)
- DDA Disability Discrimination Act
- DEA Disability Employment Advisor prior to 1992 known as DRO Disablement Resettlement Officer
- DWP Department for Works and Pensions
- ERC Employment Rehabilitation Centre
- ERS Employment Rehabilitation Service
- ES Employment Service
- GCS Glasgow Coma Scale
- IB Incapacity benefits. There are a number of *incapacity benefits*.
- MSC Manpower Services Commission
- NHS National Health Service
- NDDP National Disability Development Programme
- NTBIS National Traumatic Brain Injury Study
- PACTS Placement Assessment and Counselling Teams
- PCAS Pension Contribution Assessment System
- PTA Post-traumatic amnesia
- RA Random assignment
- RCT Randomised controlled trial
- RE Realistic Evaluation
- RNIB Royal National Institute for the Blind
- RtW Return to work
- SOC (British) Standard Occupational Classification (system)
- SPSS Statistical Package for the Social Science
- TBI Traumatic brain injury
- VR Vocational rehabilitation

# Part 1

# INTRODUCTION, LITERATURE REVIEW AND VOCATIONAL REHABILITATION (VR) PRACTICE

Chapter 1	Introduction, Aims and Objectives	24
Chapter 2	The Incidence and Nature of Traumatic Brain Injury (TBI)	35
Chapter 3	Literature Review: Return to Work Studies	43
Chapter 4	The Development of Vocational Rehabilitation Services for People with Traumatic Brain Injury	114

# CHAPTER 1

# INTRODUCTION, AIMS AND OBJECTIVES

#### **Contents**

1.0	Overview	24
1.1	Why This Research Needs to be Undertaken: The	
	Development of a Personal Interest in the Employment of People	
	Following Traumatic Brain Injury (TBI)	24
1.2	The Nature of the Problem	27
1.3	Aims and Objectives	28

**1.0 Overview:** Chapter 1.1 addresses the development of a personal interest in brain injury vocational rehabilitation and states why this research is important, both for improving the employment prospects of individuals sustaining TBI and running efficacious VR programmes within the context of current reforms to the UK's incapacity benefits system.

Chapter 1.2 describes the nature of employment problems following traumatic brain injury and condition management programmes currently being 'rolled-out' by Jobcentre Plus. It introduces the argument that generic Jobcentre Plus return to work services are failing to meet the needs of the TBI population.

Chapter 1.3 addresses the means whereby it is proposed to meet the stated Aims and Objectives of the thesis and how the argument is to be tested. In doing so it outlines the contents of each Chapter.

**1.1 Why This Research Needs to be Undertaken: The Development of a Personal Interest in the Employment of People Following Traumatic Brain Injury (TBI):** By the mid 1990s I had over 20 years experience in the vocational rehabilitation (VR) sector, including 17 years in what was the Manpower Services Commission's Employment Rehabilitation Service. During this period I had seen comparatively few people with TBI seeking to return to work (in contrast to other disabilities). I began working in the private sector in 1990 and people with TBI were increasingly referred to me by solicitors for reports on their employment prospects and advice on vocational rehabilitation. I also began to hear expert medical consultants regularly express opposed opinion on such matters in the High Court.

A quest for a greater knowledge of the subject of TBI and employment identified little published

UK data (seven studies by neuropsychologists over a period of 25 years) and, at the time, only one location offered a specialist TBI VR programme. In addition, whilst there was a consensus amongst clinicians that the number of people with TBI was large, and growing, such were official records that nobody seemed to be capable of defining the extent of the problem. As so often happens it takes initiatives from outside a problem area to provide fresh impetus and knowledge to do something about it, and an Irish organisation, Rehab, began to establish TBI VR centres in the UK from the mid 1990s onwards, the first one in Glasgow. However, even now, there are only three such centres serving England and Wales (Newcastle, Birmingham and London). In the late 1990s a centre was opened in Manchester but it had to close when European Social Fund start up money was not replaced by local NHS, Jobcentre and insurance funding. During the latter part of the 1990s, I found that attendance on a number of short courses (designed primarily for clinicians) and the experience of working with people sustaining TBI, including a number participating in a VR case management programme I had established, led to a greater degree of personal expertise. However, I perceived inadequacies in the nature of existing provision.

I could only offer a VR TBI case management service within a specified distance from the office. Such were the needs of the clients that they required regular monitoring and available support should anything go amiss. Outside the business, staff to provide job coaching support could not be found.

The national generic work preparation programmes provided by the Employment Service were not suitable for many TBI clients. Staff frequently lacked expertise in working with TBI subjects, the courses were too short and they did not include specific measure to address the problems faced by clients.

Besides Rehab (UK) specialist TBI VR services that were beginning to develop were few and far between. They were expensive and, sometimes, appeared to take (and keep) referrals because the funding was available, rather than being able to specify how the service would assist that particular client to reach a stated objective.

Hence, I decided to investigate the problem of TBI and employment further. In respect of TBI clients referred to me I wanted to be able to:

- Have a better understanding of the factors influencing labour market participation.
- Identify, *and deliver* the steps that needed to be taken to meet the objective of a return to work

- Refer to a standardised instrument (measurement scale) to be able to say how far a particular person was from being able to (re)enter the labour market.
  - Measure the distance travelled from the referral status to a defined employment outcome (hence specifying the contribution of any intervention).

This study reflects progress towards the first and second objectives. The third and fourth points would rely upon the development of scales, and the research requirements to achieve such objectives are currently not readily available in the UK. These are discussed in the conclusion to this study.

From 2003 the focus of the research developed as a consequence of running a pilot condition management (VR) programme for Jobcentre Plus to return to work incapacity benefit (IB) customers reporting chronic pain conditions, Back to Work (BtW). In 2002 the DWP reported less than 1m people in receipt of the Jobseekers Allowance in contrast to 2.7m people receiving incapacity benefits, this latter number having tripled over the previous 20 years. In the late 1990s the government established the National Disability Development Programme (NDDP), as part of the Employment Service (now Jobcentre Plus), to oversee a number of contracted research programmes to investigate this problem. This included the BtW programme. Experience of BtW led to a view that there was a need to build on addressing the position of individual subjects with TBI to one of developing appropriate VR programmes on a national scale based on objective research findings.

From the end of 2006 the government has been 'rolling out' combined NHS/Jobcentre Plus condition management programmes for all IB claimants. Although the pilots addressed three specific conditions the national roll-out is based on a generic approach. It is clearly an argument of this thesis that people sustaining TBI require specialist services. Although in 2001 a House of Commons Select Committee recommended that all NHS Trusts should adopt the brain injury VR programme, Working Out, developed at the Aylesbury NHS Trust as the demonstration project for the National Traumatic Brain Injury Study (NTBIS, 1998), not one has done so. Apart from having no statutory obligation to do so, NHS Trusts could not afford this model at a cost of around £10,000 per person (a figure provided to me by the Programme Director). There are just three specialist Brain Injury Vocational Rehabilitation Centres in England, none in Wales, and three in Scotland run by Rehab UK (known as Momentum in Scotland). The cost for a typical 12 months programme with Rehab UK is around £26,000. Whilst there are other locations offering a TBI VR service, particularly Banstead Place in Surrey and the Papworth Trust in Cambridgeshire, these are "add on" facilities to generic practices.

Whilst the needs of people sustaining TBI require additional resources to those found on generic VR programmes, cost-effective means of facilitating resettlement need to be found if those sustaining TBI, are not to remain disabled *and* unemployed.

**1.2 The Nature of the Problem:** It will be recognised from the epidemiological evidence in this study (Chapter 2.1) and the way the Department for Works and Pensions (DWP), the body overseeing Jobcentre Plus, collects health data (Chapter 5) that the numbers of unemployed brain injured people in the UK has not been officially recognised.

For most people work is a central feature of adult life, providing income, status, social contact and personal satisfaction. A traumatic brain injury (TBI), defined as: "... an insult to the brain, not of a degenerative or congenital nature, but caused by an external force, that may produce a diminished or altered state of consciousness" (National Head Injury Foundation, 1985) can pose many obstacles to successful vocational integration. The need to find solutions to the problems is even more apparent when one considers that head injury<sup>1</sup> commonly affects young people, frequently in education or training, or at the start of their working lives. Adults established in a career may not be able to resume their previous level of employment, if capable of working at all.

Even a return to work is not necessarily a symptom of occupational success. Employers often complain about brain injury survivors' irregular punctuality and attendance, their interpersonal problems with co-workers, and the inability to manage their personal lives along with their work (Kay et al, 1988; Prigatano et al, 1994) and literature contains many references to an inability to hold down jobs of a lowered status (Sale et al 1991). The financial cost of incurring a TBI, both to the individual, the family and society, is potentially enormous as well as resulting in much misery. McGregor and Pentland (1997) reviewed studies attempting to measure the financial cost of a head injury (not a subject of this study). Insurance companies (meaning those who buy insurance policies) pay the cost of TBI to many road traffic accident victims. In many cases, this will mean compensation for a full continuing loss of earnings. Those who suffer head injury as a consequence of other accidents may be entitled to compensation through employer liability or public liability insurance. Those who suffer assaults may receive compensation from the Criminal Injuries Compensation Board (CICB). For those who are not entitled to compensation, the State has to intervene. A substantial proportion of this cost relates to the loss of earnings through the payment of benefits.

<sup>&</sup>lt;sup>1</sup> Throughout this study the terms 'brain injury' and 'head injury' are used interchangeably although, strictly speaking, not everyone sustaining a head injury will continue to experience the effects of a brain injury.

During the 1990s, political awareness of the incidence and consequences of brain injury contributed to resources being allocated towards rehabilitation research, principally the National Traumatic Brain Injury Study (NTBIS, 1998). This was followed by the House of Commons Health Committee's reports on Head Injury Rehabilitation (2001). In spite of a recognition of low rates of return to work following brain injury, there has been no systematic evaluation of the vocational rehabilitation (VR) process (and only one demonstration project was part of NTBIS) yet, throughout the 1990s, there was a growth in the provision of state, private and voluntary sector services (mainly of a generic nature). Although provision for the TBI population is comparatively expensive (compared to other disabilities), its efficacy is unproven. (Resettlement statistics are reported without reference to those who had a reasonable prospect of a spontaneous return to work or those continuing to experience significant employment problems. The process of rehabilitation itself is not defined, enabling investigators to identify what approach works best with whom and why).

This study is substantially theory driven and seeks to test the opinion that limitations on the availability of expert VR services in the UK are likely to be reflected in irregular RTW rates, that is some people may return to work whereas others, less severely injured, may not do so. The difficulty in making predictions as to those likely to benefit from vocational rehabilitation is likely to be exacerbated by problems in establishing definitive relationships between clinical and demographic variables and a RTW. Nevertheless, it ought to be possible to identify and address many of the problems arising from TBI by considering appropriate vocational rehabilitation strategies, and developing compensatory approaches developed for use in the workplace and based on a framework for analysing individual barriers to employment.

It is maintained that because of inadequate data systems the DWP has failed to recognise the incidence of brain injury, and, in order to address the unemployment problems of this sizeable group, there needs to be a radical move away from providing pre-placement assessment and support to one of in-situ support and continuing follow-up. To this end a 'model' TBI vocational rehabilitation programme is developed.

**1.3 Aims and Objectives:** The aims are to investigate variables influencing vocational outcomes following TBI, to identify barriers to gaining and sustaining employment and to identify the effect of variables on the type of work activity following TBI with a view to designing a potentially efficacious theoretical vocational rehabilitation model. Two sets of independent variables considered are individual and injury-related factors, that is demographic and clinical factors. Effectiveness, in respect of the influence of any intervention, is reflected by drawing a distinction between the intervention and its effects, these being tested both quantitatively and qualitatively.

It is proposed to address the aims of this thesis through the following intermediate objectives :

- i. Critically analysing the literature on TBI and employment to determine the current state of knowledge on the subject.
- ii. Identifying clinical, demographic and other variables reported to influence employment outcomes in the literature and within the study sample, the latter analysed through description and association statistics.
- iii. Identifying practical issues to be addressed when recruiting subjects to a VR programme reported in the literature, through a qualitative review of the Back to Work research programme and tracking the experiences of the study sample.
- iv. Empirically describing and accounting for the post-injury employment experience of the study sample.
- v. Relying on realistic evaluation to analyse the problems the case studies experienced in their attempts to return to work.
- vi. Developing a framework for analysing individual barriers to employment.

The aims and objectives are systematically pursued throughout the thesis. The literature review at Chapter 3 is used to identify major clinical and demographic variables and the way they are reported to influence outcomes. In recognising that most of the literature is of North American origin (and there may be limitations on the extent this can be applied to a UK population) the final table of selected variables in Chapter 6, collected from the study sample and tested for statistical significance, was only made following the literature review and reading the study sample histories. The study sample data is reported from Chapter 7. At the outset there was no way of knowing how many subjects would be offered clinical and/or vocational rehabilitation or support by Jobcentre Plus. Their experience, relating independent clinical and demographic variables identified in the literature to employment outcomes, is initially reported through association and description statistics. Because of limitations on applying group data to individuals the data is then supplemented in Chapter 8 by applying a realist approach to the case studies, that is defining the context in which a person with TBI may find themselves following injury and the way mechanisms (which at this juncture may be loosely described as including the influence of stakeholders and intervention strategies) contributed to the final outcome. Although a need for brevity prevented the application of this process to more case studies, and the development of any empirical generalisations, this process provides further in-depth analysis to the discussion on the statistical outcomes. Factors emerging as important, such as the frequency of certain specific clinical symptoms, access to appropriate VR programmes and the need for *in situ* support for employees and employers, are then built into the theoretical model VR programme in the Conclusion at Chapter 12.

At Chapter 9 Back to Work, a randomised controlled trial briefly discussed in Chapter 5, is revisited to examine issues relating to customer identification, engagement, recruitment, retention and compliance. The identification of a significant job retention problem amongst the study sample, and a lack of appropriate support from Jobcentre Plus, leads to further discussion on these issues and, at (an unanticipated) Chapter 10, an examination of the important (but oft neglected) role of employers in the resettlement process. This contributes to the framework for mapping employment outcomes following traumatic brain injury.

At Part 3, Chapter 11, the thesis concludes with a review of the main study sample findings and, in Chapter 12, the building of a framework for analysing the variables that may influence the potential employment outcome of an individual experiencing TBI and recommendations for a joint NHS/Jobcentre Plus TBI model vocational rehabilitation programme. In Chapter 13 there is a discussion of factors affecting research in this sector and recommendations for improving practice.

This sequential approach towards meeting the aims and objectives is supplemented in a number of areas. Following the literature review in Chapter 3, Chapter 4 provides a review of brain injury return to work strategies in the UK and USA in order to provide the background to existing UK services and identify 'best practice'. The process of testing the theory in respect of a need to meet the needs of brain-injured people by changing the delivery of services, starts, in Part 2 at Chapter 5, with an examination of research methodology used in employment and disability studies. Reference to the Back to Work programme, relying upon a randomised controlled trial (RCT) but failing to recruit a sufficient number of subjects to support the methodology, highlights both the need for a 'workable' research methodology and issues affecting subject recruitment to VR programmes.

The realist approach, presented In Chapter 5, required the generation of a number of hypotheses to be tested. These relate to the severity of injury and a return to work (RTW), the significance of clinical, demographic and other variables in the RTW process, the provision of expert VR services , problems in developing a predictive RTW model, choice of methodology and planning VR intervention. All of these matters contribute towards meeting the aims and objectives of the thesis. As part of the pluralist methodological strategy there is a reliance on all the data presented In Part 2, at Chapter 11 in the Conclusion, to revisit the hypotheses and examine to what extent there is evidence to support or refute them and, in turn, to what extent the aims and objectives of the thesis are met.

# CHAPTER 2

# THE INCIDENCE AND NATURE OF TRAUMATIC BRAIN INJURY

# **Contents**

2.0	Overview	31
2.1	Epidemiological Incidence of Brain Injury	32
2.2	Causes of Traumatic Brain Injury	33
2.3	Traumatic Brain Injury Defined by Periods of Post-Traumatic Amnesia	
	(PTA) and Common Impairments	33
2.4	Residual Deficits of TBI Classified by Clinical Groupings	34
2.5	Summary and Main Points	41

**2.0 Overview:** In Chapter 1 it was maintained that DWP data systems do not accurately reflect the number of people with TBI experiencing employment problems. It follows that there are insufficient dedicated resources. This matter is further addressed when considering the development of UK services and examining the experiences of the study sample. This Chapter, 2.1, reviews the epidemiology of brain injury in the UK and Chapter 2.2 the main causes of TBI.

When planning any vocational intervention there is a need to take into consideration the functional consequences of an injury. In order to do this Chapter 2.3 defines the severity of a brain injury by reference to periods of post-traumatic amnesia (PTA) and then the following Chapter, 2.4, groups this data by reference to clinical disciplines and common impairments. This systematic approach is designed to enable the reader, and any VR practitioner, organise a large amount of clinical information and understand the potential implications for future employment.

In this fashion Chapter 2 seeks to answer the following questions:

'How common is traumatic brain injury?' 'What are the causes of TBI?' 'What are the major clinical consequences of TBI?' 'How can one begin to sort such information when considering rehabilitation and employment needs?'

By addressing such questions it is considered one can begin to establish an understanding of

the clinical problems faced by people with TBI, the role of the major clinical professions in identifying such deficits and the type of problems that may be experienced by people with TBI.

**2.1 Epidemiological Incidence of Brain Injury:** It is difficult to establish the incidence of TBI because of inconsistent variables used in epidemiological studies and the lack of a register. Several issues contribute to this problem, for example, inconsistent definitions of head injury and a lack of a standardised reporting mechanism.

The National Traumatic Brain Injury Study (1998) reported that each year over 100,000 adults are discharged from hospital in the UK with a diagnosis of head injury. Using the estimated annual incidence of TBI quoted by the Medical Disability Society (MDS) (now British Society for Rehabilitation Medicine) in 1988 and applying it to the UK population Hawley et al (2000) anticipated an incidence of 4,160 new cases of severe TBI each year (Chapter 2.3 defines TBI by severity). They added that the majority of head injury victims are young (between the ages of 15 and 30 years), and having a brain injury rarely reduces life expectancy (Rimmel et al, 1990; NHS Health Advisory Service (HAS), 1996). It has been estimated that as many as 500,000 people in the UK may be currently living with the consequences of TBI (McMillan & Greenwood, 1991).

The British Society for Rehabilitation Medicine has more recently confirmed its 1988 figures (1998) considering little has changed. The report divides incidence into 8 cases of severe head injury per 100,000, approximately 18 moderate injuries per 100,000 and between 280 and 300 mild head injuries per 100,000 of the population. Deprived urban areas have higher incidence rates.

The House of Commons Health Committee report on brain injury (2001) criticised the Department of Health's collection of head injury data. The Health Committee cited Thornhill's Glasgow study (2000) suggesting a much higher incidence than DoH estimates (about 4.5 times higher). Thornhill et al (2000) also recorded a much higher level of unrecognised problems on discharge than previously supposed and that "only" 28% of their surviving study sample received rehabilitation services.

The most recent Department of Health figures (Tenant 2005) suggest an incidence of 175 traumatic brain injuries per 100,000 of the population and a prevalence of 1,250 per 100,000 people in the UK with long-term problems arising from brain injury giving an incidence of 420,000 up to the age of 65. To put some perspective on the figures, brain injury is said to be 24 times more frequent than spinal injury although the DoH figures also include non traumatic brain injuries.

Hence, figures are not consistently reported. Whilst, to an extent, this may be a consequence

of definitions, Thornhill's study suggests that accurate recording is also an issue.

**2.2 Causes of Traumatic Brain Injury:** In the National Traumatic Brain Injury Study (1998) 58% of injuries were due to road traffic accidents - 18% pedestrians, 7% bicycles, 7% motorcycles and 25% in cars or goods vehicles. Falls accounted for 18% and assaults for 15% of injuries. In 161 cases (32%) it was reported that alcohol was involved.

**2.3 Traumatic Brain Injury Defined by Post-Traumatic Amnesia (PTA) and Common Impairments:** Post-traumatic amnesia (PTA) and the Glasgow Coma Scale (GCS) are the most commonly found clinical criteria for defining the severity of a traumatic brain injury (see Glossary for definitions). This study has adopted PTA because of its availability and the frequency with which it is reported in return to work (RTW) studies.

**Mild head injury** constitutes 85% of all brain injuries (Fraser, McMahon and Vogenthaler, 1988). Persons with such injuries may have a brief or no loss of consciousness (usually less than 20 minutes) and a post-traumatic amnesia (PTA) of less than one hour. While neurological examinations are often normal, permanent structural microscopic nerve damage can result in deficits, termed the *post concussion or concussive syndrome*, including fatigue, headache, dizziness, lethargy, irritability, personality changes, cognitive deficits, decreased information processing speed and perceptual difficulties. Those who sustain mild head injuries are only likely to become involved with vocational rehabilitation services after they have returned to work and failed.

**Moderate head injury** accounts for roughly 10% of all brain injuries (Fraser, McMahon and Vogenthaler, 1988). This is characterised by a period of unconsciousness and PTA ranging from one to twenty-four hours. There is a wide variability in respect of permanent physical and cognitive impairment. The literature indicates that muscle spasticity, poor co-ordination, paralysis, seizures and sensory communication problems can be found. Similarly impaired planning, organisation, judgement, reasoning, functional language, computational skills and psychosocial problems may arise. The American Twelfth Institute on Rehabilitation Issues (TIRI, 1985) reported that it is usually 6-12 months before many such patients consider returning or attempt to return to work. Experience suggests that most people sustaining injury of this severity in the UK are likely to return to work sooner than this.

There is a common assumption in medical and rehabilitation circles that most people with mild and moderate injuries are likely to return to work relatively unhindered. In the absence of a vocational assessment and guidance it is possible that many such people return too soon and struggle with post-concussional symptoms. Whilst their symptoms will sometimes resolve themselves, on other occasions they will not. Self-doubt, fatigue, an inability to adapt to changed working circumstances and relate appropriately to colleagues and employers, may all result in a subsequent loss of employment.

Wrightson and Gronwall (1981) undertook a prospective study of 66 men aged 17 to 48 with minor head injuries, that is not defined as 'severe'. The mean time off work was 4.7 days with a range from 0 to 26 days. Sixty per cent of the patients had symptoms on return to work and 46% could not do their job as well as usual for a mean time of 14 days. Ninety days after the accident, 20% still had symptoms, mostly defects of memory, concentration and work capacity. Four patients still had symptoms two years later. Although describing symptoms, all the patients were back at their usual work.

Wrightson and Gronwall (1981) considered that such information highlights the need for a better management of even minor injury. In particular they opined that in all cases following injury there is a need for the symptomatology to be assessed with regard to the patient's capacity to work. This should include advising of an appropriate time to return to work.

**Severe Head Injury**. Approximately 5% of all brain injuries can be categorised as severe (Fraser, McMahon and Vogenthaler, 1988), characterised by a period of unconsciousness or PTA in excess of 24 hours or, in the case of **very severe**, unconsciousness of at least 48 hours and/or PTA of at least 7 days. In addition to disabilities arising at other severity levels, such individuals may have brain stem damage resulting in severe permanent physical disabilities. Speech is often adversely affected. Progress can be slow and it may be several months or years before any attempt is made to return to work.

**2.4 Residual Deficits of TBI Classified by Clinical Groupings:** Head injuries can be broadly classified as either *open* or *penetrating* injuries, or *closed head* injuries (Powell, 1994). Penetrating injuries, such as a bullet, tend to result in more localised damage and relatively more predictable and discreet disabilities than closed head injuries. In closed head injury, often a result of the collision of the head with another surface, for example a car windscreen, the nature of the diffuse brain damage resulting from the brain mass rotating and the tearing of nerve tissue results in a wide range of disability. Additional widespread damage can result from secondary factors, such as increased intra-cranial pressure and lack of oxygen.

34
In short three primary causal mechanisms of closed head injuries are often identified, frontaltemporal contusions, often resulting in executive dysfunctions (see Glossary), coup-contra coup injury and diffuse axonal injury. In a coup-contracoup injury, when the skull is struck in a particular location with sufficient intensity, the brain will be driven against the opposite wall of the skull, so that brain tissue on the other side is also bruised. This type of damage is most likely to occur when the stationary head is struck by a moving object. When it occurs, it superimposes a pattern of localised brain damage and, hence, more circumscribed cognitive deficits upon the underlying background of diffuse and frontal-temporal damage. Sensory, motor, perceptual, constructional or language functions may be selectively impaired following a coup-contracoup injury. In a diffuse axonal injury brain damage results from the stretching and tearing of nerve fibres throughout the brain. It is typified by the head moving at high speed. Upon impact, a "shock wave" of rotational forces apply to the brain, which results in the stretching of billions of nerve connections (axons) resulting in widespread diffuse injury.

For the benefit of gathering and organising data when planning vocational rehabilitation it is suggested that the residual deficits resulting from closed head injury can be grouped into four broad areas<sup>2</sup>:

- · neurological deficits
- · cognitive deficits
- · deficits in executive functions
- psycho-social deficits

Whilst a full range of physical deficits are possible after head injury, six common neurological areas of concern can be identified (Corthell, 1990):

#### Neurological Deficits:

#### Sensory/motor deficits

These are common, often following skull fractures and caused by damage to cranial nerves in the brain stem or surface damage to sensory or motor cortex. Such deficits might include loss of smell and taste, loss or decreased hearing or tactile sensation, visual disturbances (especially due to loss of control over eye movements) and difficulties with balance.

 $<sup>^{2}</sup>$  In litigation, there is often dispute amongst experts as to whose province a particular symptom belongs. In reality there is often territorial overlapping and the classifications used in this study reflect my own preference for sorting and presenting a large number of clinical deficits.

## Motor Control and Co-ordination Problems (ataxia)

These may occur in more severe head injuries and then are often due to brain stem damage. Although the injured person's ability to use language correctly may be intact, there may still be difficulty in articulating words (dysarthria). An awkward gait and poor control over hand and arm movements are also typically found.

## Fatigue

Fatigue is commonly reported. This is associated with cognitive as well as physical activity. Head injured people may show difficulties staying awake; slowness in reacting to and in processing information, including responding to others; a tendency to become readily tired and, frequently, inconsistency in quality of performance.

## Seizure Disorder or Epilepsy

Epilepsy is more likely to occur following contusions and bleeding within the brain, and most often develops within the first year post-trauma (although late onset does occur). Because of the susceptibility of the temporal lobes to contusion, temporal lobe epilepsy is particularly common after concussive head injury. This is typified by seizures involving altered states of consciousness, loss of the passage of time, repetitive movements and often bizarre and inappropriate behaviour.

The fifth residual physical deficit of head injury is a *decreased tolerance for drugs* and *alcohol*. The final deficit, *post-traumatic headache*, can be recurrent and debilitating.

# **Cognitive Deficits:**

Invariably, psychological deficits create the most commonly found problems for employment, particularly in respect of:

- a) problems with learning and memory;
- b) problems with planning, organisation and problem solving (executive deficits) often exacerbated by reduced insight, attention and concentration; and
- c) problems with emotional and behavioural control.

**Learning and Memory:** Learning and memory deficits are frequently manifest as a contrast between retained old learning and skills and impairments in registering, storing and retrieving new information. Deep temporal lobe lesions may cause true amnesias, directly impacting the

ability to retrieve new information. Frontal lobe lesions may result in memory problems because of the inability to focus attention and organisation at the input stage. Damage to the left or right side of the brain may result in selective impairment of verbal or visual memory, respectively. Rehabilitation clients vary in their ability to benefit from environmental cuing to aid recall.

### **Deficits in Executive Functions:**

As a result of damage to the frontal lobes related problems are often collectively referred to as deficits in executive functions. Executive functions include the abilities to plan, initiate, organise, carry out, monitor and self-correct goal-directed behaviour (Ponsford et al, 1995). Those with frontal lobe executive dysfunction (also expressed as a **dysexecutive syndrome**) fail to formulate realistic goals and develop effective strategies for meeting goals. They fail to monitor and correct performance errors, and have difficulty in planning and organisation, as well as being aware of the impact they are having on others. An example from personal experience is the client placed in a supermarket. He was given a 'price gun' to label the price on tins of peas. When he had finished the peas he simply carried on labelling the adjacent beans with the same price label. There is often the impression of competence, whereas families and employers may report a lack of motivation, disorganisation and unfulfilled promise. An inability to evaluate their own strengths and limitations realistically may contribute to this process. Such impairments in executive function may not necessarily be related to the severity of injury. They can occur in milder injuries where there has been a relatively brief loss of consciousness but where frontal lobe structures have been damaged. Neurological examination may be normal and good test scores may be obtained on standard neuropsychological examination.

A persistent manifestation of executive deficit is that essential ideas do not occur to the person concerned. For example, there may be a failure to call in sick from work or set an alarm the night before an important appointment. This is not a memory problem per se, nor a lack of motivation and concern, but a manifestation of executive deficit. Only when it is recognised as such can an effective compensatory strategy plan be implemented.

**Problem solving:** Problem solving functions include thinking abstractly, developing appropriate strategies to solve problems and integrating diverse information to make appropriate judgements. Those with frontal lobe dysfunction may be unable to abstract meaning out of a situation and generalise it to a new situation. They may be limited in their ability to conceptualise and solve problems, especially in unfamiliar situations or when circumstances

change unexpectedly. The result is that what is learned or accomplished under one set of circumstances does not generalise to another set of circumstances. Residual deficits in the capacities for abstraction, conceptualisation and problem-solving manifest themselves in higher cognitive processes and may not be immediately apparent. Rehabilitation clients with such impairments may appear to understand the content, meaning and rationale of what is being said, however they cannot profit from the experience. Frequently they cannot abstract or conceptualise the essence of a message from the concrete details of the situation in which it is presented. Therefore, they may fail to apply it appropriately when the situation arises. Alternatively, they may simply miss the point of what is being said. Additionally, individuals with TBI are often inflexible in their thinking, with the resultant deficit in developing adaptive problem-solving strategies in new situations. Having learned to approach a situation or task in one way, they simply fail to adjust when the situation changes and the task is altered.

Hence, a problem affecting many vocational rehabilitation agencies is in respect of transferring and maintaining any learned adjustments from an in-house course to the work place. Clients with cognitive problems may apply and continue to re-apply to new situations what has been successful in the past, even when it is inappropriate in a new position. A failure to consider all the relevant variables or information in new situations often leads to poor judgement on the part of the head injured person and can lead to the termination of employment, following what may initially appear to be a successful return to work. There are, therefore, lessons in respect of rehabilitation strategies with regard to cognitive transfer, generalisation and the need for longer-term support. One response has been the provision of job coaches to work alongside the injured person particularly when starting a new job.

Attention and Concentration: Deficits in attention and concentration can be manifest in distractibility, the inability to "filter out" irrelevant information; failure to attend to the central elements of a situation; a loss of focus in conversations, manifest in rambling; a break-down in thinking during extended mental concentration and difficulties sustaining intense mental activity for any extended period of time. Attention and concentration deficits are most likely to manifest themselves when tasks are unstructured and extended. In this regard, it is important to note that most evaluations tend to consist of brief, structured tasks that by their nature focus attention and make minimal demands on extended concentration. Vocational rehabilitation clients with attention/concentration problems may perform adequately under such circumstances but inadequately in the unstructured, tiring, stressful circumstance of a work setting.

Behaviour: Those with frontal lobe damage may have poorly controlled behaviour. This may

be reflected in impulsive or disinhibited behaviour, doing things they would not have done before the injury. There may also be difficulty in controlling anger. The abilities to modulate, monitor, evaluate, regulate and self-correct behaviour, as well as the inability to recognise nonverbal feedback, may result in inappropriate behaviour that alienates peers and, in an employment setting, co-workers and line managers.

The failure to self-correct is of particular significance in the work situation. Endeavours to confront error-prone work and inappropriate behaviour may be met with indignation and denial. Meaningful rehabilitation may only be gained when the injured person can appreciate and accept the nature and implication of the deficit.

Conversely, damaged connections to the parts of the brain mediating drive can result in apathy and a lack of spontaneous behaviour. Those with such frontal lobe damage may appear to be lazy, unmotivated, unrealistic, careless and unreliable. Because such behaviour is the consequence of organic damage to the brain and not psychologically based, it is difficult to address in rehabilitation programmes. Problems with arousal include a reduced ability to maintain a steady state of alertness. Such head injured people may show difficulties staying awake; slowness in reacting to and in processing information, including responding to others; a tendency to become readily tired and, frequently, inconsistency in quality of performance. Problems with arousal are more common after brain stem damage, long periods of coma and right hemisphere cortical damage.

### Psycho-social Deficits:

The impact of executive deficits extends into the area of psycho-social functioning such as impulsive and disinhibited behaviour. Other inappropriate behaviour may be sexual disinhibition and a lack of initiative. One of the study sample for this research returned to work in a hairdresser's salon where he continued to make improper suggestions to female customers despite a number of warnings. He even acknowledged he should not be doing this but he could not change his behaviour. An injured person may possess the desire but lack the capacity to initiate and maintain appropriate vocational activity. The combination of psychosocial impairments often reflects a changed personality with family and friends describing the person as "not the same person". The person concerned is often unaware as to how they are perceived. Until the person becomes aware of these changes and accepts their changed self with new limitation, acquiring new goals, rehabilitation is unlikely to succeed. As Kay and Lezak (1990) state:

"Experience with retraining programmes and careful occupational placement of head injured persons makes it clear that where failure occurs, it is often <u>not</u> because of lack of skills, instead the problem is the person's behaviour which alienates his bosses and peers. The vocational candidate who has not gone through this process of awareness, acceptance and internalised the message of being a changed person, is simply unprepared to attempt vocational placement."

The problems described above are all primary in the sense that they result directly from damage to the brain. Further psycho-social problems are secondary in nature, as they occur as a consequence of reaction to change in the self. Problems in this area can include an inability to adjust to new limitations and realities; anger and resentment; anxiety and avoidance behaviour because of a fear of failure and embarrassment; and frustration, depression and isolation.

In 1992, the Department of Health commenced five years funding for initiatives at twelve National Health Service (NHS) sites designed to develop community rehabilitation services for adults who had sustained TBI, including the one specifically addressing vocational rehabilitation, the "Working Out" project at the NHS Aylesbury Trust. Ten of the sites participated in a case register exercise and produced a study group of 563 persons aged between 16 and 65 years at the time of injury, 507 received follow up interviews. The sample in this National Traumatic Brain Injury Study (1998) reported the deficits in Table 2.1. Of those in work at the time of injury, 60% of those with mild or moderate injuries returned to work within three years of injury and 30% of those with severe/very severe injuries.

Main Class	No. persons and percentage	Minor Class	Percentage of all reported	
Problems	509 (00%)	impoirments of emotion offect & mood	in main class	
impairments	508 (9070)	impairments of behaviour pattern	16%	
mpannents		impairments of psychomotor functions	11%	
		impairments of attention	8%	
		impairment of drives	7%	
		impairments of sleep/wakefulness pattern	7%	
		other	17%	
Intellectual	416 (74%)	impairments of memory impairment of flow and form of	48%	
		thought processes	22%	
		impairment of thought content	10%	
		other	20%	
Generalised	248 (44%)	headaches	69%	
impairments:		generalised pain or back pain	17%	
		other	14%	
Skeletal				
impairments	270(48%)	all	100%	
Aural				
impairments	228(41%)	impairment of vestibular and		
		balance functions	70%	
		auditory imp.	24%	
		other	6%	
Visceral imp.	93 (16.5%)	related to olfaction	61%	
······	()	mastication/swallowing	19%	
		other	20%	
NTBIS (1998)				

### Table 2 .1: Numbers and Percentages of Persons Reporting Various Problems

**2.5 Summary and Main Points:** In responding to the questions asked at 2.0, this chapter has examined the incidence of traumatic brain injury, the main causes and clinical consequences. It has defined the severity of injury by reference to post-traumatic injury (PTA), a measure that is used throughout this study. It has organised the residual deficits by clinical groupings in order to facilitate:

- i) an understanding of the clinical consequences of TBI.
- ii) vocational rehabilitation planning, by first identifying the clinical area of expertise when information is required on a TBI subject and, secondly, organising a large amount of clinical data with a view to addressing a specific subject's deficits within a rehabilitation programme.

A simple overview of the residual deficits is shown in Table 2.2:

Neurological	Cognitive	Executive	Psycho social	
Sensory/motor	Arousal	Organisation,	Impulsive/disinhibited	
Motor control and co-	Attention/concentration	Initiation	Lack of initiative	
Fatigue	Learning		Secondary problems	
Epilepsy	Memory			
Decreased tolerance	Speed & capacity of			
Post-traumatic	Abstraction,			

 Table 2.2: Overview of Residual Deficits by Clinical Groupings

Although these deficits primarily fall within the neurological and neuropsychological domains, there are also other disciplines that may have an important role in the assessment of deficits affecting vocational resettlement, for example ophthalmologists in respect of subjects who may have experienced some visual disturbance, neuropsychiatrists for those with behavioural problems and orthopaedic surgeons for those with physical difficulties. When planning VR programmes it also needs to be remembered that other rehabilitation specialists, such as occupational therapists and speech and language therapists, may be able to make a vital contribution to this process.

Vocational rehabilitation professionals are likely to work more with clients who have sustained severe head injuries than other categories. For those with very severe injuries, a return to education, training or employment is more difficult to achieve, even at a reduced level. However, one of the factors distinguishing the head injured population from other disability groups is that some individuals appear more independent and vocationally competent than experience will bear out (Lezak, 1987). Furthermore, they often maintain their pre-injury vocational aspirations, even though their job-related skills may be considerably reduced (Thomas and Menz, 1990). The cognitive, personality and behavioural deficits as a result of cognitive dysfunction are often not immediately recognised by lay-persons (Thomas and Menz, 1990) and it is common to find even those who have sustained severe injury remain confident of their capacity to return to work soon after discharge from hospital. Without guidance, and sometimes even contrary to it, some insist on returning to work, thereby placing their future job security on the line. Employers may often welcome back their employees after a period of sickness and, for a while, colleagues support the return, but such a return to work is often short-sighted and short-lived being based on a fallacious expectation of 'recovery'.

### **CHAPTER 3**

### LITERATURE REVIEW

#### **Contents**

3.0	Overview	43
3.1	Defining Employment	45
3.2	The Value of Understanding Employment Outcomes	46
3.3	Return to Work Studies: Studies Reporting Outcomes and Identifying	
	Variables Said to Influence or Predict Outcomes	52
3.4	Studies Reporting the Effectiveness of Vocational Rehabilitation	
	Programmes	73
3.5	Variables Associated and Not Associated with a Return to Work	85
3.5.1	Demographic Variables	87
3.5.2	Neurological and Other Injury Factors	92
3.5.3	Cognitive and Neurological Deficits	95
3.5.4	Psychosoial Factors	99
3.5.5	Workplace Factors	101
3.6	Four Matters Arising From the Analysis of Variables:	103
a)	The significance of the family	103
b)	The use of neuropsychological tests	105
c)	Severity of injury	107
d)	Type and duration of post-injury rehabilitation	107
3.7	Summary and Main Points	109

**3.0 Overview:** 'Whereas for the very severely injured the goal of rehabilitation is to reduce the amount of personal care required, for the majority the prime objective is a successful return to work." (Oddy et al, 1996).

The previous two chapters have set the background to this thesis by providing information on the nature and incidence of TBI with accompanying employment-related problems. This is with a view to establishing the need for more specific resources, a theme pursued throughout this thesis. Chapter 3 builds on the preceding two chapters by focussing on the employment outcomes following TBI, the variables said to contribute to these outcomes and measures

taken to improve RTW<sup>3</sup> rates. Chapter 3.1 initially considers one of the explanations contributing to the widespread variation in findings amongst return to work (RTW) studies, varying definitions of employment, and further considers additional reasons for difficulty in understanding RTW outcomes. Chapter 3.2 discusses the value of being able to assess potential outcomes. At Chapters 3.3 and 3.4 there is a review of RTW studies respectively divided between those reporting outcomes and significant variables, and those examining the efficacy of vocational intervention.

Chapter 3.5 summarises the return to work literature by reference to variables said to:

- i) negatively influence outcomes
- ii) have no relationship with outcomes
- iii) positively influence outcomes.

Chapter 3.6 addresses four important matters arising from the RTW studies but often subject to little discussion. These are the role of the family and social support in the return to work process, the value of neuropsychological tests results, the significance of the severity of injury and the type and duration of post-injury rehabilitation.

Chapter 3 contributes towards the aims and objectives of the thesis by increasing the understanding and knowledge of employment outcomes following TBI, providing a critical understanding as to the potential value of outcome research; identifying demographic, clinical and other variables reported in the literature as influencing employment outcomes following TBI and identifying the salient aspects of vocational rehabilitation programmes contributing towards positive employment outcomes. In doing so this chapter seeks to answer such questions as:

'What employment outcomes are reported following TBI?'

'How have researchers sought to develop VR programmes to meet identified needs?'

'How do demographic variables influence employment outcomes?'

'What are the common clinical sequelae following TBI and how are they said to influence

<sup>&</sup>lt;sup>3</sup> Whilst throughout this study, and others, the expression 'return to work' is used, as many study sample members have been pupils/students at the time of injury, strictly speaking the expression 'return to work/start work' would be more appropriate.

future employment ?'

'What is the role of the family/social support in the return to work process?'

'What is the significance of neuropsychological tests and how should they be used - to predict employment outcomes and/or identify factors to be taken into consideration when planning a return to work?'

**3.1 Defining Employment:** Given a head injured population consisting primarily of young adult males, the ability to return to work (RTW) may be viewed as the most socially relevant measure of outcome. It is often the most salient rehabilitation goal and it has the apparent virtue of being easy to measure. However, there is a danger in over-simplifying `return to work' as an outcome variable. There are problems in respect of defining employment.

Paid employment may seem a simple matter. However, as Kay (1993) states, there are levels of employment. Whether a former headmaster returns to work as a teacher, teaching assistant or caretaker reflects different outcomes, even though they can all be defined as `employment'. Secondly, employment varies in its regularity. Working two hours every other day has a different demand to working four hours every day, or all day every day. Thirdly, there are both quantitative and qualitative differences in *productivity*, the amount and quality of work a person with a brain injury produces can vary in comparison to other workers. Fourthly, employment can vary in the amount of structure required to sustain it. At one end of the spectrum is the independent worker who needs neither continuing nor periodic monitoring; at the other end is the worker in supported employment who requires personal support and structure in order to perform the job. The fifth point is that employment varies in *temporal* aspects; outcome criteria cannot be limited to obtaining a job. Some studies have used the criterion that employment at any time after injury has constituted a return to work, when a significant issue may be in respect of the capacity to maintain normal continuity of employment (Bond, 1983; Marinelli and Dell Orto, 1986). Other studies have used employment status at specified points of time (Ezrachi et al 1991); others still use employment status at the time of contact (Brooks et al, 1987a; Rao et al, 1990). Ideally, all five aspects of employment should be taken into account when defining outcome criteria for a competitive job placement of any given individual although the practicalities of obtaining all such information are recognised. Kay (1993) goes on to argue that one also needs to take into consideration social productivity which might also include voluntary and sheltered work. Whilst studies frequently distinguish between employment in the open labour market or under special conditions (characterised by reference to open and sheltered employment) there are categories of 'special conditions' that also require refining.

**3.2 The Value of Understanding Employment Outcomes:** There are significant problems when describing employment outcomes following injury, including TBI, and rehabilitation. Rehabilitation providers have long believed that appropriate rehabilitation programmes lead to improved function and recovery in patients with brain injury and, it would follow, improve their employment prospects. Within the UK, there have been few controlled studies conducted to support this belief. Consequently, there is much room for debate as to the effectiveness of intervention, particularly as vocational rehabilitation studies invariably present "global" figures, for instance, stating a particular percentage of clients returned to work, rather than expressing individual benefits, never mind how they may have occurred. Problems in understanding individual outcomes and the benefit of any intervention start with the definition of injury severity and go on to include selection and intervention biases, the (lack of) use of instruments of appropriate validity and sensitivity, a lack of uniformity in describing clinical sequelae and varying measures of employment outcomes.

Although studies, primarily from the USA, have documented substantial improvement after vocational rehabilitation, even in difficult cases believed to have a poor prognosis (Vogenthaler et al, 1989; Prigatano et al, 1994) without a control group, improvements resulting from rehabilitation are indistinguishable from those resulting from spontaneous recovery or to a person's own efforts at self-rehabilitation. In the vocational sector it has not been possible to identify one study of subjects receiving vocational rehabilitation contrasted with subjects receiving no such support when there is sufficient information in respect of client characteristics to know that studies are comparing like with like.

Whilst observations from clinical rehabilitation programmes incorporating vocational rehabilitation may have potential relevance in the UK, the starting point for the patients of clinical services may not be the same as that for those clients of vocational rehabilitation services with the sole objective of returning the client to the labour market. Clinical services may have a more severely injured client group. Moreover, one still has the problem of outcomes being inferred and not measured. Whilst the National Traumatic Brain Injury Study (1998) data set reveals many examples of directed intervention associated with improvement, it was considered that *"in many cases where the intervention took the form of arranging suitable employment ..... it would be perverse to deny a causal link"*, nevertheless there were also a number of examples of *"prolonged intervention which achieved very little ..... especially, in terms of community outcome."* 

The findings of the NTBIS team did not receive universal support. The House of Commons Health Committee (2001) heard evidence from the Department of Health that "good evidence on the efficacy of rehabilitation for head-injured people is not available. It appears to base its proposition almost entirely on its own study, *"The National Traumatic Brain Injury Study"*. The Committee went on to say that, *"Many witnesses, however, claimed that this study was very flawed and did not represent a reliable stamp by which to argue the weakness of scientific evidence on rehabilitation."* 

It is suspected that some critics read summaries and not the full research report. The data collection and analysis (multi-variate) were exhaustive but the findings and attempt to move away from a medical model of disability were not well received in some influential quarters. The researchers did *not* conclude that rehabilitation does not work (as perceived by some critics) but that better measures are needed to explain and account for outcomes.

It will be noted that although issues are commonly addressed in terms of 'outcomes' following injury, the 'real issue', for those offered it, is rehabilitation effectiveness. Rehabilitation effectiveness requires more than an inference of outcome measures alone. What is required is a system of input, process and outcome measures that demonstrate whether or not improvement is beyond what may have occurred through spontaneous recovery.

The expression 'rehabilitation outcomes' implies a (causal) connection to the preceding intervention. Although establishing causality is difficult because many factors affect rehabilitation outcomes, outcome measures need to have a logical and empirical relationship to programme interventions. Specifying vocational rehabilitation outcomes ought to entail research bridging the gap between intervention processes and the subsequent capacity to obtain and maintain employment. Many survivors of head injury may improve on the basis of their own efforts, aided by family or employer and without intensive professional intervention. Consequently, to ascribe improvement in function and employment status to the efforts of rehabilitation alone may not be warranted.

Brain injury vocational rehabilitation is a relatively new and specialised activity in the UK, experiencing a growth during the 1990s and given the recent development of condition management programmes (DWP 2002) may receive a further boost. Its quality standards are voluntary and implicit. As well as a need to balance effective rehabilitation within budgetary constraints, outcome monitoring systems are needed to establish guidelines by which informed decisions can be made in respect of financial support. This introduces two concepts - the first is in respect of measuring the individual outcome and the second is in respect of measuring the performance of the organisation offering the service. The first issue is of concern to this study, in particular reflecting outcome measures that mirror the experience of the subjects. It may

seem that the two activities are measures of each other - but this is not necessarily the case. A brain injured person may be offered the most capable of vocational services but, for example, if he/she lives in an area where there is a lack of local employment opportunity, or funding for supported employment, then he/she will statistically count as a negative outcome. On the other hand, if a service is screening out more severely disabled people at an early stage then its outcome figures may be biased by such a measure (although it may be argued that the measures which are being used are justified on the basis of selecting out those unlikely to benefit).

In spite of the limitations to reporting employment outcomes, there is evidential value in being aware of the existing data. To the extent that successfully maintaining a job is socially, psychologically and financially meaningful in a person's life it is useful to know how a TBI affects this ability and to what extent rehabilitation programmes enhance the probability of returning to work, particularly recognising those who are likely to benefit from rehabilitation programmes. There are, however, difficulties in interpreting RTW studies. Many contain methodological flaws. For instance:

- Those that attempt to establish RTW rates as a function of severity of injury, for example Johnson (1998) understandably rely on the medical profession for the period of posttraumatic amnesia (PTA) or unconsciousness (Glasgow Coma Scale). Whilst such information may be generally reliable, it is apparent that, due to the effects of medication, or other factors, such as alcohol, the length or severity of such conditions is not always clear.
- Small sample sizes in many studies, for example 39 in Burke et al (1988) and 18 control in Prigatano et al (1984).
- The short period of most follow-up studies, typically 2 to 4 years, for example Gonser et al (1992), although there are shorter, 12 months in Fraser et al (1988) and 6 months, Ruff et al (1993). There are exceptions, for example, up to 15 years, Gilchrist and Wilkinson, 1979, 2 to 7 years, Brooks et al, 1987a, and 15 years, Scwab et al (1993).
- The lack of baseline rates of employment, that is, how many people in the studies are likely to have been in employment in any event and, if so, to what extent. This criticism applies to virtually all studies although a number, Jacobs (1987), Stambrook et al (1990) and Johnson (1998) give an indication of how many subjects were in employment at the time of injury. However, there is often an implicit assumption, Fraser et al (1988), that in the ordinary course of events employment would be 'a very natural occurrence'.

- A lack of comparator groups. There are problems in determining the criteria for selecting comparators. Fraser et al (1988) selected friends of the study sample on the basis that they were likely to be drawn from the same socio-economic backgrounds.
- A lack of consideration as to the influence of vocational rehabilitation. An example is Dikmen et al (1994).
- External circumstances are frequently not reported. It may be the availability of appropriate jobs, adequate support, a family business, and so on, that determine whether a head injured person will return to work, not just the injury itself.
- Because there is rarely any data on pre-morbid characteristics, any reference to 'distance travelled' in rehabilitation is invariably made only by reference to the severity of injury and the dichotomous use of employed/unemployed status. Johnson (1998) reflects a typical approach. The severity of injury, not previous employment history, occupations or educational status, is reported and the outcome is measured by reference to being employed or unemployed. Whilst such an approach assists in identifying those likely to benefit from support in terms of severity of injury and the timing of interventions (and, unusually, he suggests strategy) the data collection can only allow for a basic presentation of outcomes and it is not possible to identify 'distance travelled'. For example, there may have been those who failed to obtain employment with other (than head injury) resettlement problems.

Despite limitations, it is considered that much can be learned from studies that have taken place to date. Whilst there are a number of methodological problems in considering RTW studies, particularly the lack of a comprehensive measurement process to ensure all relevant factors are assessed, a review of relevant studies provides a great deal of information to be taken into account when considering the benefits of intervention, albeit the factors affecting any individual's return to work after experiencing a brain injury are numerous and it is difficult to predict individual outcomes based on generalisations made from any one particular study. Nevertheless a major consideration in RTW studies has been the identification of factors allowing future employment capacity to be predicted, thereby facilitating the appropriate allocation of expensive and limited resources.

Ip, Dornan and Schentag (1995) recognised that the ability to predict outcome for those who sustain TBI could facilitate effective rehabilitation planning. A sample of TBI subjects who had completed their rehabilitation were contacted post-discharge to identify predictive

factors in respect of a return to work or school. Subjects were given a telephone interview and their records were examined along five sub-sets of variables: sociodemographics, chronicity, indices of severity, physical impairment and cognitive functioning. Forty-five subjects were used as the study sample to investigate their vocational and educational outcome and to generate the best predictive model for return to work/school. Twenty subjects made up the test sample used to evaluate the generalisation of the predictive model. Performance IQ score measured by the WAIS-R (Wechsler, 1981), emerged as the most predictive return to work or school variable. The small sample used in this study may explain some of the findings such as brain injury severity, as measured by GCS, not being related to RTW. Of significance in respect of this study and the approach to evaluation is the fact that authors considered that the development of a regression model to predict RTW could not be produced due to the high inter-correlations between various variables.

Even though research to date has not been able to develop a predictive model, the search for factors likely to be significant in the vocational resettlement of any one individual remains important for the following reasons:

- i. When considering selection to a vocational programme there remains a need to ensure the most appropriate allocation of resources, not only are public resources limited but nothing is likely to make those funding intervention more sceptical as to its value than a lack of success.
- ii. Ashley and colleagues (1993) noted that rehabilitation providers faced an increased demand for analysis of their outcomes and cost of services (Evans and Ruff, 1992; Malkmus and Johnson, 1992; Papastrat, 1992). It would appear from recent developments in the United States, and the 'Ticket for Work' (TFW) programme, that payment to service providers (State Vocational Rehabilitation Agencies and Employment Networks) has moved entirely to outcome related funding (Rupp and Bell, 2003). It will be noted in Chapter 4.4 that the Supported Employment Programme in the UK now has a significant output related element. To date the NHS Trusts and other providers of the condition management programmes have been guaranteed funding but the long term basis for payment remains to be seen.
- Within any vocational programme an understanding of the factors adversely impacting upon the positive vocational outcome of a participant should lead to a better directed use of resources in order to meet client

needs. Accurate predictions (based on a knowledge of potential outcomes) suggests differential vocational planning for individual clients, allowing a more judicious allocation of resources. Those with a high probability of a spontaneous return to work may require only limited support. Greater vocational effort could be targeted to those offering a reasonable probability of return to work but requiring specialised services. This type of planning would allow the provision of appropriate support for each client and the coordination of a service delivery amongst interested bodies, including public and private sector clinical services, vocational rehabilitation agencies, Jobcentre Plus and insurance companies..

- iv. A greater understanding of those most likely to benefit from support may also help reduce the duration of intervention through the formulation of relevant goals for the client. For example, the knowledge that a client's injury severity is likely to lead to long-term difficulties may allow the rehabilitation team to lessen the goals. For instance a clinical rehabilitation team may emphasise developing independent living skills instead of less obtainable vocational goals. It is recognised that allocating limited resources raises ethical issues that are not easily resolved, particularly in 'marginal' cases.
- v. The expected return to work rates also provide a framework for determining the gains which need to be made in order to meet such expectations. One matter rarely addressed in RTW studies is the differing starting points of the clients/patients. This is a different matter to reporting the severity of the injury. Typically, the common starting point is that the subject has sustained a head injury of some degree and he/she is unemployed understanding "distance travelled" needs to be more sophisticated than this by taking on board different starting points. Some patients/clients will have better or worse prospects of resettlement than others - in the same way that same able-bodied people will always have better prospects on the open labour market than others. Whilst clinical rehabilitation may seek to address the direct consequence of the injury with regard to community reentry, vocational rehabilitation may also need to address factors that may have occupationally disadvantaged a person in any event.
- vi. Those working in the vocational rehabilitation sector may be asked to provide an expert report or a witness statement for use in personal injuries litigation; the Courts being faced with the task of assessing future employment and earnings prospects. A knowledge of relevant factors

should ensure that balanced and informed opinion is provided.

- vii. Prediction and validation of vocational outcome is important in research. Whilst many people sustaining TBI in the UK may not receive vocational support, others are being offered a variety of (expensive) approaches to vocational rehabilitation and these have not been evaluated by wellcontrolled studies to determine their effectiveness.
- viii. Brain injury rehabilitation also has a consumer movement. In the UK such organisations as Headways, the Children's Brain Injury Trust and the United Kingdom Acquired Brain Injury Forum promote debate on the provision of resources. Referral sources, insurers and policy makers also ask for information on optimal rehabilitation interventions and their effectiveness. If measurable outcomes could be defined following vocational rehabilitation it would ultimately follow that there would be a database for a better understanding of what works with whom and why.

### 3.3 Return to Work Studies: Studies Reporting Outcomes and Identifying Variable

**Said to Influence or Predict Outcomes:** The reviewed literature has been drawn from five sources, literature with which I was already familiar as a consequence of work activity; a literature search at the British Library Documents Centre (Boston Spa) using key words 'traumatic brain injury' and 'vocational rehabilitation'; references within the literature; searching through the indexes of relevant publications e.g. *Brain Injury* and supervisory guidance.

The literature search identified over 140 world-wide return to work studies. Primarily English language studies considered to add to the general body of knowledge are summarised in more detail than ones considered 'only' to add weight to earlier findings. No reference is made to a number of studies because they were considered to add little new to the field or because of limitations in the presentation of data.

In spite of the social and human costs of brain injury, there has been little research into vocational outcomes in the UK in the last 25 years. The exceptions are a number of return to work (RTW) studies undertaken by neuropsychologists (Brooks et al, 1987a and b; Weddell, Oddy and Jenkins, 1980; Oddy, Couglan, Tyerman and Jenkins, 1985; Johnson, 1987a, 1989 and 1998). Hence, most of the literature is of North American origin. There are no published studies analysing vocational rehabilitation facilities, the process of vocational rehabilitation and eventual outcomes, other than the reports of Johnson and that of Tyerman (1999), associated with the 'Working Out' project, part of the 1990s National Traumatic Brain Injury Study (NTBIS).

There has been no systematic analysis to critically evaluate the effectiveness of what works with whom and under what conditions.

There is an absence of literature on the employment experience of the substantial group of people sustaining a head injury in the UK not receiving rehabilitation (Thornhill et al, 2000), other than the reporting of RTW statistics, for example Brooks et al (1987a).

Historically, RTW studies invariably focussed upon pre-morbid demographic and injury variables and outcomes. Until the mid 1990s there was much less attention given to *how* people with TBI return to work and the process of vocational rehabilitation. Whilst there are many studies considering neurological and neuropsychological sequelae in general and relationship to employment (Roberts, 1976; Levin et al, 1979; Lamb et al, 1991; Malec et al, 1993) and studies considering the efficacy of vocational rehabilitation (Thomas and Menz, 1990; Kay, 1993; Prigatano et al, 1984; Burke, Wesalowski and Guth, 1988; Ben-Yishay et al, 1987) almost all are of American origin (and many may be regarded as dated). Throughout the 1990s there were fewer studies seeking to predict a return to work following TBI but more studies reporting compensatory approaches, for example Curl et al (1996) and Van den Broek et al (2000)

Particular points to note amongst the studies are the way return to work is invariably presented as a unitary phenomenon; practical difficulties faced by researchers, such as identifying the severity of injury; the inability of many studies to identify subjects receiving clinical and/or vocational rehabilitation; varying periods of follow-up; the lack of indication as to how many subjects were likely to have been in employment in any event, or were employed before injury and varying means of analysis, developing from univariate to multivariate analysis but also including case studies.

Such factors are considered to weaken the comparative value of many such studies and, undoubtedly, have contributed to difficulties in drawing definitive conclusions in respect of identifying variables influencing outcomes. They are particularly evident in this thesis when considering the findings of the seminal multivariate study of Crepeau and Scherzer (1993)and identifying factors influencing outcomes.

Methodological issues also emerge that affect the value of the findings (and reflect a need to find alternative ways to account for RTW outcomes).

It is difficult to simply categorise the main methodologies used in most studies although, in

considering options for this study, Chapter 5 recognises two strands, pragmatism (or methodological pluralism) and empirical practice. The former relies upon non-experimental quantitative approaches, such as surveys. Perhaps surprisingly such an approach is rarely accompanied with comparator data. There are practical difficulties in establishing and tracking comparators over a prolonged period. Empirical practice invariably relies upon testing the subjects in experimental approaches. Both methodological practices will be recognised in the discussed studies, and they both produce problems that weaken the value of the findings and contribute towards a search for alternative approaches.

In the studies relying upon surveys it is often difficult to identify what it is that contributes to the outcomes, whether or not it is the injury Itself or some other factors. Whilst the quality of reporting has improved over the years even 'basic' information can be missing, such as whether or not the subjects received rehabilitation.

Testing produces different problems and the value of neuropsychological testing is discussed later in this chapter. Clinicians may use a range of tests and even when relying on the 'same' ones it is apparent that not all the same sub-tests may be administered, hence comparing results from different programmes is fraught with difficulty. In addition, it will be noted that when regression techniques have been used (for example identifying the particular significance of neuropsychological sequelae) variables have often correlated too closely to distinguish the significance of a single factor.

On top of these limitations one still needs a great deal of demographic data in order to know that the findings are based on comparable populations.

In an ideal world it is considered that the presentation of the literature studies would be based on an algorithm setting out the studies comparable or distinguishable by:

- demography,
- tests used,
- results and findings

would enable the reader to form an opinion as to the respective value of the studies (in terms of what contributes towards the outcomes). An alternative approach would be to establish certain criteria to be met, for instance:

- UK studies within the last 15 years,
- relying upon the Wechsler Adult Intelligence Scale-Revised (Wechsler 1981) and Halstead-Reitan Test Battery (Halstead, 1947), with a
- minimum sample size of 60 followed-up for a minimum of 3 years.

In such a case the number of studies to be reported would be one (Johnson, 1998). It would be nil if even more stringent research criteria were applied, such as a randomised controlled trial (RCT). Even broadening the criteria to include world-wide studies and any studies using comparators of any description would not vastly increase the number. One would need a large spread sheet to set out all the various approaches and criteria used in RTW studies. It could be done (Crepeau and Scherzer, 1993) but this would be a lengthy research programme within itself. So what is the purpose and value of the literature review?

- 1. To provide a chronological understanding of the development of RTW studies.
- 2. To report the outcomes identified by the researchers.
- 3. To identify variables *they* considered significantly affecting the outcomes (and these are considered in further detail in Chapter 4) in order that any consensus would inform the data to be collected for this study.
- 4. To identify methodological strengths and weaknesses, again to inform this study.

What the review is not is a detailed critique of each individual study for comparative purposes, that is an attempt to 'explain' the respective findings by reference to such factors as the demography of the study sample, nature of the injuries, tests used, etc. This is not possible because of the manner in which findings are often reported. Nevertheless pertinent criticisms are made when it is considered that the findings of a particular study cannot be justified by reference to the given data.

An early review of RTW studies was undertaken in the UK by Oddy and Humphrey (1980). They considered the literature on occupational resettlement after head injury confounded by varying standards of clinical severity and social outcome. Because this review is now dated reference is only made to a few of the studies with large sample sizes.

Steadman and Graham (1970) studied all the head injury admissions to a Cardiff teaching hospital in 1958. Five years later they were able to contact all but 23 of the 438 survivors. Only five patients (1.2%) were unemployed, though another six were permanently downgraded. This means that all but 3% had returned to school or their normal work, despite complaints of personality changes in 10% of the series. Unfortunately, there is a lack of information with regard to the severity of injury.

Similarly, Rowbotham et al (1954) produced impressive figures for a return to work, with only 10 patients out of 250 failing to return to any form of employment (although another 10 had been unable to work regularly) but there is no indication as to the severity of injury.

Hpay (1971) drew on a population of more than 3,000 patients treated in the Head and Spinal Injuries Research Unit of the Department of Surgical Neurology at Edinburgh Royal Infirmary over a three year period. There was evidence of severe cortical and/or central basal brain damage in 211 patients. Only 86 of these patients had survived (a mortality of almost 60%) with 58 (67%) available for interview. Only 10 patients failed to resume work but, again, there was a need for considerable down-grading. There was a higher incidence of psychological disturbance (67%) than of physical disability (36%).

Oddy et al (1978) reported the resettlement rate of 45 patients who had been working full-time before head injury. Of the 8 who were not working at the end of the year, one was caring for his home and children after a divorce, whilst another had withdrawn from her profession in the hope of starting a family. Excluding these two, the proportion of resettlement rose to 87% and although the authors considered that some tolerance on the part of employers was needed, there was little evidence of down-grading.

Bruckner and Randle (1972) followed up all but 5 of 93 consecutive admissions to a rehabilitation centre after severe head injury. More than one-third were still unemployed, the rest had taken an average of 15 months to return to work, with a range of 3 months to 7 years. It was found that psychological factors were the most important influence on return to work. These included cognitive defects and behavioural problems.

Heiskanen and Sipponen (1970) followed up 102 head injured subjects 3 to 5 years after injury, all of whom had been unconscious for at least 24 hours. Overall, 53% had been able to return to work or school. This rate, however, was shown to be strongly influenced by the age of the subject. For example, 70% of those under the age of 20 had returned to work or school, as compared to only 30% of those over 50. The authors also demonstrated a further interaction between age and severity of injury. In this sample, no subject unconscious for more than four weeks spontaneously returned to work within the follow-up period. No subject between 21 and 40 returned to work if unconscious more than three weeks and no subject between 41 and 60 returned to work if unconscious more than one week. No subject over 60 returned to work if unconscious for more than one week.

Richardson (1971) followed up 121 patients admitted to a rehabilitation centre and assessed by the Workman's Compensation Board of Ontario. The average age of 40 years is high in comparison with most other studies but all the participants were of working age. Head injuries

were classified as minor, moderate or severe according to the duration of post-traumatic amnesia. Only 8 of the 33 patients with minor injury were back at work 5 years later, whilst, paradoxically, 38 patients with moderate injury were in work. Almost three-quarters of the severe group (36 out of 50) were unemployed.

Although dated, Gilchrist and Wilkinson's 1979 study reported findings (Table 3.1) that have continued to be supported by further studies. A total of 72 people with head injuries were followed up 1 to 15 years after their injury. At the time of follow-up, 39% of the sample had returned to some kind of work. Whilst the more severe the injury, the lower the likelihood of spontaneously returning to work, this relationship was one of probability: regardless of the level of severity, some head-injured people returned to work and others did not.

Sample Characteristics Sample size Loss of conciousness % unconscious >1week Follow-up	72 >24 hours 85 I to 15 years	
Length of "Unconsciousness" < 1 week 2-4 weeks 5-7 weeks > 8 weeks	Return to any Work 82 47 18 11	<b>Unemployed</b> 18 53 82 89
<b>Deficits</b> No/Mild Mental Impairments Mod/Severe Mental Impairments	62 23	38 77
Overall Return to Work Same Level Lower Level Unemployed	24 15 61	

#### Table 3.1: Study Sample Characteristics

Gilchrist and Wilkinson (1979)

Gilchrist & Wilkinson (1979) also found that the chances of returning to work rose from 21% in unskilled jobs to 50% in managerial positions which, they suggested, may offer greater flexibility in both the time and opportunity for the effective use of compensatory strategies.

Brooks and colleagues (1987a) examined return to work rates for a group of brain-injured patients in Glasgow. Follow-up information was obtained from relatives at intervals ranging from 2 to 7 years after injury. Seventy four per cent of the patients were working either full or part-time prior to their injury. In contrast, only 29% were working at the time of the follow-up (25 out of 70 patients). Whilst the unemployment rate remained relatively stable beyond two years after injury it is suggested that this probably reflects a balance between the number of

initially unemployed persons who later found work and the number who were initially employed but later quit or were dismissed. Few of the subjects aged above 45 years sustaining severe head injury were found in employment.

Fraser, et al (1988) examined the pre-injury employment status of 102 head-injured subjects, profiling the employment status of those working at the time of their injuries (n=48) and examined various correlates of employment re-entry. This study used a control group. This consisted of 102 individuals selected from friends of the participants, based on the assumption that one usually chooses friends similar to oneself. The friends were expected to be roughly similar on potentially important cognitive and psycho-social characteristics.

As part of the psycho-social assessment, employment status and specific job titles were recorded at one month and one year post-injury. All job titles were classified according to the *Dictionary of Occupational Titles (1977)*. The results showed a considerable spread of pre-injury jobs - Professional, Managerial (23%); Clerical and Sales (23%); Service (17%) and Structural (17%) - even within these categories there was considerable diversity. Work involving other DOT categories varied from 2% in benchwork occupations to 8% in machine trades.

A person was defined as working at the time of the injury if he or she was working for more than four hours per day for at least five months before injury. A total of 48 participants (47% of the sample) fell into this bracket. The study focussed on this group assuming that vocational re-entry should be a "*very natural occurrence*". An additional 19 participants (19%) were working for several months in the year prior to injury but were not employed at the time of injury. Twenty-one participants (20%) were primarily students at the time of injury with no significant employment history. The remainder were either home makers (11%) or people for whom insufficient vocational information was available (3%). At the one year follow-up, 35 of the 48 (73%) participants originally working at the time of injury returned to the job market. However, these 35 participants often had interruptions in their employment. Use of the DOT complexity ratings<sup>4</sup>, suggested that 5 had moved into more complex work activity whilst 5 were working in less complex jobs. Approximately 25% (13) of those working at the time of injury were no longer in the job market. Of those not working, 9 of the 13 had not worked at all during the year post-injury and were still dealing with head injury effects that precluded their return to

<sup>&</sup>lt;sup>4</sup> Differences between the American Dictionary of Occupational Titles (DOT) and the British Standard Occupational Classification (SOC) system, including complexity ratings are discussed in the conclusion at Part 3.

work. Of the 9, three were students who were in school because they believed that they were at the time unemployable. Therefore, of those working at the time of injury, it seems that, at a minimum, 9 (17%) were unemployed because of head injury effects. As in prior research, for example Brooks et al (1987b), few (5) received any vocational support.

Fraser and colleagues presented neurological, neuropsychological, psychosocial, demographic individuals who returned to work and those who did not. The group not returning to work within one year had significantly more difficulties, especially on measures of motor speed, cognitive flexibility, visual-spatial memory, visual-spatial problem solving and manipulation skills. It was concluded that the neurological severity of a head injury is related to employment status. On average, the unemployed respondents had a longer (>24 hrs vs. <1 hr) coma than the employed cohorts.

Jacobs (1987) described the Los Angeles Head Injury Survey. This project was designed to identify the long-term needs of people with severe head injuries by assessing functional skills one to six years post-trauma. An instrument containing over 700 questions relating to the ability to engage in productive and self-sufficient living skills was developed for use with 142 families of people with severe head injury. The results indicated a broad spectrum of deficits and needs. No one course of recovery was noted for individual survivors and residual deficits were noted for at least some portion of the surveyed population across every topic that was covered. Most survivors lived with their families, did not work or attend school and were dependent upon others for skills, finances and services outside the home. It was considered that the combination of deficits across basic and higher-order skills was more significantly noted in education, work and living arrangements. Because the average age of participants was 22 years at the time of injury, most had already completed their education. Of the 25% still in school at the time of injury, one third returned to their studies after approximately one year; 32% of the total population applied to school subsequent to injury and 20.6% of the total sample were attending school at the time of the survey. Placements included college (13.8%), high school (15.5%), trades school (10.3%), private rehabilitation programmes (18.9%) and community college (41.4%), where most participants were in special needs programmes. Approximately half of the sample who began school subsequent to injury were still in school, 13.6% graduated and 37.8% dropped out before completing their programmes (a drop-out to graduation ratio of 2.8:1).

Wages were the primary source of income for 77.9% pre-injury, compared to 26.7% at the time of the survey. Of those working, 63% were employed in full-time positions. An additional 12.5% of the total population returned to work post-injury but were not able to maintain employment;

70% of all previously employed left their jobs due to the injury and an additional 10% were laid off or fired after the injury. Only 2.2% continued in their work relatively uninterrupted postinjury. Of those working at the time of the survey, 36.7% returned to their previous employer; the remainder had to find new opportunities. Relatives and friends were the most frequent source of contact for new jobs. Families reported that the primary causes of unemployment related to comprehension, attention span, ability to learn and remember new tasks, behavioural problems, stamina and perceptual problems.

Kay et al(1988b) followed a sample of subjects, described below (Table 3.2), for a five-year period, tested on a neuropsychological battery 3, 6 and 12 months post-injury. The aim of the study was to determine what cognitive skills are best correlated with levels of returning to work years later. An unexpected outcome of this research was to expose the methodological flaws of extrapolating from group data to individual recovery. The researchers looked at statistical significant changes in each individual's subject's performance over time. They found that the commonly accepted notion that widespread neuropsychological recovery occurs in the first year, followed by significant slow down in improvement, was an artefact of collating data from separate studies. They considered that, within the first year, the extent of an individual making major changes is overstated. Another group's significant improvement resulted not from modest gains from almost all subjects, but major gains by some and no significant changes by others. Conversely, the amount of change that occurred between 1 and 3 years post-trauma was under-estimated by the failure of the group to change statistically. This was because 4 distinct sub-patterns were being averaged and cancelling each other out: some subjects continued to improve steadily, some declined, other showed random improvements and declines, and some made no change. There was evidence that it was the group showing most ability in test performance over time that was most likely to be employed.

Demographic	Percentages/Means (N=25)
Sex Male Female	72 28
Age Average Range	27.2 18-56
Education High School Diploma Technical Certificate	56 20
Loss of Consciousness Less than 1 Day 1 Day to 6 Weeks	40 60

#### Table 3.2: Demographic Data

Kay, Ezrachi, Cavello (1988)

The sample was rated by four vocational outcomes at five years: (i) persons returning to work at levels comparable to the pre-injury status and reporting no difficulties; (ii) persons returning to work at comparable levels but reporting injury-related difficulties; (iii) persons working at a reduced capacity, and (iv) persons not working at all. Students and homemakers were considered "employed" along the same dimensions. The results are given in Table 3.3:

Return to Work Status	N	Total Sample (N=25)	Employed Sample (N=16)
Comparable Level, No Problems	5	20	31
Comparable Level, Residual Problems Reduced Capacity	6	24	38
Unable to Return to Work	5	20	31
	9	36	-

Table 3.3: Work Status at Five Years Post Trauma

Kay, Ezrachi, Cavalo and Newman (1988)

In total 64% of the study sample were able to return to some level of productivity five years after injury, although only 20% returned to work at a comparable level and reported no problems. The largest sub-group, one-third of the total sample, was unemployed. Subjects whom at five years were working at comparable levels returned to work earlier than subjects working at reduced levels, 100% of the group working at comparable levels within five years had returned to work within 2 years of their injury; the majority of those who returned at reduced levels, returned between 2 and 5 years post-injury.

Stambrook and colleagues (1990) noted the work of Brooks et al (1987a) in respect of the RTW work rate of those sustaining severe head injury (29%). They considered this study suffered from limitations in respect of generalisation, as it focused only on victims of severe head injury using several non-standardised instruments and examined unemployment in a dichotomous fashion (working/not working). They sought to extend this study by examining employment outcome amongst a group of 131 males sustaining mild, moderate and severe closed injury at one to eight years post-injury. Subjects were placed in the "severe" category when the Glasgow Coma Scale (GCS) on admission was less than or equal to 8; "moderate" when the admission GCS was greater than 8 and less than 13; and "mild" when GCS on admission was 13 or greater. Results are indicated in Table 3.5

Variable	Group	- (j) 	
	Severe (n=50)	Moderate (n=55)	Mild (n=26)
	Mean SD	Mean SD	Mean SD
Age (years)	36.00 14.07	43.25 18.24	39.46 17.14
Months post-CHI	46.98 24.48	41.86 21.49	48.88 22.08
Coma duration (days)	6.07 5.08	0.54 0.66	0.56 0.68
Length of PTA (days)	34.47 30.00	5.79 14.16	3.23 5.03
GCS (admission)	6.24 1.97	13.33 2.01	13.23 2.58
Residual problems %	38.95 9.96	34.64 9.03	35.04 9.80
Garrd and Bennett activity scale	1.33 2.41	0.26 0.77	0.18 0.37
Occupational status			
Pre-injury	38.42 19.50	37.55 19.38	39.59 17.58
Post-injury	22.69 19.28	32.37 20.41	38.68 21.07

#### Table 3.4: Demographical and medical characteristics

#### Table 3.5: Pre- and post-closed head injury employment status

Group	Employment status *	Pre-injury		Post- injury		Percentage returning to same status
		n	%	n	%	
Severe (n=50)	Full-time Part-time Unemployed Student	31 5 9 5	62.0 10.0 18.0 10.0	17 4 26 3	34.0 8.0 52.0 6.0	54.8 80.0 + 100.0 60.0
Moderate (n+50)	Full-time Part-time Unemployed Student	36 4 11 4	65.5 7.3 20.0 7.3	29 5 20 1	52.7 9.1 36.4 1.8	80.6 + 100.0 + 100.0 25.0
Mild (n=50)	Full-time Part-time Unemployed Student	16 2 5 3	61.5 7.7 19.2 11.5	14 3 7 2	53.8 11.5 26.9 7.7	87.5 + 100.0 + 100.0 66.6

\* Bishen B (1967) a Socio-Economic Index for Occupations in Canada. A Canadian review of the sociology & anthropology 4:41-53. Stambrook et al (1990)

The major finding of this study is that out of the 31 people in the severe group employed fulltime prior to injury only 17 (55%) were employed at a full-time level subsequent to injury and at a significantly reduced level of status. Moderately injured patients also experienced a loss of status although 80% of patients previously employed full-time returned to this level of activity.

Lamb et al (1991) reviewed the results of a survey on employment outcomes and the relationship to neuropsychological data for 40 people with TBI discharged from a mid-Western State rehabilitation centre in 1986. The mean age at follow up was 31 years, with a range from 20 to 56 years. The mean age at the time of injury was 26 years, ranging from 17 to 49 years. On average, participants were 23 months post-injury on follow up. The average stay in the rehabilitation centre was 6 months.

Nineteen (48%) of the 40 participants surveyed were employed on follow-up. An additional 6 had worked in some capacity since discharge but were not working at the time of the interview. The remaining 15 participants had not worked since discharge, although one was in a non-paid work trial. Prior to the injuries, 4 participants were "home makers". These were not employed outside the home at follow-up and they were considered to be in the unemployed group. Of the 19 participants employed, 12 (63%) were working in competitive employment, 6 (31.6%) in sheltered workshops and one (5.3%) in supported employment. Categories of employment outcome were defined as competitively employed, marginally employed and unemployed.

It was concluded that the results of this study support the detrimental impact of head injuries on vocational capability found in other employment outcome studies. Those in work had higher cognitive functioning, better visuo-spatial memory and less distractibility. A point made by the authors is that it is wrong to consider employed people with head injuries as an homogenous group and that the term "employed" should be defined in terms of more specific categories, such as volunteer work, sheltered work, supported work, competitive work part-time and competitive work full-time. They also considered that the measure of vocational outcomes could be further expanded to include pre-injury and post-injury wage loss, occupational changes, job tenure, career mobility, job difficulties and job satisfaction. An acknowledged potential criticism of the study is the small sample size.

Paniak et al (1992) examined vocational functioning at least two years post-injury in a group of 57 severely closed-head injured (CHI) patients and 50 non-brain-injured spinal chord injured (SCI) patients. The two groups were equated on age, education, socio-economic status (SES), male/female ratio and marital status. The CHI and SCI patients had a similar number of members who were employed on follow-up. However, the difference in vocational functioning

between SCI and CHI groups was evident when vocational status was quantified with the SES parameter. The authors considered that while previous studies of vocational status (Brooks, et al., 1987a; Rappaport, et al, 1989; Thomsen, 1984) often used parameters such as employed/unemployed or productive/non-productive, and while such studies generally found more than 50% of severe CHI survivors to be unemployed, they did not detect the degree to which even those working sustained losses in vocational functioning. Results of their study suggest that a more sensitive measure, such as SES, is needed to adequately evaluate vocational functioning after CHI.

Ruff et al (1993) considered that most studies of TBI survivors isolate predictors of outcome following mild, moderate and severe injury without attempting to integrate them into an algorithm using the best of the predictors.

Their study examined employment status (or return to school) at 6 and 12 months following injury. Data was collected from the Traumatic Coma Data Bank (TCDB) using specific selection criteria (Marshall. Becker, Bowas, 1983) and procedures for measuring the demographic, physiological, neuropsychological and psychosocial status (Levin, Gary, Eisenberg, 1990). A sample study of 93 people was selected with 242 comparators. The data matrix contained hundreds of variables although the sample sizes were not large enough to justify statistical methods to isolate valid predictors although 11 significant variables were identified as indicated (Table 3.6).

Age was selected as the most important demographic variable, since the literature typically demonstrated that older adults experienced poorer outcomes (Alexander, Colombo, Nertempi, 1983; Levin et al, 1979). Length of coma was also used as an important medical predictor (Lundholm, Jepsen and Thornval, 1975).

Predictor	Values anticipated
<i>Demographic</i> 1. Age	Younger
<i>Medical</i> 1. Length of coma	Shorter (> 20 days worse)
<i>Neuropsychological</i> 3. Manual motor speed (Finger-tapping) 4. Selective attention (2 & 7 - Speed)	Faster (<37 average taps = impaired) Faster (<170 hits =
(2 and 7 - Efficiency)	impaired)
5. Short-term memory (Wechsler Short Stories)	More accurate (<80% of (hits - errors/hits) x 100 = impaired)
6. Spatial integration (WAIS-R Block Design	Greater (<7 average immediate items recalled = impaired)
7. Information processing (Trail-making)	Higher (<6 scale score = impaired)
8. Depression (KAS Withdrawal and Depression)	Faster (>95 secs =impaired) Not withdrawn or depressed (>13 = impaired)
9. Social tactfulness (KAS Social Obstreperousness)	Mild-mannered (no score available)
Pre-morbid estimated verbal intelligence 10. (WAIS-R Vocabulary)	Higher (<6 scale score = impaired)

Table 3.6 : Predictors and direction of association

Ruff et al (1993)

The 6-month cohort study contained 75 males and 18 females with a mean age of 25.7 years. The proportion returning to work during the first 6 months was 18% for former workers and 62% for former students. For those not back to work at 6 months and for whom there was follow-up data at one year, the proportion back to work was 31% for workers and 66% for students. There was a strong association between return to work, age and length of coma. The research indicated a lack of significance with regard to the Katz Withdrawal/Depression scale (Katz and Lyerly, 1963) and a return to work, "..... the lack of significance of social obstreperousness was indeed surprising, since we thought that poor interpersonal skills all too frequently sabotage return to work". Using a 20-day cut-off, subjects with less than 20 days in coma were 2.7 times more likely to return to work in the first six months than those with a longer coma. In the six months to one year period manual motor speed was considered a "significant predictor". Correlation studies identified three significant predictors in the same

order of importance: WAIS-R Vocabulary (Wechsler, 1981), age and Selective Attention Speed. It was considered noteworthy that speed was highly associated with a return to work whereas efficiency, relating speed to accuracy, was not. It was considered that speed of work may be more a critical asset rather than performing to high accuracy rates.

Schwab, Grafman, Salazar and Kraft (1993) investigated the relationship of neurological, neuropsychological and social interaction impairments with regard to the work status of a large sample of patients with penetrating head injuries wounded some 15 years earlier during combat in Vietnam. They considered that head injury studies were generally constrained by a small number of subjects, lack of appropriate controls and indirect or meagre neurological and psychological examinations. Hence, it was difficult to identify which residual impairments contributed significantly to a patient's inability to work.

Standardised testing of neurological, neuropsychological and social function was undertaken at follow-up on each subject (n=520), as well as on a sample of uninjured controls (n=85). Fifty-six percent of the head-injured patients were working at follow-up compared with 82% of the uninjured controls.

Seven impairments most correlated with work status. These were post-traumatic epilepsy, paresis, visual field loss, verbal memory loss, visual memory loss, psychological problems and violent behaviour. These disabilities had a cumulative and nearly equal effect upon the likelihood of work. It was suggested that a simple summed score of the number of these seven disabilities could yield a residual "disability score" which could prove to be a practical tool for assessing the likelihood of a return to work for patients in this population and, perhaps, in other brain-injured populations. This could serve to focus rehabilitation efforts.

It is noted that many subjects in this study received penetrating injuries, as a consequence of shrapnel and, as such, are more likely to have sustained specific injury as opposed to the type of diffuse injury resulting from car crashes, a more typical causation of civilian TBI.

Gonser (1992) followed-up 122 patients with severe head injuries 2 to 4 years after trauma. Less than half of the patients (43%) were found to have no employment handicap, whilst the remainder showed various degrees of occupational difficulty. Most of the patients had significant long-term problems relating to cognitive and psycho-social dysfunction. Whilst the cognitive disorder, physical handicap, age and duration of unconsciousness were all important prognostic factors for vocational re-integration, the neuropsychological impairment was the most important single one. Greenspan et al (1996) examined the individual contribution of the motor and cognitive aspects of the Fone FIM<sup>5</sup> to injury-related failure to return to work although these were so highly corollated they could not be taken as separate variables. The results of this study show the importance of functional independence as a factor in RTW among persons with TBI. Of the 127 people reporting injury-related failure to return to work at one year, only 9% also reported complete functional independence. Stratification by TBI severity revealed that, regardless of severity, it was those who reported functional limitations at one year who failed to RTW. The findings suggested that it is not the severity of the injury *per se*, but its relationship to functional independence that influences RTW. This is consistent with the findings of previous studies (Fraser et al, 1988; McMordie et al 1990; Rao et al 1990; Weddel et al 1980; Prigatano et al 1984).

Younger persons were found to have higher levels of community and social integration and productivity than older participants. Additionally pre-injury occupational status was also found to be a significant predictor of a return to work. Post-traumatic amnesia emerged as the most useful of the injury indices in the prediction of productivity and vocational outcomes. It was concluded that whilst it is possible to generate statistically significant prediction equations using a combination of various demographic factors, injury severity indices and rehabilitation assessment measures, the extent to which any one predictor is able to explain the outcome is "very modest".

As indicated earlier, the number of studies seeking to identify predictive variables appears to have declined throughout the 1990s in favour of examining approaches to overcoming barriers to employment, and possibly, because further investigations in this area have not added anything new to existing knowledge and/or the results may reflect methodological limitations. For instance, Cattelani et al (2002) selected 35 TBI subjects from 228, according to pre-morbid clinical and demographic characteristics matching the established selection criteria. All subjects who were successfully employed obtained significantly better scores on length of coma and PTA, intellectual status, cognitive function and behavioural competence. Other specific measures of injury severity (CT Scan) abnormalities, GCS score level, and Bartel Activity of Daily Living Index were unrelated to a return to work. The authors concluded that the initial TBI severity level, especially indicated by duration of coma and PTA, are related to a return to work. Any confounding outcomes, in contrast to other studies, may be explained by

<sup>&</sup>lt;sup>5</sup> Fone FIM is a telephone variation of the Functional Independence Measure (FIM), a clinical scale for assessing functional capability.

the small sample size increasing the likelihood of chance findings.

Whilst a multi-variate approach may result in a more satisfactory prediction, only a relatively small number of studies have taken such an approach to the prediction of future employment. Crepeau and Scherzer's 1993 study considered that the heterogeneity of studies reporting RTW data after TBI leads to a lack of clarity and reliability. They identified 140 studies with only 41 meeting the criteria for their evaluation: the study was limited to subjects with TBI, at least one quantitative predictor or severity indicator measure and one measure of return to work, school or home maker status.

Crepeau and Scherzer found that age was only related to work in studies that included subjects over 60, while gender and number of years education seemed to have a minimal relationship to outcome and there was only a small tendency for those with more skilled employment backgrounds to be more likely to return to work.

Few studies were identified that related neuro anatomical or neurophysiological damage to vocational outcome. Two studies showed converging moderate results: abnormalities detected on a CT scan were associated with a decreased probability of return to work (Klonoff, 1984; Rao et al, 1990). A weaker, but significant correlation was obtained in the case of frontal lobe damage. In the case of projectile wounds, bilateral lesions had a more negative repercussion on work status than a unilateral lesion (Newcombe, 1969). Penetrating missile wounds were also associated with a poor prognosis in respect of a return to work (Dresser et al, 1973; Newcombe 1969).

Few studies reported on the depth of coma using the Glasgow Coma Scale (GCS) (Jennett & Bond, 1975; Fraser et al, 1988; Stambrook et al, 1990; Uzzellet al1987; Vogenthaler et al, 1989).

Whilst the duration of coma was the most frequently used variable in the literature Crepeau and Scherzer (1993) considered that the results were often based on a vague definition. The authors considered that a visual examination of the results suggested that the statistical relationship depends on the severity of the sample. The predictive value of coma was higher in cases of less severe samples (p=0.06). In eight studies, when more than 65% of the samples were employed post-trauma, that is less severely damaged individuals, the results tended to be homogeneous (Adey, 1967; Brennan, 1981; Dresser et al, 1973; Dye et al, 1981; Fraser et al, 1988; Haramburu, 1981; London, 1967; Rao et al, 1990) with a combined correlation of 0.33. The results in the more severe groups (Gilchrist and Wilkinson, 1979; McMordie et al, 1990;

Najenson et al, 1980; Violon and De Mol, 1974) were heterogeneous .

The results of nine studies of post-traumatic amnesia (PTA) were very heterogeneous. A visual inspection of the results revealed that the prognostic value of PTA was very low except in the case of minimal severity. A statistically significant effect was obtained when the sample included a large proportion of subjects with a short PTA (less than 1 day). Three studies that included subjects with a wide range of PTA showed a combined significant correlation of 0.48 between work status and duration of the amnesia (Ainsley and Gliner, 1989; Richardson, 1971; Van Zomeren and Van den Burg, 1985). However, studies limited to subjects with a PTA greater than 1 day or 1 week showed a weak correlation (r = 0.18) (Brooks et all, 1987a; Johnson, 1987; Oddy and Humphrey, 1980; Rao et al, 1990).

Among the list of specific sequelae that had been studied, epilepsy appeared predictive of work status for subjects with penetrating projectile head injury (Dresser et al, 1973). In the evaluation of physical sequelae (Fraser et al, 1988; Gilchrist and Wilkinson, 1979; Rao et al., 1990) deficits in motor skills, were only moderately related to work status. Similarly, visual and aphasic sequelae had a weak prognostic value, although visual deficits were more significant than language deficits (Dresser et al, 1973; Gilchrist and Wilkinson, 1979; Grosswasser et al, 1990; Johnson 1987).

Two studies (McMordie et al, 1990; Rao et al, 1990) demonstrated that longer hospitalisation is moderately associated with a failure to return to work. Such a variable probably reflects the severity of injury.

Other sequelae, such as cognitive dysfunctions and personality changes, were noted in the early recovery phase. The presence of any one dysfunction, or change in the early recovery phase, such as memory problems, lack of concentration, confusion, irritability, or apathy, was associated negatively with work status (London, 1967). At the cognitive level, performance on neuropsychological tests one month post-trauma was associated significantly with work status one year later (Fraser et al, 1988). However, another study (Haramburu, 1981) did not show any relationship between performance on memory tests and future work status.

Two studies (Prigatano et al, 1984; Walker et al, 1987) suggested certain personality variables were related to work status. However, Crepeau and Scherzer (1993) considered that the results of the two studies were obtained from small samples using a large number of measures which increased the probability of finding significant relationships purely by chance; the results

remaining to be confirmed. However, Rao et al, (1990) show that in evaluations by rehabilitation therapists (Patient Evaluation Conference Scale) neuropsychological functions were related to work status 2 to 6 months later.

In summary, Crepeau and Scherzer's findings are mixed. Whilst, age, gender, pre-injury employment status and neuro-anatomic findings, level of consciousness, length of hospitalisation, neurological severity of injury, cognitive status, behaviour, loss of autonomy, post-injury vocational rehabilitation and family support variables were found to be related to work status after TBI the position was not confirmed by all studies.

Crepeau and Scherzer also evaluated external indicators such as duration of rehabilitation, litigation involvement and family relations. Three studies indicated that receiving vocational rehabilitation was highly correlated to work status, although this can involve a self-selection factor. Involvement in litigation produced contradictory results. There appeared to be little relationship between being awarded a financial compensation and work status.

Crepeau and Scherzer believed that damage reflected purely by existing measures such as coma duration, PTA and other early post-trauma symptoms could be difficult to report consistently. The meta-analysis suggests that the most promising predictor variables appear to be post-coma activity level, post-trauma sequelae (such as neurological functioning) and duration of hospitalisation.

The subject's post-acute self-care activity level, level of dependency and capacity to drive a car seemed to have better correlations with employment outcome than the marginal correlations given by the factors immediately related to the post-injury clinical status. However executive functioning and deficits in cognitive flexibility also appeared important in relation to RTW.

Around the same time, and subsequent to Crepeau and Scherzer's study, other research has refined their findings, particularly with regard to non-clinical variables, but their study remains the most exhaustive in this field.

A New Zealand study, Godfrey et al (1993), assessed the effects of a range of cognitive and psychosocial variables on employment outcomes for 66 patients. Multi-variate regression analysis indicated that cognitive variables, specifically the number of neuropsychological impairments on a neuropsychological impairment scale, are the strongest predictors of RTW but this information was not related to demographic data.
Dikmen et al (1994) compared 366 hospital patients with traumatic head injuries with 95 comparators who sustained traumatic injury to the body, but not the head. Work return was related to the pre-trauma characteristics of the TBI patients, for example age, education, preinjury work history; the severity of the head injury (using GCS), associated neuropsychology status at one month post-injury (Halstead-Reitan) and the severity of other system injury. Through establishing individual composite scores, survival analysis methodology provided a means of assessing the patients likely to experience protracted post-injury unemployment and those with a higher probability of RTW with limited support. Whilst this study may be seen to lay the ground work for differentiated planning and the effective utilisation of resources, there are limitations. Outcomes related solely to the first return to work and there was no examination of job retention. The study does not seem to have taken into consideration those who did and did not receive clinical rehabilitation and/or vocational services. The provision of treatment was neither random nor controlled.

Ponsford et al (1995) considered that no study had attempted a cross-validation of findings, essential for verifying the predicted value of a given set of variables. Their study used a multivariate approach to investigate which of a range of variables relating to demographic factors, injury severity and degree of disability on admission to rehabilitation are the best predictors of employment status 2 years after TBI. Subjects were 74 TBI patients working prior to injury and undergoing rehabilitation at Bethesda Hospital, Melbourne, and attending a review clinic two years after injury. A cross-validation sample consists of a further 50 such subjects. Following preliminary analysis four input variables were selected: age under or over 40 at time of injury, Glasgow Coma Scale score on acute hospital admission, duration of PTA and total score on the Disability Rating Scale (DRS) (Rappaport et al, 1982) on admission to rehabilitation. The scale is indicated below:

Category	ltem	Score range
Arousability, awareness and responsivity	Eye opening Verbalization Motor response	0-3 0-4 0-5
Cognitive ability for self-care activities	Feeding Toileting Grooming	0-3 0-3 0-3
Dependence on others	Functional level	0-5
Psychosocial adaptability	Employability	0-3
	Level of disability None Mild Partial Moderate Moderately severe Severe Extremely severe Vegetative state Extreme vegetative state Death	Score 0 1 2-3 4-6 7-11 12-16 17-21 22-24 25-29 30

#### Table 3.7: Disability Rating Scale

Rappaport et al (1982)

Ponsford and colleagues concluded that the employment status at 2 years after TBI may be predicted by a combination of variables relating to demographic factors, injury severity and degree of disability on admission to rehabilitation; namely age, under or over 40 at the time of injury, GCS score on acute hospital admission and total score on the DRS at the time of entering rehabilitation. The reliability of this prediction equation, correctly classifying around 70% of cases, was confirmed by cross-validation. The score on the DRS was by far the greatest contributor to the discriminant function, with a correlation of 0.86. Around 1 in 5 of those who were previously employed full-time were only working part-time two years after injury.

Tate and Broe (1999) noted that whilst studies identifying the significant variables affecting psycho-social adjustment after TBI included reference to work, they did not measure their respective contributions. Apart from Bowman (1996), they considered few studies included a comprehensive range of measures including demographic and clinical variables. Bowman found in predicting RTW, demographic and neuropsychological variables accounted for greater amounts of variance (27% and 21% respectively) than did bio-medical or emotional variables

#### (2% and 7% respectively).

A more recent example of the multivariate approach is provided by Fleming et al (1999). The research aimed to (1) investigate the predictive validity of a selection of functional assessments used in occupational therapy with adults with TBI; (2) identify neurological and demographic indicators of community integration and vocational outcome following TBI; (3) examine the long-term outcomes (2-5 years post-injury) in respect of vocational outcome and level of community integration.

Of the 208 participants on whom return to work data was available, 38 (18.3%) were unemployed prior to the accident. Of these, only one indicated that they were working on follow-up. Of 170 who had worked pre-morbidly, 79 (46.5%) were working on follow-up and while 23 (13.5%) had originally returned to work after rehabilitation, they were no longer working on follow-up. Of those working at follow-up, 59 (74.7%) were working in the same or a similar job to that held pre-morbidly, 68 of the 170 had not attempted a return to work.

What has been learned from a review of RTW studies is considered in the Summary and Main Points, following a review of studies reporting the effectiveness of vocational rehabilitation programmes.

#### 3.4 Studies Reporting the Effectiveness of Vocational Rehabilitation Programmes:

Chapter 3.4 reports studies examining the efficacy of:

- clinical rehabilitation;
- clinical rehabilitation with occupational trials;
- clinical rehabilitation plus a combination of supported arrangements, eg. easier work, work trials, part-time work;
- a work re-entry programme including a vocational assessment and structured placement activity;
- a case study approach identifying and addressing individual barriers to employment including the development of compensatory strategies.

Prior to the 1980s, specific brain injury vocational rehabilitation programmes were uncommon, even in the United States. In the United Kingdom there was no development until the 1990s. As a consequence of low RTW figures, rehabilitation professionals in the United States attempted to improve the situation by developing community-based programmes addressing the most common problems, including the generalisation of learning, neurobehavioural deficits and inappropriate interpersonal relationships. However, studies have not always reported whether or not a subject experienced any rehabilitation programme, either clinical or vocational.

During the 1980s into the 1990s, in the USA, three models of brain injury vocational rehabilitation began to emerge (Haffey and Lewis, 1989):

- i) Comprehensive neuropsychological rehabilitation;
- ii) Comprehensive neuropsychological rehabilitation with occupational trials;
- iii) Supported work.

There are few early reports on the efficacy of rehabilitation, notable exceptions being Prigatano et al (1984) and Ben-Yishay et al (1985). Prigatano et al (1984) described the Neuropsychological Rehabilitation Program (NRP) at the Presbyterian Hospital in Oklahoma and the initial outcome data on 18 closed head injury patients and 17 untreated controls. They reported that whilst the value of cognitive retraining and resocialisation skills was being increasingly recognised studies did not use control groups nor did they report the characteristics of patients most likely to benefit from such treatment. In addition, whilst rehabilitation programmes emphasised cognitive retraining, many severely head injured patients had emotional and motivational problems not systematically addressed.

The subjects for their study were provided with both small group and an individual treatment format, the treatment staff consisting of neuropsychologists, a speech and language pathologist, an occupational therapist and a physical therapist. Various neuropsychological measures were used to test performance, including the WAIS-R (Weschler Adult Intelligence Scale Revised, 1981) and the Halstead Reitan Neurological Test Battery.

The NRP patients and controls were compared on whether or not they were gainfully employed (part-time or full-time) or actively engaged in a school programme at the time of follow-up. Nine of the 18 NRP patients (50%) were classified as productive on this basis, 9 were not. Five of the controls (36%) were productive at follow-up, 8 were not. Three were lost to follow-up. The neuropsychological and personality characteristics of the 9 NRP patients who were working at the time of follow-up were contrasted to those NRP patients who had failed to do so. There were no significant differences in educational level, age or chronicity for the patients employed during the follow-up in contrast to those who were not.

Similarly, whilst there was a trend on some measures for the unemployed group to have more impaired neuropsychological functioning, there were no statistical significant differences between the two groups on any of the neuropsychological measures. The authors considered that the "outcome on sustained employment are sobering". They had anticipated that between

60% and 65% of the patients would work following their neuropsychological rehabilitation programme. Given the passage of time, the figure dropped to 50%, whilst 36% of the controls returned to employment without such rehabilitation - the latter figure being compatible with other reports of between 33% and 40% employment for what they described as traditional rehabilitative care. There was, therefore, a question in respect of why there was only a 14% difference and whether or not this figure could be improved.

Prigatano et al (1984) concluded that the methods used in their programme were primarily designed to enhance neuropsychological functioning, particularly speed of information processing and personality adjustment. To a degree these goals were accomplished. It was hoped that this would automatically lead to greater worker productivity. On reflection this was a naive assumption. Improving neuropsychological status and personality skills are necessary but not sufficient conditions, for accomplishing a successful and sustained return to work. It was apparent that specific training in this area was needed.

Ben-Yishay et al (1987) described the New York University (NYU) Head Trauma Program. It was designed to provide remedial intervention to severely head injured young adults who had failed to benefit from conventional rehabilitation approaches and remained unemployable. The report examined two questions:

What percentage of the patients who attended the programme subsequently proved capable of obtaining competitive employment?

How stable is the long term vocational adjustment of these patients?

Clinical and demographic detail are indicated in Table 3.8.

The setting for treatment was an out-patient day programme operated as a "therapeutic community". All participants received a comprehensive neuropsychological, functionalbehavioural and interpersonal assessment. The first phase of the study related to holistic remedial intervention. The second phase was in respect of individualised, guided occupational trials, culminating in a vocational placement with appropriate liaison, maintenance and, the third phase, follow-up.

 Table 3.8 : Sample Characteristics

Variable	Mean	SD	Range
Age at injury (yr)	27.11	9.69	15-60
Education (yr)	14.15	2.56	8-20
Time in coma (days)	34.40	33.64	1-120
Time from injury to entry into progra	36.46	31.33	4-207
Behavioural Competence Index	6.60	1.45	2.38-8.69
		Frequency	%
Etiology: Acceleration-deceleration	concussion	91	97
Anoxic encephalopathy		2	2
Post-infectious sequelae		1	1
Sex: Males		71	78
Females		23	22

Ben-Yishay et al (1987)

The first part of the exercise involved individual or group remedial activity for periods of 5 hours each day, four days a week, over a period of 20 consecutive weeks. The treatment "packages" are detailed in a number of studies by Ben-Yishay and colleagues. These procedures were designed to ameliorate cognitive deficits and improve basic attention (Ben-Yishay et al, 1979, 1980, 1986), finger dexterity (Ben-Yishay et al, 1978), constructional praxis (Ben-Yishay et al, 1978), visual-spatial information processing (Rattok et al, 1981). In addition to the cognitive remedial treatments small-group procedure was designed to improve interpersonal communication, social competence and an awareness and acceptance of the consequences of the head injury (Ben-Yishay et al, 1979 and Ben-Yishay et al, 1980). In addition, as part of the programme, there was wider family and social involvement in an educational/therapeutic programme (Ross et al, 1982 and Ross et al, 1983).

The second phase was the guided occupational trials (Silver et al, 1982; Silver et al, 1983; Ben-Yishay, et al, 1985). The occupational trials were usually conducted within the NYU Medical Center in offices, shops and libraries under the guidance of the Head Vocational Counsellor. Each patient's work ability was judged against expected work norms and compared with the performance of paid personnel doing the same job. The duration of the trials varied from a minimum of three months to a maximum of nine months. There was some movement between placements until optimal work capability was established. The patient was judged to be reliably competent if he or she proved capable of performing the assigned job comparable with the paid employee for a minimum of six weeks. Once a patient's work potential was determined an "employability rating" was assigned according to the 10 point rating scheme outlined in Table 3.9 (part-time gainful employment was assigned half a unit for each respective rating, for example a part-time semi-skilled job was rated 5.5):

Level of productivity	Rating	Definition	
Unproductive	1	Remains unemployable/unable to study in any	
Productive but	2	Sheltered workshop: Restricted	
	3	Sheltered workshop: Unrestricted	
	4	Open work market: Doing circumscribed aspect(s)	
Full or part-time	5	Unskilled work	
	6	(1) Semi-skilled work or (2) lower level clerical	
	7	(1) Skilled work or (2) higher level clerical work,	
	8	(1) Resumed formal academic studies or (2) skilled	
	9	Job requires (pre-injury attained) academic	
	10	Returned to academic level position; no qualifications	

# Table 3.9: Employability Rating Scale

Ben-Yishay et al (1987)

After discharge the patients were followed up and rated on an employability scale at successive six-month intervals. The results are in Table 3.10. The differing sample sizes for each successive rating interval reflect differences in time of completion of programme and are not due to subject attrition. Employability ratings at follow-up periods reflect actual employment rather than the capacity to be employed.

Rating	Level of Productivity	N=9 4	6 mnths	12 mnths	18 mnths	24 mnths	30 mnths	36 mnths
1	Unemployable in any capacity	16	20	22	30	24	23	30
2-4	Productive but non- competitive	21	23	21	20	20	19	22
4.5-6	Competitive, gainful employed low level clerical, unskilled to semi-skilled	23	24	26	19	24	24	25
6.5-8	Skilled, higher level clerical	37	29	28	30	28	29	19
8.5-10	Academic range	3	3	3	2	4	4	6

Table 3.10: Distribution of employability ratings (%) at the conclusion of occupational trials and at successive 6 months intervals up to 3 years

Ben-Yishay et al (1987)

On completion of the occupational trials, 84% of the previously unemployable/unproductive patients were found to have attained the ability to engage in productive work, 63% at a competitive level and 21% in a subsidised capacity only; 16% were rated as unemployable/unproductive in any capacity. A break-down of the 63% who achieved a competitive level of employment indicated that 3% were considered employable within the academic range, 37% within the skilled or higher-level clerical range and 23% within the unskilled or lower level clerical range and 23% within the unskilled or lower level clerical range and 23% within the general efficacy of the programme. In particular, the results demonstrated that the use of occupational trials is a valid and reliable method of assessing and predicting employability. Finally, the relative stability of work status over the three years period of follow up indicated that with this approach it is possible to attain some 50-60% long-term vocational outcomes.

It was concluded that the principal reasons accounting for these outcomes included:

- i) improvements in self-awareness, discipline and regulation of emotional responses;
- ii) increases in the effectiveness of functional application of the residual information processing abilities (rather than an increment in the capacity levels per se); and
- iii) significant improvements in the acceptance by patients of their situation.

Community-based support was considered to be "of paramount importance if one is to ensure the long term personal vocational adjustment of the traumatically head injured".

Johnson (1987) followed up 37 men and 10 women with a mean age of 30.9 years, sustaining a post-traumatic amnesia (PTA) of more than one week and seen on the Rehabilitation Unit Addenbrooke's Hospital, between January 1980 and June 1983. The subjects were divided into three groups:

**Group I** Those who returned to work successfully. The criterion was that they had remained in continuous employment for at least one year following their injury.

**Group II** Those who returned to work following injury, but failed to stay employed. These people did not remain in any job for as long as a year; they either had a series of short jobs or made one attempt to return to work and then remained unemployed.

Group III Those who made no attempt to work. None of these people worked at any time

following their injury.

Return to work followed one of two patterns:

- 1. A return to normal conditions of work; either full-time or part-time.
- 2. Return under special conditions, the nature of these conditions varied but included, in all cases, three or more of the following:
  - i) part-time work as a temporary arrangement with the aim of eventually returning to full-time work;
  - ii) easier work;
  - iii) a work trial;
  - iv) an informal return, e.g. working on an unpaid and flexible basis before resuming full-time duties;
  - v) liaison with the Rehabilitation Unit to provide support;
  - vi) training to provide assistance with specific problems at work, e.g. organisational skills and memory problems;
  - vii) workplace support, e.g. a colleague being detailed to help an individual; tolerance being exercised by the employer and/or colleagues until improvement was shown.

A successful return to work was accomplished by 38% of the sample; 34% did not go back to work at all and 28% failed in their attempts to do so. The results are reported by gender, age, severity of injury, occupation and time in employment, nature of disability, whether or not a compensation claim was pending, changes in occupation, special conditions of work, time delay before returning to work and difficulties at work.

Johnson's patients reported a PTA of between 10 days and 24 weeks (mean 5.8 weeks) and their ages ranged from 16 to 61 years (mean 31 years). Within these limits there was no significant relationship between severity of injury or age and work outcome, in contrast to previous studies suggesting a relationship between the length of PTA and age (Humphrey et al, 1980; Lewin et al, 1979; Roberts, 1976; Oddy, 1984).

It was found that those who returned to work were more likely to go back to the job they were doing before the injury and more likely to have the opportunity for a work trial, or for initial changes in conditions of work, that made the job easier. Such factors appeared to be of greater importance in determining work outcome than age or PTA. Within the follow-up time, there was little change in the employment status of those surveyed.

Johnson further considered that people with behavioural and intellectual changes, typical of frontal lobe damage, may *"have been a little less likely to achieve work"*, but there are also a number of people with such changes who coped with work again. There was *"no simple relationship between the nature of handicap and return to work. It cannot be concluded that certain deficits will specifically preclude work."* 

It was considered '*striking*' that the average duration of work trials or easier conditions was longer than the average time the return to work lasted for those who lost their jobs, suggesting that special conditions at work should continue for months rather than weeks if they are to be useful.

Johnson concluded that occupational class, gender and the nature of the disability are less likely to influence outcome than that of working conditions. Moreover, the first two cannot be altered and little can be done about the third by the time a return to work is made. However, modifying the conditions at work may be possible.

Haffey and Abrams (1991) described RTW outcomes for 130 persons with TBI participating in a vocational rehabilitation programme (Work Re-entry Programme). There was a 68% placement rate into paid employment, a 71% employment retention rate and 75% employment stability rate. Two comparator groups were used, TBI patients attending a day-treatment programme and a group who received only in-patient rehabilitation. They attained employment placement rates of less than 40%. The subject characteristics are indicated in Table 3.11:

	Total population	Comparison group (in-patient rehab)	Day treatment only	Work re-entry
Av age (yrs) Gender (%male)	32 71	33 65	31 81	32 72
Ethnicity White Black Hispanic Other	80 4 9 7	72 4 10 14	82 7 9 2	86 3 8 3
Educ level (%) <12years 12 years 13-15 years 16+ years	18 33 30 19	24 35 22 19	23 31 37 9	18 31 32 19
Av educ (years)	13	13	13	13

#### **Table 3.11: Study Sample Characteristics**

Haffey and Abrams (1991)

The Work Re-entry Programme (WRP) focussed on barriers to employment experienced by clients and featured:

intake to determine the feasibility of a return to the previous job and to gather initial data;

vocational assessment;

work hardening using real and simulated work activities;

*job development* through which vocational counsellors established relationships with potential employers to identify placement opportunities;

job analysis to ensure a "good fit" between the client's needs and the demands of the job;

*Transitional Employment Programme (TEP).* This involved placing the subject in a designated position within the hospital's own services, with a job coach, for a three or four months period in order to improve stamina, productivity and work behaviour. TEP clients received a competitive wage in contrast to the work hardening programme, which did not involve any employment position or wage.

### job placement;

short-term support and long-term follow-up in which vocational counsellors provided a limited

on-the-job support in the first 60 days.

Haffey and Abrams (1991) considered that preliminary return-to-work rates (68%) and employment retention rates (71%) suggested that the WRP resulted in favourable comparisons with the supported employment approach described by Wehman and associates (1990a). (The extent to which this is a valid criticism is open to question. It is considered that there is insufficient data in respect of user characteristics to draw definite conclusions). Haffey and Abrams considered that the two approaches focussed specifically on assisting the person with TBI identify and locate secure paid employment and that this did not typically occur in rehabilitation programmes. (At the time TBI VR was something emerging from clinical rehabilitation). However, they also considered that the two approaches differed in fundamental ways. The supported employment model (Wehman) emphasised on-the-job training, substantial job-coaching support, and continuing case-management. In contrast, the WRP emphasised assessment, job development and job analysis to match client capabilities to job requirements. On-the-job support was concentrated in the first month. In reality the approaches could just reflect the varying needs of the clients. For example people with learning difficulties could probably benefit more from the first approach and experienced workers experiencing an illness or injury more likely to benefit from the latter strategy.

Johnson (1998) provided a ten years follow-up study on 64 patients. All had sustained a very severe head injury (PTA >7 days). Of the total, 42% re-established themselves in employment. A further 20% showed an irregular pattern of work. There were few changes in work status once 18 months to 2 years post-injury had elapsed. The settlement of compensation claims did not lead to an improvement in work status and in several cases, the converse was true.

Subjects were assisted by a combination of temporary part-time arrangements, easier work, work trials, liaison between rehabilitation services and employer, retraining strategies and support from a colleague. Those who successfully returned to work depended upon support for about 8 months on average. The approach was flexible, according to the circumstances of each individual. The importance of such an approach has been noted by others (Parente, Stapleton and Wheatley, 1994)

An example of a case study approach is provided by Target and colleagues (1998). Emphasis on the different types of accommodations, including the design of implementation of compensatory strategies, is illustrated for one of the (three) studies.

#### Case Study (Target et al, 1998) - Rodney

Rodney is reported to have been a 47 year old man with a severe TBI. He had a history of alcohol abuse. Following graduation from High School he served in the military for three years, subsequently working in a factory and then re-enlisting for a further seven years. Afterwards, Rodney reported working as a truck driver, packer and sign painter. As a result of the injury, Rodney sustained partial vision loss in addition to cognitive problems. A neuropsychological evaluation revealed significant impairments in attention/sustained concentration, mental flexibility, speed of information processing, arithmetical computation/reasoning, reading speed and comprehension, general fund of information, verbal and non-verbal learning/memory, motor speed/dexterity, and common sense/judgment of safety. He also demonstrated impaired frustration tolerance.

*Employment Intervention :* Rodney was referred to a supported employment programme. At the time he was residing in a group home and was anxious to find an independent living situation. He was also reported to have been attending Alcoholics Anonymous.

A few months after referral he received a job offer as a mail sorter in the accounts receivable department of a furniture company. The job was accepted because the environment appeared pleasant and the location suitable. Rodney felt that he could learn to do the job if provided with one to one on-the-job skill training. In the morning cheques were written and recorded, then mail was sorted, date-stamped and distributed throughout the division. Next, Rodney performed credit processing. This required entering data into a computer, recording information onto credit slips, and keeping a summary of entries. At the end of the day, filing was done. After one month Rodney had reached skill acquisition on all tasks.

*Problems presented and nature of intervention*: Some difficulties that arose during training and the strategies use to accommodate these issues are illustrated in the discussion following the tables.

An employment specialist also provided a case management service that included helping Rodney move from the group home into a home he could afford.

*Outcome measure*: As of October 1997, Rodney is reported to have been employed for eight years.

<u>Circumstances</u>	Intervention	Outcome
Demographic	Rehabilitation	Employment
Unemployed (with TBI)	Referral to supported	
Unskilled/semi-skilled manual employment history		Placement as a mail sorter
Unhappy living in group home	Assistance with domestic problem (housing)	
Clinical		
Very severe TBI		
History of alcohol abuse	Arranged attendance at AA	
Partial vision loss Frustration	In situ job coaching	
Impaired attention/concentration	Use of compensatory strategies	
Reduced speed of information processing	Use of compensatory strategies	
Reduced motor speed/dexterity	Use of compensatory strategies	
Lack of mental flexibility	Use of compensatory strategies	
Learning deficits	Use of compensatory strategies	
Reduced computational/reasoning ability	Use of compensatory strategies	8 years continuity of employment

Table 3.12: Rodney, Case Study from Literature

Looking at the way factors affecting Rodney's resettlement were handled (Table 3.13), it is considered strategies to address the clinical deficits, developed by reference to presenting issues, were crucial.

Neuropsychological Deficits	Presenting Issues	Strategies
Impaired attention/concentration	Inability to keep track of information	A ruler was purchased and used
Partial vision loss	Difficulty seeing paper work	Desk light
Reduced motor speed/dexterity Reduced speed of information processing	Writing cheques slowly	Self-monitoring of production
Reduced computational learning ability	Confusion or forgetting where to write information	Data recording sheet to record recurring problem areas

Table 3.13: Rodney - From Clinical Deficits to Adaptive Mechanisms

In the above fashion, or a comparable way, studies have increasingly addressed individual barriers to employment.

So far the cited rehabilitation reports from the UK have addressed programmes in which the emphasis has been on pre-placement intervention and support, a characteristic of VR programmes in the UK. It will be noted how the US studies reflect more in situ support. This is a matter further developed in Chapter 4.5.

# 3.5 Variables Associated and Not Associated with a Return to Work

It will be noted from the literature review that it is difficult to identify consistent TBI variables affecting outcomes. When considering studies, and their findings, there is an apparent need to be able to organise the variables into a workable framework identifying factors affecting an individual if personal barriers to employment are to be appropriately addressed within a VR programme.

The organisation of the variables in this study adopts an approach developed by Scallon (2000). This exercise is by way of identifying variables identified in the studies and not necessarily how the findings were reached. In the latter respect two points are emphasised:

 As indicated a wide range of tests are used by clinicians. Whilst Table 3.14 collates the findings of various studies the extent to which differences in findings are a consequence of differing measurement instruments would require a review of tests used in every reported study although, on its own, this would not help valid comparisons without a similar exercise being conducted in respect of the study samples. This is not feasible because of length and the availability of data. On the whole studies rely upon standard recognised measures, e.g. PTA, GCS, WAIS-R (Wechsler 1981), Halstead-Reitan (Halstead 1947) but the need for a more standardised approach to such assessments is discussed in Part 3.

• The subjects under discussion may vary. In the preceding chapter an example was given (Schwab et al 1993) of the researchers relying on Vietnam veterans who may have sustained more penetrating injuries than the general civilian TBI population.

Variable	Negative Relationship	No Relationship	Positive	
1. Demographic	Age Marital Status Family Reaction Ethnicity. Educational Status Occupation	Age Marital Status Ethnicity Educational Status Occupation Gender	Younger Age Marital Status Supportive Family Educational Status Occupation Gender	
2. Neurological and other injury factors	Coma Length Severity of Injury Length of Hospitalisation Loss of Consciousness Neurological Deficits Speech Impairments Functional Status Injury to other Body Systems	Coma Length Severity of Injury Neurological Deficits Anosmia Aphasia/Dysphasia Visual Impairments Functional Status Injury to other Body Systems	Coma Length Severity of Injury Functional Status	
3. Cognitive and other neuropsychological deficits	Attention Deficits Executive Functions Dysphasia Speed of Info. Process. Memory Intelligence Self Awareness Other Neurological Deficits	Attention IQ Speed Info.Process. Memory Other Neuropsychol Deficits	IQ Speed of Information Processing	
4. Psychosocial factors	Pre-Injury Personality Social/Family Circs Substance Abuse Adaptive Deficits Communication Deficits Sleep Complaints Litigation Status	Pre-Injury Personality Social/Family Circs. Pain Litigation Status	Pre-Injury Personality Social/Family Circs. Work History Self Awareness	
5. Work place factors	Employer Characteristics RTW Time Lapse	RTW Time Lapse	Employer Characteristics Supported Employ. RTW Time Lapse	

Table 3.14: Organisation of Variables and Relationships to Employment Outcomes

\*

Table 3.14 is further developed in the following discussion:

#### 3.5.1 Demographic Variables:

#### i) Negative Relationship with RTW:

*Age*: Severe TBI at a young age significantly impacts upon later employment prospects (Asikainen et al, 1996; Nybo and Koskiniemi 1999). Older age (typically over 40 years at the time of injury), has been found to negatively correlate with the likelihood of returning to work in a number of studies (Levin et al, 1979; Alexander et al, 1983; Gogstad and Kajellman, 1976; Johnson, 1987; McMordie et al, 1990; Ruff et al, 1993; Schalan et al, 1994; Ponsford et al, 1995; Vilkki et al, 1995). Unfortunately none of the studies provide comparative 'normal' age-related employment statistics. Crepéau and Scherzer's (1993) meta analysis showed that age was only significant insofar as those subjects aged 60 years or more may be less likely to return to work and one might have thought that anyone in this age group sustaining injury or losing their job would be less likely to return to work.

Heiskanen and Sipponen (1970) followed-up 102 head injured subjects, all of whom had been unconscious for at least 24 hours, 3-5 years after injury. Overall, 53% were able to return to work or school. However, 70% of those under the age of 20 returned to work or school, as compared to only 30% of those over 50. The authors also demonstrated a further interaction between age and severity of injury. In their sample, no subject between 41 and 60 returned to work if unconscious more than one week. No subject over 60 returned to work if unconscious for more than one day.

Brooks et al (1987a) found the chances of returning to work after very severe head injury fell to 12% in those aged over 45 compared with 39% in those aged under 45. This was considered to reflect a combination of reduced adaptability and a reluctance on the part of employers to take back persons with a limited working life ahead of them.

#### Marital Status:

Ip et al (1995) found subjects with partners had lower RTW rates in contrast to single people.

#### Family Reaction:

Romano (1974) found prolonged family denial of disability could undermine the vocational rehabilitation process.

## Ethnicity:

At a 15 years follow-up of Vietnam veterans with TBI, blacks were found to be less likely to return to work than whites (Kraft et al, 1993). However, this study does not contrast such a finding with the usual employment rates in the community.

## Educational Status and Intellectual Ability:

A study of 864 veterans of the Korean War found that pre-injury intellectual ability was a key factor in return to work 15 years after head injury (Dresser, et al. 1973). However, the nature of many of the injuries, from penetrating shrapnel, is likely to have resulted in more localised injury than the widespread diffuse damage typically found following road traffic accidents.

Pre-Injury educational status lower than High School level has been associated with poorer prognosis for RTW rates one-year post-TBI (Greenspan et al, 1996). In a two years post-TBI follow-up, a 46% RTW rate was found amongst subjects with less than High School education in contrast to a76% RTW rate amongst those with High School education.

In contrast, Asikainen et al (1996) found that severe TBI subjects with the highest pre-injury educational status had the highest rates of inability to return to work, with 58% being unable to work post-injury. A confounding variable may be age, in so much as better educated subjects were also older at the time of injury. It would also appear that the better educated subjects are likely to have been employed in more demanding occupations demanding a higher level of post-injury intellectual capability.

### Pre-Injury Occupation:

Blair and Spellacy (1989) reviewed the perceived suitability of various entry-level occupations for those sustaining TBI using an employer questionnaire (reported on the assumption that anyone out of work is likely to look towards their previous sector of employment). The subjects were 122 employers (with a 39.3% response) in manufacturing/ construction, agricultural/forestry, wholesale and retail trade and the service sector. Employers were asked to describe the acceptability of specified behavioural sequelae of TBI for the occupations within their industry. Employers in the manufacturing and construction, and agricultural and forestry industries, found the behavioural symptoms of those sustaining TBI more acceptable than employers in the retail and service sectors. All the fields of employment found distractibility to be the least acceptable symptom.

During a ten-years follow-up period, Rappaport et al (1989) found that none of the severe TBI patients who previously held professional positions were able to return to them. Stambrook et

al (1990) found that severe and moderately injured TBI subjects were unable to return to positions that had equivalent vocational status in comparison to their pre-injury status.

Greenspan et al (1996) found that pre-injury occupational status to be a significant predictor (the lower the status the worse the prospects).

### ii) No Relationship with RTW:

### Age:

At one year post-TBI Cifu et al (1997) found that employed and unemployed subjects did not differ in terms of age. However, the age range of the sample was restricted. Others have also found age to be unrelated to RTW rates (Johnson, 1987; Girard et al, 1996; Lubusko et al, 1994; Ruffolo et al, 1999; Weddell et al, 1980).

### Marital Status:

Cifu et al (1997); Girard et al (1996); Ruffolo et al (1999) reported that marital status was not related to RTW rates amongst TBI subjects

### Ethnicity:

The ethnicity of TBI subjects was found to be unrelated to post-injury status by Cifu et al (1997) and Girard et al (1996). There are no UK studies on this subject. Experience of working with Muslims suggests that cultural factors may be an issue. This includes the subjects withdrawing from the community into extended family networks.

### Pre-Injury Educational Status:

Cifu et al (1997) found that employed and unemployed TBI subjects at one year TBI did not differ in terms of their education. Others have also found no relationship between education and RTW amongst both mild TBI subjects (Ruffolo et al, 1999) and severe TBI subjects (Fabiano and Crewe, 1995). Lubusko (1994) and Ponsford et al (1995) also found that the number of years in education was not related to post-injury employment history as did Crepeau and Scherzer (1993).

### **Pre-Injury Occupation:**

Johnson (1987) found that the type of employment at the time of injury did not differentiate between TBI subjects who did and did not return to work, a matter supported by Fabiano and Crewe (1995); Girard et al (1996) and Lubusko et al (1994).

# Gender:

The gender of the subjects has not been found to impact on employment status one year postinjury (Cifu et al, 1997; Gollaher et al, 1998), two years post-injury (Ponsford et al, 1995) or three years post-injury (Girard et al, 1996). Crepeau and Scherzer (1993) also found no relationship between gender and a return to work.

# iii) Positive Relationship with RTW:

## Younger Age:

Ashley et al (1997) found that subjects aged 17-25 at the time of injury had the best employment outcomes. Heiskanen and Sipponen (1970) reported the highest RTW rate amongst those under 20.

## Marital Status:

Greenspan and colleagues (1996) found 58% of unmarried subjects returned to work in comparison to 69% of married subjects.

### Supportive Family:

One-year post-injury Kaplan (1988) found a positive relationship between continuing family support and successful vocational outcomes

### Pre-Injury Educational Status:

Asikainen et al (1996) postulated that skills learned in professional training were retained better than other skills and more easily applied post-injury. This was used to explain why the highest RTW rates were found amongst their severe TBI subjects who had attended vocational school, technical college or university. The extent to which this only reflects pre-injury intellectual ability is not clear. Gollaher et al (1998) and Kraft et al (1993) also found a higher pre-injury educational level associated with higher chances of RTW.

# Pre-Injury Occupation:

Fraser and associates (1988) found that those employed in structural occupations, for example building trades, were more likely to return to work in their former occupations than professional, managerial, clerical or service workers. Blair and Spellacy's (1989) postulation that the nature of such occupations may enable the injured party to work at his or her own pace, without a great deal of contact with others, and that problems with work speed, cognition and behaviour are more readily tolerated, is difficult to recognise in the UK labour market where there is so much emphasis on contract work. Najenson et al (1980) and Vogenthaler et al (1989) also

found that those with more education and technical skills more likely to return to employment. In the UK, Brooks et al (1987) found that the chances of returning to work rose from 21% in unskilled jobs to 33% amongst skilled manual jobs and to 50% in managerial positions, which they suggested may offer greater flexibility in both the time and opportunity for the effective use of compensatory strategies.

Ruffolo et al (1999) found that mild TBI subjects were more likely to return to work if their preinjury position was in a more independent/greater decision-making category, for example student, professional, semi-professional or management than in a less independent category, for example clerical, sales-service or manual labour.

Wehman et al (1995) suggested that an explanation for the discrepancy in findings may be due to some people in professional or technical occupations being able to return to work in jobs requiring less skill or expertise, whilst those in blue-collar jobs are more likely to have to return to work in jobs comparable to their pre-injury occupation.

#### Gender:

Groswasser et al (1998) found that 47.2% of females returned to their previous level of work/school capacity compared to 30.2% of males. Brooks et al (1987a) found some evidence that females were more likely to be able to return to work following a severe TBI, but due to a small number of cases in their sample, there was no statistical significance.

### 3.5.2 Neurological and Other Injury Factors:

### i) Negative Relationship with RTW:

### Coma Length:

Relying on the Glasgow Coma Scale, Vogenthaler et al (1989) found no decrease in the level of full-time employment amongst subjects with mild injury, a modest decrease (13%) after moderate but a marked decrease (42%) after severe head injury. Lundholm et al (1975) also found the length of coma a negative factor.

### Severity of Brain Injury:

The severity of injury (measured by GCS), length of hospitalisation and duration of PTA have been consistently negatively related to the likelihood of returning to work (Prigatano et al, 1994; Najenson et al, 1980; 1990; Ezrachi, et al, 1991; Oddy, 1984; Oddy, Humphrey and Ottley,1978; McModie et al, 1990; Rao et al, 1990; Ponsford et al, 1995; Wehman et al., 1995; Cattelani et al, 2002). Dacey et al (1991), Dikmen et al (1993) and Vogenthaler et al (1989) found that subjects with severe TBI were less likely to return to work than moderate TBI subjects, moderate TBI subjects were less likely to return to work in comparison to minor TBI subjects.

Longer PTA lengths amongst those with a failure to return to work have also been reported by Cifu et al (1997); Annoni et al (1992); Johnson (1987); Lubusko et al (1994); Oddy and Humphrey (1980); Van Zomeren and Van den Burg (1985); Van der Nallt et al (1999); Vilkki et al (1994).

### Length of Hospital Stay:

Cifu et al (1997) found that TBI subjects not returning to work one-year post-injury had longer hospital stays than their employed counterparts (30 days v 18 days), as was the length of stay in rehabilitation units (48 days v 26 days) supporting earlier findings made by McMordie et al (1990) and Rao et al (1990). Lubusko et al (1994) also reported similar findings. Such findings appear to reflect the general severity of injuries.

#### Loss of Consciousness:

Gilchrist and Wilkinson (1979) reported results of a study of 72 subjects followed up 1 to 15 years after their injury. At the time of follow-up, 39% of the sample had returned to some kind of work. However, when vocational outcome was broken down by severity of injury, as measured by the length of `unconsciousness', when a meaningful response to the environment occurred within one week, 82% of the subjects returned to work. At the other extreme, when response to the environment took more than 8 weeks, only 11% returned to work. Intermediate levels of severity had intermediate rates of return. Whilst the more severe the injury, the lower the likelihood of spontaneously returning to work, this relationship was one of probability: regardless of the level of severity, some head-injured people returned to work and others did not.

McMordie et al (1990) found less than 2% of TBI subjects with a loss of consciousness greater than one month were able to return to work (75% of their TBI subjects who returned to work had a loss of consciousness of two weeks or less).

#### Neurological Deficits:

Miller and Stern (1965) found a negative relationship between 'mental changes' and epilepsy and a return to work. Schwab et al (1993) found that work status fifteen years post-injury was negatively correlated with epilepsy, paresis and visual field loss with TBI subjects who had been injured in combat in Vietnam.

#### Speech Impairments:

Gilchrist and Wilkinson (1979) found that RTW rates for TBI patients with a speech disorder were lower than rates for subjects with normal speech.

#### Functional Status:

Functional status on rehabilitation omission was lower for subjects unemployed one-year postinjury in comparison with subjects who were employed (Cook et al, 1994). A lack of functional independence has been related to low RTW rates by Fraser et al, 1988; McMordie et al, 1990; Rao et al, 1990; Prigatano et al, 1985 and Ponsford et al, 1995.

#### Injury to other Body Systems:

Among subjects with mild or moderate TBI, those with other systems injuries, for example orthopaedic, were found to be less likely to return to work one-month post-injury, in comparison to those subjects with similar TBI but no associated other-systems injuries (Dikmen et al, 1986). As Dikmen et al (1994) pointed out, those with severe other (than brain) injuries also have the most severe brain injuries, hence reaching conclusive deductions about the influence of other-systems injuries is tenuous. Physical problems such as moving slowly, fatigue, and trouble lifting heavy objects are more commonly reported by TBI subjects who fail to return to work (Sander et al, 1997).

#### Anosmia:

Varney (1988) found that the presence of post-traumatic amnosia, an indicator of frontal lobe damage, related to total and partial anosmics being less likely to return to work two years post-injury. Whilst it is possible to understand this finding in respect of occupations requiring a sense of smell, the issue would appear to be the extent to which such a symptom is indicative of wider frontal lobe damage and this is not clear in the study.

#### ii) No Relationship with RTW:

#### Coma Length/Severity of Injury:

Ip et al (1995) found that RTW rates did not relate to injury severity, measured by GCS scores. Brooks et al (1987a) considered that specific types of cognitive, physical and psychosocial impairments associated with TBI are likely to be more reliable predictors of a return to work than the measure of injury severity, for example the presence of significant physical disability (McKinlay, Brooks and Bond, 1983).

## Neurological Deficits:

Ip et al (1995) found that the presence of neurological deficits, that is paralysis, ataxia, contractures, visual or auditory impairments and speech deficits, were not correlated with RTW outcomes.

### Anosmia:

Bruckner et al (1972) found that complete anosmia did not impact upon RTW rates amongst severe TBI subjects.

## Aphasia/Dysphasia:

Gil et al (1996) found that the presence of aphasia in severe TBI subjects was not related to RTW, supporting a previous finding by Gogstad and Kjellman (1976). (Again, one has the issue as to what extent other symptoms arising from the severe TBI are significant). Grosswasser et al (1990) found aphasia to have weak predictive value.

## Visual Impairment:

RTW rates for severe TBI subjects with visual impairments did not significantly differ from those without visual impairments, 44.4% cf. 30% (Gilchrist and Wilkinson, 1979). (It is considered the categorisation of 'visual impairment' in this study requires revisiting although it is noted that Cifu et al (1997) found that visual injuries did not differentiate between those TBI subjects who were and were not employed one-year post-injury.)

### Functional Status:

One-year post-injury functional status at rehabilitation did not differentiate between subjects who returned, and did not return, to employment (Cifu et al, 1997).

# Injury to Other Body Systems:

Brooks et al (1987a) found that physical deficits, for example sensory and motor disturbances; gait disturbances and cranial nerve deficits were not significant predictors of RTW rates. The presence of fractured limbs had no relation to work status two years post-injury (Ponsford et al, 1995).

# iii) Positive Relationship with RTW:

# Coma Length

Fabiano and Crewe (1995) found shorter periods of coma amongst TBI subjects who returned to work within two years as opposed to three years, as did Cattelani et al (2002).

### Severity of Brain Injury

Asikainen et al (1998) reported PTA of less than four weeks amongst subjects aged 18 to 40 years is positively correlated with working post-injury. Cattelani et al (2002) also reported a positive relationship between shorter PTA and RTW rates. Powell et al (1996) found that 95% of mild TBI subjects returned to work three months post-injury even though many continued to report symptoms.

Whilst research has suggested that the duration of PTA may be of some significance when considering future employability, the evidence is not consistent and the generality of the situation does not always apply to specific cases (Paniak et al, 1992). In the latter's study of 57 severely closed head-injured patients no previously gainfully employed individual with PTA of more than 33 days was able to regain or improve on the premorbid socio-economic status (SES). However, the heterogeneity of vocational outcome after severe TBI is illustrated by one individual with 150 days PTA participating in gainful employment, albeit at a lower level than was premorbidly held.

#### **Functional Status**

Relying upon the Disability Rating Scale Cifu et al (1997) and Gollaher et al (1998) found that TBI subjects who were employed one-year post-TBI were functioning at a higher level than those unemployed on both rehabilitation admission and discharge. In their multi-variate prediction study, Ponsford et al (1995) found functional status at the start of rehabilitation the best predictor of employment status two-years post-injury.

#### 3.5.3 Cognitive and Neuropsychological Deficits

#### i) Negative Relation with Return to Work:

#### Attentional Deficits:

Brooks et al (1987a) found subjects with lower scores on the Paced Auditory Serial Addition Test, a measure of attention, less likely to return to work. Asikainen et al (1999) and Leahy and Lamb (1998) also found a low score on the Stroop Test, assessing divided attention and processing speed, associated with an inability to return to work. Similarly, Ruff et al (1993) found a lower score on a Selective Attention Speed Index was a significant predictor of a failure to return to work. Mazaux et al (1997) and Girard et al (1996) found deficits in higher level attention skills associated with poor RTW outcomes.

#### Executive Functions:

Whilst Bayles et al (1999) found that subjects unable to return to work two years or more post-TBI almost exclusively failed the Tinker Toy Test (assessing executive functions), the prognostic value is limited by the fact that almost half of the work disabled TBI subjects performed normally on the test. Girard et al (1996) also found executive function deficits related to poor RTW outcomes.

#### Dysphasia:

Persistent dysphasia negatively impacted upon RTW prospects (Brook and Randle, 1972).

#### Speed of Information Processing:

Girard et al (1996) found a relationship between reduced speed of information processing and poor RTW outcomes.

#### Memory Deficits:

TBI subjects unemployed up to two-years post-injury demonstrated higher rates of memory deficits (Mazaux et al, 1997; Weddell et al, 1980; Thomsen, 1984 and Van den Burgh, 1985). Severe TBI subjects who failed to return to work obtained lower scores on tests of verbal memory (Brooks et al, 1987a; Cifu et al, 1997; Girard et al, 1996; Schwab et al, 1993). Lower scores on short-term visual memory tests were also found amongst those who failed to RTW (Ip et al, 1995). A number of studies, for instance, Bruckner (1972); Bond (1975) reported on a cluster of deficits indicating that subjects with greater memory, learning and personality deficits have poorer work adjustments than those with similar severity of head injury but lesser deficits in memory, learning and personality.

#### Intelligence/Cognitive Status:

Lower WAIS-R Vocabulary Scores were found amongst TBI subjects who did not return to work (Ruff et al, 1993). Lower performance IQ scores were also found to be related to lower rates of RTW (Ip et al, 1995).

Brooks et al (1997a) found a number of factors predicting the ability to return to work, including being described as "energetic" by 'significant other persons' (family and clinicians); the absence of behavioural, emotional and communication deficits; and a cluster of cognitive variables, including higher performance on tests of verbal learning, verbal memory communication skills and attention.

### Other Neuropsychological Impairments:

Mazaux et al (1997) found RTW rates negatively correlated with motor slowing; difficulty in mental flexibility; conceptual disorganisation; difficulty planning; mental fatigue and decreased initiative/motivation. Ip et al (1995) found that impairments in eye-hand co-ordination and finger dexterity were negative prognostic indicators for RTW.

#### Self-awareness:

Self-awareness, with an accompanying acceptance of disability and the impact on employment, appears to be critical to the VR process (Ben-Yishay and Lakin, 1989). Trudel and colleagues (1998) found a relationship between the employment outcome and self-awareness as assessed by a participant's self-awareness rating score compared to treating rehabilitation staff (the higher the difference, the poorer the outcome).

### ii) No Relationship with Return to Work:

#### Memory Deficits:

Leahy and Lam (1988) found no relationship between scores on the Wechsler Memory Scale -Revised (WMS-R) and RTW, likewise Haramburu (1981).

#### Intelligence:

Lamb et al (1991) found no relationship between post-injury Verbal IQ and a return to work. Fabiano and Crewe (1995) found that assessed pre-morbid IQ was not a significant predictor of employment status six years post-injury.

#### Attention Deficits:

Mild TBI subjects who did and did not return to work did not differ on tests of information processing (Ruffolo et al, 1999).

#### Speed of Information Processing:

Similarly, Ruffolo et al (1999) found that mild TBI patients who did and did not RTW showed no difference on speed of information processing.

### Other Neuropsychological Impairments:

Asikainen et al (1999) found that visual and auditory reaction times did not differentiate subjects with moderate or severe TBI in respect of RTW rates.

# iii) Positive Relationship with RTW:

# Intelligence/Cognitive Status:

Fabiano and Crewe (1995) found that amongst their sample of severe TBI subjects whose employment status was assessed up to six years post-injury, those who were employed fulltime had higher WAIS-R Full Scale IQs compared to those in sheltered or supported employment, those employed part-time, and those unemployed. In the same study sample, subjects with higher Full Scale IQs were also likely to return to work within two years postinjury. Subjects employed full-time also demonstrated less disparity between their estimated pre-morbid IQ and their post-injury IQ in comparison to other groups in supported/sheltered employment, part-time employment or unemployed. (It must be remembered that a Full Scale IQ is a composite score. A high Full Scale IQ suggests that some Performance or Verbal scores are probably relatively intact).

# Speed of Information Processing:

Girard et al (1996) found better performance on a test of speed of information processing was a predictor of a return to work.

# 3.5.4 Psychosocial Factors:

# i) Negative Relation with Return to Work:

# Pre-Injury Personality Factors:

Oddy and Humphrey (1980) found that severe TBI in subjects rated by relatives as premorbidly nervous and suspicious resulted in reduced RTW rates.

### Social/Family Circumstances:

Mazaux et al (1997) reported that emotional withdrawal was negatively correlated with RTW rates and, similarly, Schwab et al (1993) found that self-reported social isolation amongst Vietnam veterans with TBI negatively correlated with RTW rates. It is recognised that one could recognise such matters as relating to personality and not necessarily family matters. In any event because association does not imply causation it is difficult interpreting the relationship of social/family factors in many studies. Gilchrist and Wilkinson (1979) found that severe TBI subjects classified as having a "stable personality or family background" had higher RTW rates in comparison to subjects with an "unstable personality or family background".

# History of Substance Abuse :

Ip et al (1995) reported an inverse relationship between history of alcohol abuse and RTW and Corrigan et al (1997) found that TBI subjects with a history of alcohol or drug abuse were less likely to be working at one-year post-rehabilitation admission compared to those without such a history.

## Adaptive Deficits:

Brooks and colleagues (1987a) found that the inability to take responsibility for self-care and household work were strong predictors of post-injury work status amongst severe TBI subjects.

### Communication Deficits:

Wehman et al (1993a) investigated factors hindering the employment in 67 adults with severe TBI. The subjects were divided into two groups: (1) least difficult to employ and maintain in a job and (2) most difficult to employ and maintain in a job. Those who were most difficult to employ and maintain in a job were those most likely to be working in a position that required frequent work-related interactions with co-workers or the general public. Communication problems were evident. Subjects identified as difficult to employ repeatedly asked for assistance and directions, occasionally acted or spoke aggressively and responded inappropriately to non-verbal social cues. In a review of 41 vocational outcome studies, Fraser and Wehman (1995) concluded that language and visual-spatial abilities appear to have moderate associations with employment outcomes. The authors did not expand on this observation.

### Sleep Complaints:

Cohen et al (1992) found that TBI subjects reporting problems sleeping two to three years postinjury demonstrated lower rates of employment compared to those without sleep complaints.

### Litigation Status:

Cook (1997) found that subjects with a minor head injury and a compensation claim took longer (88 days) to return to work than those without claims (24 days).

### ii) No Relationship with a Return to Work:

### Pre-Injury Personality Factors:

On assessing subjects three years post-injury, Girard et al (1996) found that pre-morbid psychiatric history was not a significant predictor of RTW.

## Social/Family Factors:

Family status, living alone or with their family, did not impact upon RTW rates 18 to 24 months post-injury (Gogstad and Kjellman, 1976). Ruffolo et al (1999) also found living arrangements did not correlate with RTW rates amongst mild TBI subjects.

## Chronic Pain:

A general view (Uomoto and Esselman, 1993; Lahz and Bryant, 1996; Andary et al, 1997) is that whilst chronic pain compounds cognitive deficits and functional capacity in TBI patients, it need not necessarily adversely impact upon post-injury employment rates provided there is treatment for both the TBI and pain (Anderson et al, 1990).

## Litigation Status:

Kelly and Smith (1981) refuted some common opinion in respect of head-injured patients and litigation including, namely, no-one recovers and returns to work before settlement. This particular study was undertaken to discover whether or not there was any reliable evidence to support a contention that patients return to work symptom-free, once their claim has been settled. The sample size (43) may be considered too small to draw firm conclusions about factors which may or may not influence the return to work.

# iii) Positive Relationship with Return to Work:

### Pre-Injury Personality:

Subjects who successfully return to work post-severe TBI were rated as more energetic preinjury, compared to ratings for those who did not return to work, by relatives (Brooks et al, 1987b).

# Social/Family Factors:

Kaplan (1988) reported that subjects who had good pre-injury family relationships were more likely to return to work than those without such a background.

# Pre-Injury Work History:

Dikmen et al (1994) indicated that 80% of TBI subjects with a stable pre-injury work history, defined as employment for a minimum of six months, immediately prior to injury, returned to work two years post-injury compared to 60% of subjects without such a record. Gollaher et al (1998) reported that pre-injury productivity, defined as employee and student status at the time of injury, correlated with the likelihood of returning to work at a one year follow-up.

#### Self-Awareness:

Ezrachi et al (1991) and Sherer et al (1988) reported that an accurate self-awareness of functioning post-injury correlated with a return to work.

### Time Lapse to Rehabilitation:

The issue of rehabilitation is discussed further in this chapter.

### 3.5.5 Work Place Factors

#### i) Negative Relationship with a Return to Work

#### Employer Characteristics:

Johnson (1987) found that severe TBI subjects who began working with a new employer postinjury were less likely to remain successfully employed than those returning to the same employer. A change in the nature of the employment was a further hindrance to successful RTW.

#### Return to Work Time Lapse:

Oddy et al (1985) found that on a mean follow-up of seven years post-TBI, all subjects who had been unemployed at two years post-injury remained unemployed. Findings indicated that most severe TBI subjects who returned to work do so in the first year post-injury (Oddy and Humphrey, 1980). Similarly Johnson (1987) found that amongst his study sample, subjects rarely returned to work beyond two years post-injury. Olver et al (1996) undertook a two-year and five-years follow-up of moderately severe TBI subjects and found a decline between two and five years in terms of the number employed. Whilst they partly attributed this to economic conditions in Australia at the time, they also suggested that employers were not able to tolerate lower productivity, interpersonal difficulties or an inability to be retrained.

#### ii) No relationship with Return to Work

#### Return to Work Time Lapse:

Ip et al (1995) found no statistically significant relationship between the length of time postinjury and a return to work but reported a trend in the data suggesting that those not returning to work in the first year post-injury were less likely to do so at a later date.

#### iii) Positive Relationship with Return to Work

#### Employer Characteristics:

Asikainen et al (1996) reported that severe TBI subjects who returned to their pre-injury employment had greater success than those attempting to learn a new job. Similarly, Fabiano and Crewe (1995) reported that severe TBI subjects re-employed by the same employer showed a trend toward remaining successfully employed. Johnson (1987) indicated that a return to the same position, provision of special work conditions, for example easier work, supportive colleagues or personnel officer, and a lengthy period during which special conditions were maintained, were all factors which contributed to successfully returning to work post-TBI. West (1995) assessed subjects using a Vocational Integration Index (VII), and rating the opportunities for integration (Job Scale) and the extent to which an employee benefited from those opportunities (Consumer Scale). The subjects who retained their jobs for six months were rated higher on all sub scales and total scores for the VII, with seven of eight sub scales statistically significant.

### Supported Employment:

Wehman et al (1989a, 1990a, 1993a) found that prior to supported employment, subjects worked 15% of the total months of the time that they could have worked, compared to 75% during the implementation of supported employment. This improvement in job retention was associated with job coaching. Haffey and Abrams (1991) reported that participation in a vocational rehabilitation job development and placement programme resulted in a 68% placement rate in paid employment compared with 34% and 39% for comparator groups. West M D(1995) similarly reported supported employment improved the vocational prospects of severe TBI subjects.

#### Return to Work Time Lapse:

Fabiano and Crewe (1995) indicated that severe TBI subjects who returned to work within 24 months were more likely to be employed on follow-up (an average of six years post-injury) than the subjects who took longer than 36 months to return to work. Sbordone et al (1995) found that as time increases post-injury, in excess of two years, subjects still continued to make improvements in their return to work.

It is difficult to draw conclusions from such an apparent disparity in the findings. This is a matter addressed at 3.7 in the Summary and Main Points.

3.6 Four Matters Arising From the Analysis of Variables Said to Influence RTW Outcomes:

- a) The Role of the Family/Social Support
- b) The Use of Neuropsychological Tests
- c) Severity of Injury
- d) Type and Duration of Post-Injury Rehabilitation

It will have been noted that the literature rarely takes a holistic perspective in respect of factors influencing a return to work. Instead there is a tendency to concentrate upon a defined area of variables such as clinical factors. It is considered that some areas are particularly neglected. For example, in the experience of this researcher social factors can be crucial to the success or failure to return to work. This particular section, 4.2, addresses matters considered to be of consequence in the RTW process but either given little attention in the literature, particularly a), or subject to differing opinion, b),c) and d). In doing so it aims to clarify the significance of these important matters contributing to the development of a model VR programme.

a) The Role of the Family/Social Support in the RTW Process. Whilst the significance of TBI and the family has been extensively recorded (Lezak, 1978, 1986; Brooks and McKinlay, 1983; Mouss-Clum and Ryan, 1981), there has been less research on the influence of the family in the return to work process although it is often acknowledged (Lezak, 1978; Ross et al, 1983; Brooks and McKinlay, 1983; Rosenbaum et al, 1978).

Kaplan (1990) recognised that social support was gaining recognition in rehabilitation as an important contributor to client adjustment after disability. However, little was reported, although Kaplan (1988) had found a positive relationship between continuing family support and successful vocational outcomes one year post-injury with brain injured subjects. Kaplan's 1990 study was based on the following hypotheses:

- (i) Persons with brain injuries who feel less satisfied with their social support will show more indications of emotional distress.
- (ii) Emotional distress will be negatively related to vocational outcomes.
- (iii) Social support will be positively related to vocational outcomes.

The study sample consisted of 36 adults referred for psychological assessment during the

vocational rehabilitation process. The subjects were injured ten to thirty months prior to evaluation, ages ranged from 18 to 43 years, 27.5% were female and 72.5% men.

In respect of social support, 26 (72%) of the study sample were single and 10 (28%) were married, 4 of whom (11%) had become estranged from their partners subsequent to injury. On evaluation, a total of 14 (39%) were living with their parental families, 12 (33%) were living alone, 6 (17%) were residing with their partners and 4 (11%) were living with unrelated significant others. No one was competitively employed or attending school or training on evaluation.

Participants were tested with a battery of neuropsychological tests as well as personality tests, the 16 Personality Factor Inventory, Form A (16PF): (Cattell, 1970) and the Social Support Questionnaire (SSQ): (Saracen, et al 1983). Referring vocational rehabilitation agency counsellors were contacted approximately one year after evaluation to ascertain the vocational outcome or current status of each participant.

Results showed that clients' levels of emotional distress were related to both social support and vocational outcome. Kaplan (1990) considered that an explanation may be partly attributable to limited social support. When clients experienced stronger social support, they showed less emotional distress and a greater likelihood of a positive vocational outcome.

Since this was a correlation study, it cannot be firmly established that receiving social support alone improves vocational outcomes. The relationship of social support and vocational outcome could be the spurious result of the relationships between emotional stress and these two variables. Nevertheless, for the purpose of this study, the significance of social support has been considered potentially important. Hence, the decision to make reference to the family situation in the questionnaire (see Annex 3). The obvious problem is the difficulty in establishing if the family is a positive source of social support.

Romano (1974), describing the early reactions of families of people with head injuries, found the process of prolonged family denial of disability particularly noteworthy. Some families may be of the view that any indication by the person with head injury accepting their disability may be viewed as tantamount to 'giving up', the family clinging to the notion that determination alone will produce the desired results. In this respect, expectation to 'keep up the good fight' may sabotage vocational rehabilitation efforts. Awareness and acceptance of the limitations imposed by the injury are fundamental to the vocational rehabilitation process (Ben-Yishay et al, 1987; Trudel et al, 1998). In this study, if the family was perceived to be a 'problem', for

instance having unrealistic expectations, this was noted at interview and/or in file records. When this occurred due reference is made in the discussion.

A practical consideration of the role of the family is in respect of job placement. Job placement personnel are often judged by the number of placements obtained and taking on board another point of view, such as family opinion, may further complicate the placement process.

Nevertheless, it is considered that there is a need to recognise the change of vocational status of someone sustaining TBI and its effect upon the family, particularly in respect of vocational status and any income provided. This includes the consideration of 'role-reversal'. A crisis in respect of family income, economic stability and a perceived and/or real loss of social status could be potentially devastating depending on the number, ages and social maturity of other family members. In addition, there may be cultural and ethnic issues in respect of participation in a vocational rehabilitation programme and the expected outcome. Rehabilitation outcomes may also be influenced by such circumstances as when role reversal becomes the focus of the family transition. When the injured person is a child, there is not only the loss of parental expectations but also the eventual realisation that life-long caring may be necessary. Family engagement is essential if the child is going to be involved in supplementary courses, extra curricular activities, clubs, part-time jobs or other therapeutic programmes.

**b)** The Use of Neuropsychological Tests. The history of relating neuropsychological test scores to predict future employment status requires addressing because of any potential misunderstanding that can (and does) arise over its purpose and predictive value. In general, there appears to be some consensus that whilst test scores themselves are unreliable predictors of employment, neuropsychological disability is a major factor reducing successful labour market integration. On the face of it, such an observation appears contradictory. It needs to be remembered that neuropsychological tests are measures of highly defined and narrow aspects of human performance designed to assess brain function rather than to reflect 'real life' activities.

Neuropsychological assessment of cognitive function generally includes measures of memory, attention and concentration, speed of information processing, verbal and non-verbal reasoning, overall intelligence and executive functions. As suggested, the relationship between neuropsychological test scores and functional abilities is not clear. As long ago as 1984 Prigatano and colleagues found the trend for unemployed subjects to show a greater impairment on some neuropsychological tests but the differences were not statistically significant. This study indicated that traditional cognitive tests alone were insufficient to

describe, and be used, in predicting outcome and that behavioural and psychosocial measures would be useful in combination. Test scores of single variables have not proven consistently reliable predictors of employment status (Leahy and Lam, 1988)

Despite the lack of consistent findings it is considered that, on balance, research reflects neuropsychological tests identifying factors that are likely to influence outcomes (Fraser et al 1988; Brooks et al 1987a)

Ezrachi et al (1991) looked at outcomes both in terms of clinician-rated employability at the end of a vocational programme and at actual employment status on a six months follow-up. In addition to neuropsychological measures, group process and staff ratings were also measured both before and after completion of the programme. Among their findings was the fact that post-programme measures resulted in more accurate prediction than pre-programme measures. Neuropsychological variables, including verbal aptitude measured pre-programme and verbal aptitude and psycho-motor dexterity measured post-programme, were significant predictors of employment status on follow-up. Group process variables relating to awareness and acceptance of the programme were also important factors in prediction. They concluded that whilst there is wide variation in findings, research in the area of post-injury employment generally supports a significant contribution of psychometric data to predicting outcomes but, on its own, the predictive value of testing is reduced.

Rosenthal and Millis (1992) came to the conclusion that using neuropsychological tests as indicators of outcome had advanced the understanding of prediction but "nevertheless, it still remains an art". A promising approach appeared to be one which combined selected neuropsychological measures with other types of data. In 1994 Millis and Rosenthal reiterated that the issue was not one of statistical associations between tests and psychosocial outcome but what could be done to increase predictive power and validity.

Studies have shown that whilst functional capability improves with TBI rehabilitation, it may do so without changing neuropsychological test scores (Hartley, 1990). Even if neuropsychological scores improve, there is no convincing evidence that rehabilitation works primarily by improving such impairment. Consequently, pointing to an improvement in neuropsychological test scores may have little practical bearing on the more relevant, real-life performance abilities of the subject. Hence, neuropsychological test scores can not be taken to be the primary indicators of the success of a rehabilitation programme nor as a reliable indices to future outcomes. Nevertheless, it is considered that neuropsychological tests remain important to rehabilitation programmes particularly in respect of understanding the basis for the
subjects' cognitive and neurobehavioural limitations and strengths. Whilst they can be used to "estimate prognosis", they are most likely to be beneficial in respect of prescribing optimal rehabilitative interventions (Prigatano and Klonoff, 1988). This is a position taken by this study.

c) Severity of injury. Not all investigators have found a direct relationship between injury severity and a return to work (Brooks, et al, 1987a). Wehman and colleagues (1995), McMordie et al (1990), Rao et al (1990) noted that some individuals who sustained severe injuries were able to return to employment relatively unhindered. Specific types of cognitive, physical and psychosocial impairments associated with TBI may be more predictable of RTW than the measure of injury of severity. For example, the presence of significant physical disability (McKinlay, Brooks & Bond, 1983), psychosocial impairment (Thomsen, 1984; Lezak, 1987; Martin-Tamar, 1988) and memory/reasoning deficits (McMordie, Barker & Paolo, 1990; Martin-Tamar, 1988) have all been linked to poor outcomes. The relationship of PTA duration with vocational status may be moderated by the nature of the workplace and the amount of support that is provided (Kreutzer, 1991; Stapleton, et al., 1989).

In a later study, Johnson (1997) also suggests that there is not a straightforward relationship between injury severity and return to work. For those previously in work, and able to return after injury, to familiar routines and supported work, there was only a weak relationship between severity of injury and work outcome. Moreover, there was no significant difference in PTA duration between those in stable work and those in unstable work. In contrast, the outcome for those who were students or in training, and sought work for the first time after injury, was much more clearly linked to severity. These findings give weight to the view that the opportunity for support and help from a previous employer is most important in determining long-term outcome. Other studies (Godfrey et al, 1993) lend weight to this conclusion.

d) Type and duration of post-injury rehabilitation. Despite the limitations in many evaluations it is considered the specific *type* and duration of post-injury rehabilitation has been shown to affect a return to work. Like many other potential issues affecting outcomes following TBI, there are inconsistent findings. Whilst the provision of rehabilitation services, whether clinical and/or vocational, may be considered a significant factor influencing a return to work many rehabilitation interventions have been found to be costly and time-consuming (West et al., 1992), and they did not necessarily improve levels of employment after severe brain injury (Wehman et al., 1995). Vogenthaler et al (1989) found that the amount of post-injury rehabilitation received (primarily physical and occupational therapy) was a significant predictor of return to work. Similarly, Prigatano and colleagues (1994) reported that participation in vocational adjustment services also appeared to improve RTW outcomes, but this was

107

compounded by findings that individuals with severe injuries were less likely to receive vocational services (McMordie, Barker, Paolo, 1990; Vogenthaler et al, 1989). Generally such studies do not develop the issue of what aspects of the rehabilitation programmes worked for subjects with a range of symptoms. For instance, whilst Kaplan (1990) found no relationship between the receipt of cognitive retraining services and an eventual return to work, Prigatano et al's work (1984) suggested there needs to be some specifically focussed work activity. Prigatano and colleagues concluded that the methods used in their programme were primarily designed to enhance neuropsychological function, particularly speed of information processing and personality adjustment. To a degree these goals were accomplished. It was hoped that this would automatically lead to greater worker productivity, but, on reflection, this was a naive assumption. Improving neuropsychological status and personality skills are necessary, but not sufficient, conditions for accomplishing a successful return to work. Specific training in this area is needed if the desired goal is to get the injured person back to work and keep him/her gainfully employed.

Rehabilitation strategies designed to enhance return to work invariably can be broadly categorised as either pre-work regimes or in vivo strategies. The most common among the pre-work regimes is cognitive retraining. Pre-work intervention programmes are described by Prigatano et al (1984), Ben-Yishay et al (1987), Lewis et al (1987) Cohen (1985) and Burke et al (1988). Although these programmes have distinguishing characteristics, each used cognitive, social and vocational rehabilitation efforts concentrated before job placement, with few or no post-placement intervention. Prigatano and colleagues (1986) focused upon a cognitive rehabilitation approach. Ben Yishay and colleagues (1987) described an holistic approach using cognitive remediation, occupational trials and job placement. Prigatano and colleagues (1988) described an intensive 24 hours residential programme with behaviour modification. Pre-work/clinically based interventions subjects typically underwent training procedures to ameliorate cognitive deficits in basic attention, memory, visual-spatial information processing, verbal reasoning, interpersonal communication, social confidence, and awareness and acceptance of the head injury. Many reviews conclude that cognitive rehabilitation methods are effective in increasing attention and visuo-spatial abilities, teaching specific information and skills and developing compensatory memory strategies (Benedict, 1989; Caplan, 1988; Gouvier, Webster and Blanton, 1986), although others have challenged these conclusions (Webster and Scott, 1988; Levin, 1990; Volpe and McDowell, 1990).

Wehman and colleagues (1995) considered that the history of rehabilitation indicated how ineffective some costly rehabilitation programmes were in respect of returning participants to employment. Whilst an analysis of their clinical data suggested that the severity of injury and

neuropsychological deficits influenced outcomes, even so, intervention for more severely injured people could be more effective and that 'emergent technologies', including supported employment, assistive technology, job coaching and work place accommodations, could mitigate the effects of cognitive, physical, psychosocial impairments resulting from TBI (in vivo strategies). They considered that, *"job coaching is an effective means of helping individuals with severe TBI"*. The role, combining counsellor and training advocate, was found to be invaluable in respect of mitigating the effects of injury severity, for example impairments of memory, mobility, reasoning and social adjustment. It was noted that even in supported employment, people with severe TBI tended to move from job to job before stabilising and, in this respect, "follow -along" services were considered necessary.

Haffey and Abrams (1991) found that participation in a vocational rehabilitation job development and placement programme resulted in a 68% placement rate in contrast to 34% and 39% for comparator groups, with a 70% retention rate at a three years follow-up. The time span to rehabilitation may be an issue. Malec et al (1993) for instance, reported that TBI subjects who entered rehabilitation programmes less than one year following injury had a higher frequency and work placements in contrast to those who entered the programme more than one year post-injury.

Whilst in the absence of rehabilitation there have been consistent findings of a low rate of return to employment in the UK, in their Glasgow study, in which only 29% were employed, Brooks et al (1987) noted that rehabilitation was `patchy' at best, with many receiving none. More recently Thornhill et al (2000) have indicated that the majority of people sustaining a brain injury in the UK do not receive clinical rehabilitation and it will be noted that specialist TBI vocational rehabilitation services are few and far between. The National Traumatic Brain Injury Study (1998) found no relationship between clinical rehabilitation and a return to work, whilst citing examples of when an individual had clearly received practical assistance.

**3.7 Summary and Main Points:** RTW studies have now been reported for around three decades. The prediction of long-term outcomes subsequent to TBI is potentially useful in respect of facilitating rehabilitation strategy (Jennett et al, 1981; Bolton, 1981). Secondly, addressing one of the major sources of stress of relatives of the injured, outcome research affords the injured person's family an opportunity to appropriately adjust their expectations. Thirdly, prediction models, or simply a greater understanding of the eventual outcome based upon empirical observation, can be used as a programme evaluation tool. Prediction ability can also be useful in litigation cases. Complimenting the choice of predictor variables is the equally important task of defining the outcome.

109

The RTW process still remains to be fully understood although there is evidence that clinical rehabilitation alone cannot be relied on to produce positive employment results (Prigatano et al, 1984; Ben Yishay et al, 1987). The literature largely supports the global success of specialised vocational rehabilitation programmes. Success for the TBI population not only involves securing a job but maintaining it.

Until the early/mid 1990s few RTW studies took into consideration the nature of developing compensatory strategies in the work place and how these are positively influenced by the intervention of job coaches. There are no such studies from the UK.

Although the literature identifies barriers to employment, these barriers are not necessarily related to individual cases of TBI and the process of returning to work. It is how such factors are addressed with individuals that requires attention. Although some studies have established significant correlations between variables such as age, Glasgow Coma Score scales, duration of PTA, presence of multiple trauma and neuropsychological measures of psychomotor speed, and outcome, findings to date suggest that outcome is influenced by many different factors in each individual and the capacity to predict outcomes has been confounded by both the complexity of the problem, such as 'weighting' clinical variables that correlate with each other, and practical research issues, such as defining employment and limited sample sizes.

The multivariate studies show how multi-predictors are superior to single predictors and what some of those predictors should be, namely relevant demographics, pre-injury social characteristics, severity of injury and environmental/social variables. The difficulties in making predictions emphasise the value of work trials and observation. Historically the literature reflects a move away from prediction to examining the process of intervention.

During the 1990s there was also a move from group studies to addressing individual barriers to employment, accompanied by developing research methodology.

So what has been learned from the literature?

There are a number of important lessons to be learned from the RTW studies and an examination of the variables in respect of the objectives of this report.

• One should not generalise from a group sample in an RTW study to any one individual.

There is conflicting evidence with regards to the reasons for failure in employment. Results are not consistent and the most one can say is that certain variables <u>may</u> influence outcomes more than others. Circumstances will vary from person to person, hence the need to examine specific individual circumstances.

- There is an initial importance of obtaining an appropriate assessment of the subject's strengths and deficits. A perceived problem is the lack of any standardised neuropsychological test battery. Some tests appear to be more vocationally relevant than others.
  - Once an assessment of clinical and occupational factors is carried out, there is a need to enhance desirable behaviours and develop compensatory strategies to deal with skill deficits and functional limitations likely to interfere with the ability to work. Building upon assets and strengths to minimise bias to employment should be a focus of rehabilitation efforts (Huber and Edelberg, 1993).
  - RTW studies have not been able to identify "the best way" of returning a person with TBI to the labour market. There is probably "no best way", not surprising considering the heterogeneity of variables that may influence the outcome in a particular case. There is a need to be flexible with regard to the provision of RTW services. One factor which does emerge consistently from studies is the value of occupational trials. These are defined in a variety of ways but all involve 'trying out' real jobs, with or without job coaches.
  - The development of predictive models has been confounded by methodological problems, such as variables correlating too closely with each other to identify specific significance, and there remains a need to develop an approach to explain individual circumstances.

Whilst recognising the value of statistical analyses, it is considered that the findings can only reflect the characteristics of the study sample, and their generality does not necessarily help to explain *individual* circumstance. For example, it may well be that a particular study shows that men of a certain age with a particular deficit, or combination of deficits, have poor return to work rates, this does not necessarily mean that a man with similar demographic and clinical characteristics being considered for a vocational rehabilitation course would not benefit from it. There is a clear need to be able to better understand individual circumstances and provide *appropriate* intervention before judgment can be made in respect of the individual likelihood of benefiting from support as illustrated in the case study (Target et al, 1998).

111

There remains the need to establish a framework for analysing, and subsequently addressing, individual barriers to employment so that they can be appropriately addressed within a VR programme. In turn this requires a greater recognition of the variables that may influence individual outcomes.

RTW studies suggests that the process of integration into the labour market is influenced by many factors, some of these variables can be influenced, and potentially modified, others can not. Whilst there is scope for much debate as to the significance of variables influencing RTW outcomes one matter is clear. Factors such as length of coma (Thomsen, 1984), pre-injury work experience (Jacobs, 1987), education and intelligence (Paniak et al, 1992, Lezak, 1987) and pre-injury factors (Dikmen et al, 1994) have been related to the vocational outcome but there is nothing the rehabilitation professional can do to change these factors. Furthermore, the relationship of the skills and abilities often studied in clinical examination in respect of the ability to work and fit in at the job site may be unclear unless immediately apparent and obvious (Thomas and Menz, 1996).

To what further extent have the questions asked at 3.0 been answered?

a) The need for, and value of, outcome research is clear.

b) Researchers have deployed various strategies including univariate, multivariate analyses and case studies.

c) Whilst a multitude of variables have been identified in the literature as influencing employment outcomes there is little consistency to the findings. The same factor, or factors, can be reported in different studies as having a significant influence, to no influence, to a negative influence. Reasons may relate to such matters as the size of the study sample, the mechanism of injury and the nature of analysis. There remains a need to analyse individual circumstances.

d) In many cases clinical rehabilitation on its own is unlikely to provide a sufficient basis for maximising a likely return to work following TBI and indications are that researchers have found both occupational trials and on-site strategies are a productive way forward.

e) The way variables are said to influence outcomes has been identified.

f) The role of neuropsychological testing is considered to have been answered.

g) Similarly the significance of injury severity and the role and type of rehabilitation have been addressed.

This chapter has established the variables reported as not only influencing outcomes but *how* they are said to do so. In turn this ought to facilitate the identification of individual barriers to employment and, the next stage, the identification of appropriate intervention strategies when this is possible. The design of such intervention needs to be placed within the context of the delivery of TBI vocational services in the UK.

# CHAPTER 4

# THE DEVELOPMENT OF VOCATIONAL REHABILITATION SERVICES FOR PEOPLE WITH TRAUMATIC BRAIN INJURY

# **Contents**

4.0	Overview	114
4.1	UK: Department for Work and Pensions (DWP) Jobcentre Plus	116
4.2	Other Associated TBI Vocational Rehabilitation Services	121
4.3	Approaches to Vocational Assessment in the UK	126
4.4	Supported Employment in the UK	130
4.5	Approaches to TBI Vocational Rehabilitation in the United States	133
4.6	Job Coaching	142
4.7	Summary and Main Points	149

**4.0 Overview:** An underlying premise of this thesis is that generic vocational rehabilitation services funded by Jobcentre Plus are generally failing the TBI population. Chapter 4 builds on the previous chapters by addressing the contexts within which TBI vocational services are delivered in the UK. It also addresses developments in the USA that are considered transferable and beneficial. These services are fundamental to the development of what is considered to be a model TBI VR programme - an objective of this thesis and a theme pursued throughout the study and brought together in the Conclusion.

The RTW literature mainly refers to practice in the United States where there is generally not the same differentiation between clinical and vocational rehabilitation as in the UK. Until recently NHS Trusts have had no responsibility for providing vocational rehabilitation and the focus of clinical rehabilitation has been, and substantially remains, upon improving functional skills with a view to community re-entry. Hence, this chapter provides

- An understanding as to the nature of current employment services for people with TBI.
- A background to the (possible) experience of the study sample.
- Insight into the TBI VR process in the United States with a view to identifying efficacious strategies that could contribute towards a theoretical model within the UK.
- Information on current condition management programmes against which the theoretical model of a TBI VR programme is to be developed.

The background to the current development of condition management programmes is a tripling in the number of incapacity benefit claimants in the UK over the last 20 years. Whilst a variety of explanations are offered in a 2002 DWP Green Paper (demographic, ease of claiming and structural, e.g. the decline of heavy industries putting many older workers on the employment market) a significant factor that has been acknowledged is the lack of support for such people. It is noted (DWP, 2002) that 'we also know that doing more to support potential returns to work fits with the expectations of most people in the early stages of a claim to an incapacity benefit. At this point, 90% of people expect to get back to a job in due course. But, in practice, over 40% of those claiming the benefit will not make that transition and will still be receiving it 12 months later. And once a person has been on benefit for a year their prospects for getting back to work are likely to be very poor, whatever health condition they report. Once a person has been on an incapacity benefit for a year, they only have a one in five chance of returning to work within five years.'

The Government's response (DWP 2003) to the 2002 Green Paper sets out the intention to introduce joint Jobcentre Plus/NHS vocational rehabilitation (condition management programmes). Whilst pilot programmes have been run for (IB) customers with cardio-thoracic, musculo-skeletal/chronic pain and mental health problems the final rolled-out programme from 2007 is a generic one, not based on treatment but on IB customers learning to manage their condition. There have been no specific proposals in respect of the brain injured population although Jobcentre Plus, at local levels, has indicated that there is funding available to provide support to IB customers with specific conditions requiring additional services.

This thesis aims to provide a theoretical model of how such a service for the TBI population could be delivered. Before this can be done the preceding chapters suggest that there is a need to answer a number of questions arising from the delivery of vocational services to the TBI population in the UK:

What is the background to the development of current services for the TBI population?

How are their resettlement needs assessed?

How much support do they receive to return to work?

What services are available for them?

Chapter 4.1 describes how employment services for people with disabilities in the UK developed apart from the NHS and the nature of current Jobcentre Plus assessment and work preparation (VR) courses. Chapter 4.2 addresses other TBI VR services in the UK with particular reference to Working Out, a joint NHS/Jobcentre Plus initiative that has not been replicated, despite such a recommendation from the House of Commons Select Committee on Health (2001) .Chapter 4.3 sets out the 'typical' approach to assessing occupational, skills, abilities and aptitude of people with disabilities in the UK and Chapter 4.4 covers Supported Employment (this may be seen as ostensibly suitable for many people with TBI, either as a 'stepping stone' to open employment or for permanent employment).

Chapter 5.5 briefly considers salient aspects of TBI VR practice from the USA, reflecting matters considered to contribute towards a 'best practice' model in the UK. These are legislative underpinning, a movement away from traditional vocational evaluation practices, with an emphasis on pre-placement assessment, towards one of working in a real job placement with clients and the support of job coaches during this process. Chapter 4.6 further develops the subject of job coaching.

4.1 UK: Department for Works and Pensions (DWP) Jobcentre Plus: Historically, the Disability and Rehabilitation Services within Jobcentre Plus developed out of the 1944 Disabled Persons Employment Act, amended in 1958. The Act was based on the report of the Tomlinson Committee (1943) and concern for disabled war veterans. Tomlinson recommended three main measures to help disabled people find suitable work. Firstly, Industrial Rehabilitation Units (IRUs) were to be set up to assess occupational handicaps; this was to include individual assessment and a certain amount of reconditioning and restoring physical functioning. Further specialist training for disabled people was to be made available and a specialised job placing service was proposed. Secondly, the view of Tomlinson was that disabled people were to be integrated into the normal workforce wherever possible, with the help of a Quota scheme and a voluntary register, administered by Disablement Resettlement Officers (DROs) (renamed Disability Employment Advisors (DEAs) in 1992). Thirdly, those too severely disabled to work in open employment were to have special provision in sheltered workshops. Underlying the recommendations of Tomlinson was the proposal that rehabilitation back to work, after medical treatment, should be provided by the Ministry of Labour. Although the measures taken to introduce these proposals have gradually disappeared (the IRUs, renamed Employment Rehabilitation Centres (ERCs) in 1972, were closed in 1992, and the Quota scheme was retrenched prior to the 1995 Disability Discrimination Act) there remains a legacy. The employment rehabilitation and DRO services were developed apart from the NHS. To the present day, a positive act of referral has to be made from health to vocational

rehabilitation services funded by Jobcentre Plus. Condition management programmes seeks to address this situation.

The first comprehensive statistical breakdown of a whole year's rehabilitation client sample was published in the Ministry of Labour Gazette in 1956. Cornes (1981) indicated that between 1961 and 1976 the percentage of clients with "injuries of the head and trunk" declined from 2.4% to 2.2%. There are, however, no means of specifically identifying people sustaining a TBI.

Historically, ERC courses were an average of seven or eight weeks duration, even though it was said that they could last up to six months. In the mid-1980s the vocational evaluation process was defined as an occupational assessment followed by rehabilitation. In practice, a disabled client is likely to have received an initial interview, possibly followed by a two-days assessment relying on interviews, psychometric tests and work sampling techniques. The American VALPAR system of work samples was introduced during the 1980s (Annex 2). Only if considered necessary was a programme of rehabilitation to be offered. Rehabilitation was seen as a gentle introduction into the work environment, and/or extended practical assessment, by placement in any one of a number of the ERC's own in-house work sections, including clerical and commercial facilities, engineering workshops, gardening section, woodworking section, and 'miscellaneous' (packing, etc.) section. The Employment Rehabilitation Service Report (1991) indicates that out of a total of nearly 24,000 people seen for an assessment, only 37% were referred for rehabilitation.

There is evidence from the 1980s that the needs of people with TBI were not well served by available employment and training services.

Brooks et al (1987a) reported that only 6% (8 out of 144) of their sample of head injured patients had contact with an Employment Rehabilitation Centre. Johnson (1989) described the use of a number of MSC schemes, including training, in respect of a series of 64 severely head injured patients seen on the Rehabilitation Unit at Addenbrooke's Hospital between January 1980 and June 1983 with a PTA of one week or more; 25 people regained employment of whom 21 (84%) did so without MSC help, 16 people made use of MSC schemes but 12 (75%) were not employed at a mean follow-up time of 3 years, 10 months after injury. One person was in sheltered work.

Johnson (1989) concluded that some of those in education at the time of their injury were helped by MSC schemes but amongst those who had worked before their injury, there was an

117

inverse relationship between successful return to work and use of MSC schemes. In all, only 4 people (6%) both returned to work and made use of MSC schemes. Three were in education at the time of injury. The one person previously in employment who returned to work through an MSC scheme had his former job held open for him whilst he attended an Employment Rehabilitation Centre.

Johnson (1989) considered that the failure of MSC schemes to provide appropriate support may have been for several reasons including those who were using such schemes tended to have manual and semi-skilled backgrounds and return to work after injury may be less likely for those working at this level (Humphrey and Oddy, 1980; Brookes et al, 1987b).

It was further considered that the main reason for the failure of MSC schemes was that they did not meet the needs of head-injured people. Johnson (1987) showed that those returning to work received help for significantly longer (mean time eight months) than those who failed at work (mean time three months). The mean time spent on MSC courses by the people in the study, included schemes such as the Youth Training Scheme (YTS) lasting up to one year, was only 16.6 weeks. No one attended an ERC for more than three months. In addition, he considered that people made use of MSC facilities when it was too late. One-third of those who participated in MSC schemes did so after they had failed in other attempts at work. This meant that they had lost confidence and were likely to be more difficult to help. The mean time to attend a scheme was over two years after injury. (There are studies that show that if employment has not been re-established within two years of injury, then it may not be achieved at all (Oddy et al, 1985; Brookes et al 1987a; Johnson 1998) particularly those sustaining very severe injury.)

Following 1987 National Audit Office criticisms that:

- i) rehabilitation facilities were geographically not comprehensively available;
- ii) the ERC resources were under-utilised;
- iii) the cost effectiveness of the service was difficult to calculate,

the Employment Service (an operational name at the time) went on to publish *Employment and Training for People with Disabilities* (1990). This document summarised the intentions for assessment and rehabilitation as follows:

"a) **Employment assessment** to be provided by around fifty Employment Department Teams, working closely with DROs and DAS (Disability Advisory Service) and no longer located in Employment Rehabilitation Centres; supported by a small core network of Employment Department (ED) Centres, focussing particularly on the development of new techniques. It is also proposed to consider mounting experiments to test the case for contracting out specialist forms of assessment.

b) **Employment rehabilitation** to be provided through agents (voluntary bodies and others) supported and monitored by the fifty ED teams; and in the core network of ED Centres, which would assume a "teaching hospital" role."

Three key changes were implemented:

 During 1992, the role of DROs and ERCs were combined into Placement, Assessment and Counselling Teams (PACTs), each one with its own local occupational psychologist (now known as a work psychologist). Seven regions of the department established approximately 8 PACTs per region. The PACTs, renamed Disability Service Teams in 1999, controlled the budgets for agency rehabilitation contracts in their local areas. PACTs were disbanded during 2002 as a policy consequence of the creation of Jobcentre Plus within the DWP following the merger between Jobcentres and the Social Security arm of the Department of Health. This measure was taken as a consequence of the number of Social Security 'customers' in receipt of incapacity benefits rising to 2.7m and the perceived need within the government to address this problem with a joined-up service.

A consequence of this development has been the need to considerably expand the numbers of employment staff seeing people with disabilities/health problems. (Effectively, there is currently unannounced 'mainstreaming', that is all staff seeing people with disabilities, with specialist DEAs becoming comparatively marginalised).

- ii) The network of ERCs was closed down. Whilst nine regional Ability Development Centres (ADCs) were opened and given a responsibility for monitoring services to people with disabilities, staff training and research, these were closed during the late 1990s.
- iii) Tenders were sought from agencies in the private, public and voluntary sectors to provide rehabilitation services on a local basis, such courses to be described as work preparation. These are now largely contracted to disability organisations and training providers, and typically of six weeks duration (Banks and Riddell, 2002). During 2002 the Disability Service exceptionally agreed to extend the period for brain-injured people to 18<sup>2</sup>/<sub>3</sub>rds weeks on a full-time basis and pro-rata on a part-time basis.

External organisations providing vocational assessment and rehabilitation for head injured people did not exist in 1992 although in 1994 the Employment Service part-funded and contracted with the 'Working Out' project (Tyerman 1999), established by the NHS Aylesbury Trust as one of 12 projects agreed in 1992 as part of the National Traumatic Brain Injury Study. During the 1990s two reports examined the effectiveness of the re-arranged Employment Rehabilitation Service, Johnson (1993) and Lakey and Simpkins (1994). The latter's research had three main objectives:

- i) to assess the quality of local agency rehabilitation;
- ii) to identify ways in which agencies should be monitored;
- iii) to identify ways in which local provision should be developed to meet the needs of all clients.

In respect of five PACTs and the ten agencies delivering rehabilitation programmes, the 1994 survey found that several PACTs had managed to establish networks of local agencies within reasonable travelling distance of most potential clients.

However, problems in contracting out rehabilitation were found. These included:

- i. Some areas still had no local agency provision. The closure of ERCs meant that there was no longer any residential provision.
- ii. Many clients had limited choice in respect of what was available.
- iii. Alongside some other specific disabilities, there was a lack of facilities for people with mental illness and mental distress (it is impossible to identify if this includes people with TBI).
- iv. Staff at many agencies had limited experience of work with disabled clients.
- v. The system of funding on a "cost per head" basis, did not provide the resources for agencies to invest in improved environments, facilities and services.
- vi. Some PACTs found it difficult to attract suitable rehabilitation providers, and, as a consequence, had reduced leverage to enforce standards of quality.
- vii. The length of rehabilitation programmes was generally perceived to be too inflexible. Some clients were excluded from rehabilitation provision because the standard programmes were not long enough to prepare them for work.
- viii. Most Action Plans (following assessment) failed to provide accurate details of client needs, the long-term goals of rehabilitation or its more specific objectives. Most Action Plans left it up to agencies to decide how they would provide for clients' needs.
- ix. Most clients were not supported by their DEAs in the three months following rehabilitation.

The content of assessment, that is the measuring of interests, ability and aptitude, is not addressed in any report. The closure of ERCs in 1992 and the establishment of PACTS was followed by Disability Employment Advisors (DEAs) being trained to Level A of the British Psychological Society Occupational Testing accreditation scheme (qualifying them to use many standard tests of ability and aptitudes). Arrangements were made to consult the local occupational psychologist to undertake an assessment when a DEA recognised the limitations on his/her own skills and knowledge. Unless a client was referred to a work preparation agency the opportunity to 'check out' such testing in a practical work environment was lost (a situation that still appertains) and, even if referred, the monitoring system, concentrating on financial and administrative arrangements, does not allow for a qualitative assessment as to the extent individual needs are being met.

The indications are that the changes went some way towards addressing the criticisms made by the NAO (1987). However, there remain questions in respect of the expertise amongst some agency providers (Banks and Riddel, 2002). The changes were introduced before quality criteria, relating to outcomes and performance were developed. Whilst information is not yet available for the costs of the condition management programmes, work preparation agencies receive less than £2,000 for a work preparation course.

**4.2 Other Associated TBI Vocational Rehabilitation Services:** In the latter part of 1999, the South East region of the Employment Service signed a contract with Banstead Place in Surrey to provide a three months residential assessment/rehabilitation programme but there are only 14 places. Banstead Place is part of the Queen Elizabeth Foundation at Leatherhead and one of four specialist Residential Training Colleges (RTCs) in the UK for people with disabilities. Banstead provides a programme containing elements of personal development, work preparation and work experience.

Where Rehab UK has established centres in Newcastle, Birmingham and London, Jobcentre Plus has signed contractual agreements to support attendance as part of its work preparation provision. Similarly, the Papworth Trust in Cambridgeshire provides an "early rehabilitation" programme for people under the Work Preparation Programme for people sustaining head injuries.

#### Rehab UK

Since early 1997 the major development has been the establishment of Brain Injury Vocational Centres, run by Rehab UK (known as Momentum in Scotland), in Aberdeen, Glasgow,

Kirkcaldy, Newcastle, Birmingham and London. Programmes are typically of 12 months duration. The first three months covers cognitive rehabilitation programmes, such as modules on anxiety management and memory skills, as well as some basic education and IT provision. Job coaches support work placements, gradually withdrawing this support. In correspondence, Rehab UK has indicated that its longest established English centre, in Birmingham, has a placing rate of around 56%, with a further 12% of clients moving onto voluntary or therapeutic work. Details in respect of the severity of injury are not published. A significant feature is the cost of such courses, currently around £26,000 per annum. Few NHS Trusts will pay for such courses and Jobcentre Plus will only fund a brain injured person for a part of its provision for work preparation courses and for a maximum of 18.66 full-time weeks or pro rata on a part-time basis. (The odd figure is understood to reflect a division of the allotted budget).

### National Health Service (NHS)

The clinical rehabilitation of brain-injured people is addressed by Oddy et al (1996) and Wood and Fussey (1994). A working party report, produced by the British Society of Rehabilitation Medicine (2000), maintains that occupational therapists (OTs) are ideally placed professionals to analyse work samples, compare these to work abilities and to make recommendations regarding suitable adjustments. On the other hand, a survey into employment in this sector (Host Policy Research, 2002) found only a minority of OTs undertaking vocational activity.

The DWP's 2002 Green Paper proposals, and the government's response (2003), represent the most significant post-war development in the VR sector.

### Working Out

The Centre for Health Service Studies, University of Warwick, undertook the research for the National Traumatic Brain Injury Study (1998). This followed the establishment of a number of specialist head injury projects by the Department of Health in the early 1990s, including the "Working Out" vocational rehabilitation project undertaken by the Aylesbury Vale Community Health Care NHS Trust. The Employment Service later provided funding under the work preparation programme. The psychologist in charge of the programme, Dr Tyerman, has said that the average cost per course is around £10,000, although this appears to exclude capital costs. Dr Tyerman has undertaken the only evaluation (Tyerman, 1998). The level of staffing at Working Out also suggests that a less staff intensive delivery of a VR service is required for people with TBI.

The service is provided by a rehabilitation team comprising clinical psychologists, medical practitioners, nursing staff, occupational therapists, physiotherapists, social workers, speech therapists and administrative staff working in conjunction with local acute and community

services, including the specialist Regional Neuroscience Services and other agencies, particularly Social Services, Jobcentre Plus and the local Headways group (the national voluntary association for brain injured people).

Each client activity is given the following time span:

Vocational Programme	Typical Duration	
Initial assessment	Half-day	
Vocational assessment	3 weeks	
Work preparation	12 weeks +	
Voluntary work trial	12 weeks +	
Work placement	6 months +	

It will be immediately evident that this time span is in marked contrast to provision under the Work Preparation Programme (and the current condition management programmes), respectively a maximum of just over 18 weeks contrasted to, typically, less than 15 days attendance for clinical advice and job search guidance.

#### ASSESSMENT

The initial approach to meeting the client's needs is based upon an assessment undertaken at the weekly Head Injury Clinic. The aim is to obtain a detailed social and clinical history and a profile of current problems as perceived by the person and their family. Close family members are always requested to accompany a new referral.

The initial assessment comprises a Head Injury Background Interview (personal, family, educational, occupational and clinical history, course of recovery and review of current situation/needs), a Head Injury Problem Schedule (physical, sensory, cognitive, personality and social changes), a Head Injury Semantic Differential Scale (changes in self-concept and personality) and a Hospital Anxiety and Depression Scale (screening of emotional state).

Following the initial assessment further assessments may include medical, neuropsychological, nursing, occupational therapy, physiotherapy, speech and language therapy and specialist vocational, driving and family assessment programmes. The results of such assessments and the team recommendations are then discussed with the person's family in a feedback/planning session in the Head Injury Clinic. Subsequent rehabilitation may include a programme of individual treatment, for example, cognitive rehabilitation, occupational therapy, physiotherapy, psychological therapy, speech and language therapy, long-term psychotherapy, provided on either an in-patient or day basis.

The Programme Aims are addressed through inter-linked phases of vocational assessment, rehabilitation, voluntary work trials and long-term/supported placements.

The extended vocational assessment consists of a full three or four weeks of interviews, formal tests, group work and observation/ratings of work performance and behaviour as well as the application of other assessments tools as required, for example functional capability and work personality (Tables 4.1 and 4.2):

# Table 4.1: Functional Assessment Inventory

Adaptive Behaviour Motor Functioning Cognition Physical Condition Communication Vocational Qualifications Vision

(Crewe & Athelstan, 1984)

# Table 4.2: Work Personality Profile\*

Task Orientation Social Skills Work Motivation Work Conformance Personal Presentation

(Bolton & Roessler, 1986 a and b)

\* See Annex 5 for more detailed information.

# VOCATIONAL REHABILITATION

It is considered that subjects referred within 12-24 months of injuries and others, who have little or no specialist head injury input, are likely to require a period of vocational rehabilitation to prepare for a return to work. The aims of the rehabilitation programme are:

- 1. To facilitate further recovery and adaptation.
- 2. To assess realistic work potential.
- 3. To promote more accurate self-appraisal.

4. To foster positive work attitudes and behaviour.

Following the assessment, there is a feedback session with the client and family at which subject aims are addressed. Specific objectives are agreed and, where appropriate, with the referring agency. Rehabilitation programmes, usually of 12 weeks duration, consist of any combination of the following components:

- 1. Work preparation group.
- 2. Community rehabilitation activities.
- 3. Individual project work.
- 4. Rehabilitation counselling.
- 5. Vocational counselling.
- 6. Psychological therapy.
- 7. Personal issues group.
- 8. Cognitive rehabilitation group.
- 9. Brain injury educational programme.

In the final week of the programme, a formal review with the client, discussion with the Working Out Team and liaison with the Disability Employment Advisor and, where appropriate, other agencies, is conducted prior to a feedback/review meeting with the client and family in the Head Injury Clinic.

Following rehabilitation the client will usually progress to a voluntary work trial.

**Voluntary Work Trials:** A Placement Co-ordinator works with the client to find and set up a suitable part-time voluntary work trial, usually of up to 12 weeks in local services or businesses. These typically start half a day per week with a graded increase in line with progress. Voluntary work trials are usually run in parallel with a reducing rehabilitation programme, gradually replacing individual project work and community group activities.

The voluntary work trials serve a number of purposes, including independent assessment of work potential; identification of, and adaptation to, outstanding difficulties; the re-establishment of work routine and behaviours; supervised and graded re-building of self-confidence and an independent reference for those applying for jobs.

Trials are monitored by the Placement Co-ordinator (in some respects acting as a job coach but not attending work with a client). Any major difficulties highlighted in the trial are addressed within the rehabilitation programme. On completing the trial a review with the person and supervisor and, as appropriate, liaison with the DEA is undertaken to agree further plans. This is usually a long-term placement but in some cases a further voluntary trial will be required. Clients then graduate to one of a wide range of long-term placements depending upon their potential.

**Long-term Supported Placements:** these include full or part-time or casual employment, vocational training, supported employment, adult education, therapeutic earnings and voluntary work. The Placement Co-ordinator assists the client in identifying, finding and applying for suitable positions, in liaison with the DEA and other agencies.

Where appropriate, and as agreed with the client and employer, the Placement Co-ordinator will assist in setting up, monitoring and supporting placements. Support is also provided through a placement support group which promotes understanding and adaptation to the world of work. Once the placement is established there is a phased reduction in support from the Working Out team, although the client and family are followed-up routinely within the Head Injury Clinic at six monthly intervals. This provides an opportunity to establish long-term viability of the placement and identify and address any related or unrelated areas of difficulty.

Working Out it has not been replicated elsewhere. This is improbable on related grounds, the high level of staffing contributing to costs well in excess of what Jobcentre Plus pays for work preparation courses. An overview of Working Out is provided in Figure 1.

**4.3 Approaches to Vocational Assessment in the UK:** Unless a subject with TBI is referred to a specialist vocational rehabilitation agency in the UK, having access to their own clinical specialists, such as Working Out or Rehab UK, detailed clinical reports may not always be available. Vocational assessments are invariably based upon occupational tests. Within Jobcentre Plus, the occupational testing of customers with significant problems is undertaken by work psychologists and by occupational psychologists (supported by neuropsychologists) within Rehab UK, the Papworth Trust and Banstead Place. In contrast to the three weeks assessment programme at Working Out a Jobcentre Plus assessment normally takes a day. It is focussed on occupational interests and capability, not the gathering of clinical data and performance feedback. Working Out does not employ occupational psychologists but will call upon Jobcentre Plus psychologists if vocational testing is required. Apart from the limited number of contracted specialist brain injury vocational services there is no guarantee that Jobcentre Plus customers with TBI will receive a neuropsychological evaluation before being assessed for work or any other vocational programme.



Observations on the occupational testing of people with TBI

**Interests Tests:** Occasionally those with brain injuries may find interest tests vague because of abstraction problems or they may perceive the process as unrelated to work (Thomas and McCray, 1988). Nevertheless, there is a view that they can make a useful contribution in the initial stages.

Corthell (1993) opined: "The use of vocational interest inventories with a person who has a brain injury can provide valuable information about general as well as specific work interests and work-related needs. Regardless of the severity of the injury, the majority of persons with acquired brain injury can participate in vocational interest testing on one form or another. Picture interest tests require no or very limited reading abilities, or a written test that the consumer must either read or have read to them can be used."

Ability Tests: Depending on the individual's needs, the person undertaking the assessment may simply wish to obtain a general estimate of academic skills. This can be followed by a work sample that allows the evaluator to determine functional skills that are work related. There is debate as to the value of using work samples with a TBI population (discussed later in this Chapter).

**Aptitude Tests:** Aptitude tests commonly administered during vocational evaluation examine a wide variety of aptitudes or skills. Tests that assess motor speed and accuracy are especially useful for vocational planning. When a person excels in a particular area, the evaluator may like to further evaluate the person's skills by using work samples or the observational approach.

Results of aptitude tests need to be interpreted with caution in cases of TBI. A person may have an aptitude for various types of occupations as measured by standardised tests but may be hampered by a memory problem or an inability to accommodate various rapid changes in work method or routine.

A low score on an aptitude test may not necessarily indicate low aptitude. Instead, the result may be a function of other cognitive problems, such as the inability to attend to critical elements in pictorial stimuli. On an actual job, the person may perform adequately because it may not involve such fine discrimination.

**Work Samples:** Simulated work samples are designed to incorporate the procedure of a specific job (Power, 1991). The best known work samples in the UK are those produced by the Valpar Corporation (Annex 2). These were introduced into the Employment Rehabilitation Service during the 1980s and have subsequently been adopted by other agencies. Commercial work samples can be used with ease following appropriate training, although as Power (1991) emphasises, the predictive validity of work samples is limited because they are only simulations and do not present the many other interpersonal and physical demands that are associated with a certain job. The use of work samples for persons with TBI is a controversial topic. It has been argued that any evaluations of persons with brain injury should be done in the context of

the job in which they will be placed (Corthell and Tooman, 1985) because of difficulties in abstraction and generalisation and the fact that the social and ecological demands of an actual job site are far removed from the assessment centre. Rubin and Roessler (1995) discuss the advantages and disadvantages in respect of the use of work samples. Despite the drawbacks, Corthell (1993) considered that it is still possible to use work samples with the TBI population.

In short, work samples can provide a standardised approach to assessing factors such as assembly skills, organisation of materials, problem solving skills and a number of applied skills, such as the use of hand tools, measuring, weighing and filing. They can provide the evaluator with the opportunity to test hypotheses about work skills before attempting a situational assessment.

**Situational Assessments:** At the same time as there was a move in the UK away from assessment in situ (in a simulated setting in Employment Rehabilitation Centres) in the United States there was a move towards vocational evaluation for all disability groups using real jobs and integrated work settings (Wehman, et al, 1988a and b). Corthell (1993) considered that when working with a person who has sustained a brain injury, one has to take into account the issue of transferability (sometimes called 'ecological validity'). Transferred learning is often impaired following a head injury. Hence, one should attempt to evaluate the person in a job similar to the job in which he/she previously worked and where he/she would be placed, if not in the actual job. Wesolek and McFarlane (1992) consider that evaluations occurring in the actual work setting provide valuable insight into the person's coping skills and needs for further training. Parker et al (1989) stress the need for on-site or ecological assessment for people with TBI.

The most desirable situational assessment is a short placement in the targeted job or a similar job. If necessary, a job coach can be used until the job is learned or re-learned or until adequate accommodation can be made. If returning to the same work it may be possible to plan for a gradual return to work programme, in consultation with significant other parties. Thomas (1987) is of the opinion that placement in a situational assessment should only be undertaken after a functional skill evaluation, because perceptual memory and social deficits may cause a problem, if not a danger. Rubin and Roessler (1995) discuss the advantages and disadvantages of situational assessment.

On-the-job evaluation (OJE) provides an assessment of the functional abilities in actual work settings where disabled people are involved in activities considered to be compatible with their vocational interests and skills. In the UK this typically occurs with providers of work preparation

courses although the actual evaluation is unlikely to be formalised. The time span for such evaluations can vary considerably. Rubin and Roessler (1995) note that in the USA such evaluations *"usually take between one and two weeks"* although the time period can *"range for a day to a month or more"*.

Undertaking a job analysis and general job site inventory before placing a person in an OJE is an obviously sensible sequence but, apart from Rehab UK and Working Out, this is rarely undertaken in the UK. A job analysis provides profiles in respect of (a) vocational aptitude such as manual dexterity, (b) physical demands of the job, and (c) interpersonal skill demands. Ability to perform the particular job may suggest a potentially adequate performance in many other jobs with similar job analysis profiles. If the placed person is incapable of performing the job effectively, problem areas can be addressed. This may result in either (a) a placement with a more appropriate job analysis profile for the person or, (b) on-site support to enable the person to perform the job (Rogan and Hagner, 1990).

**4.4 Supported Employment in the UK:** 'Supported employment' gives rise to much confusion amongst those not familiar with this sector. During the 1990s the Employment Service adopted the title the Supported Employment Programme (SEP) to describe what was previously called its sheltered programme, in practice run on its behalf by organisations such as Remploy. This SEP title reflects a move away from segregated workshops into a reliance on employer placements through the Supported Placement Scheme (SPS), now rebranded Workstep, and the Remploy Interwork programme. Whilst these programmes are based on integrated settings there is no guaranteed long-term support. The extent to which this is provided varies.

For many years in the UK, local authorities and charities have had some work provision for people with disabilities, although the number of sheltered workshops has declined. In some cases a wage has been paid (usually on the lowest local authority manual grade) or a payment has been made compatible with benefits receipt, known as therapeutic earnings. Historically, the clients of local authorities have primarily been people with learning disabilities, not considered capable of work in the open labour market. Charities have tended to serve their own particular interest group.

When the Supported Placement Scheme began in the early 1990s many local authorities and charities saw this as an opportunity to increase the number of places they supported, and as a means of providing their clients the opportunity of earning a wage, and they became sponsors (and many charities began to sponsor a wide range of disabilities). The term 'supported employment' came to be seen to embrace all types of provision, from the Employment Service

programmes to charitable organisations whose clients may only receive a few pounds a week from undertaking therapeutic activity. For definition it is considered that a clear distinction needs to be made between open employment, supported employment (WorkStep or Interwork paying an open labour market wage), sheltered employment (local authority or charity workshop) paying a wage, and therapeutic work (now permitted work), comprising a payment compatible with the continuing receipt of benefits.

There are currently around 23,000 places in the Supported Employment Programme. Expenditure for 1999/2000 stood at £155.1m. with a further £5m. allocated for the year 2000/2001 and the following two years. Part of this additional payment was to pay for a series of projects to test and develop ways to improve progression into open employment as a consequence of the demand for places outstripping the supply (Honey and Williams, 1998). Historically, around 3,000 places per annum used to become available in the Supported Employment Programme (SEP). This was primarily due to people leaving , with only a small number moving into open employment, only 2.4% in 1996/97 (Jackson, Everatt & Beyer - undated). Given around 650 Disability Employment Advisors (DEAs), this has meant that each DEA, on average, has placed around 4 or 5 clients per annum into the SEP. Hence, moves to improve throughput and make the programme more widely available. There was, and remains, an assessment, selection and referral system:

- i. A vocational assessment: In many instances, staff within Jobcentre Plus recognise the limitations of the described 'snap-shot' vocational assessment model for people with TBI and will refer to a disability organisation or training provider for a longer-term work preparation course. At the end of this period there needs to be a positive recommendation.
- ii. The DEA will then have to identify a sponsor. There are essentially two models to the SEP. The first relies upon factory placements, as typified by Remploy factories. There remains about 7,000 people employed in such factories undertaking a wide range of work activity including furniture making, textiles and commercial packing, although the number is declining. The second model is the Supported Placement Scheme (Workstep from April 2001) or Remploy Interwork. This relies on employer placements. This placement model requires not only a host employer but a sponsor, usually a charity or local authority (unless an injured employee is retained, in which case the employer can be the sponsor). The sponsor is the legal contractual employer. This must be a local authority or a registered charity. Major charitable sponsors include the Shaw Trust, the RNIB and Scope.

In December 2000, with effect from April 2001, the Employment Service announced a radical overhaul of the Supported Employment Programme considered to have potential implications for the employment prospects of the TBI population. The most significant aspects have been:

- i) Eligibility criteria focussing on identifying people facing significant barriers to work and requiring additional support in order to work.
- ii) Setting progression targets to mainstream employment, put at 30% within the first two years for all new contracts and 10% for existing supported employees.
- iii) Changing the funding arrangements and replacing the existing occupancy-based mechanism said to discourage progression.

Whilst supported employment has been perceived as a 'job for life', from April 2001 this is no longer the case. The programme is now aimed at progression into open employment. The annual funding for sponsors was reduced from  $\pounds4,750$  to  $\pounds3,000$  per head. In addition, the sponsor now also receives an 'up-front'  $\pounds750$  fee for a Development Plan outlining the means whereby it is intended to move the disabled employee into open employment. All new contracts between Jobcentre Plus and sponsors are only for a two years period and subject to sponsors meeting the annual target of 30% progression into open employment. The sponsor now also receives a fee of  $\pounds500$  for every disabled person placed into open employment, and an additional  $\pounds500$  if they are still in employment six months later.

It will be noted that if the charges are successful (and there is no published evaluation) more disabled people will be served at a lesser cost with a much higher percentage moving into open employment. A concern is that it will lead to more capable disabled people being taken on board; even those who would not previously have been considered as requiring supported employment, at the expense of the 'harder to place'. Figure 2 represents an overview of employment related activity not in the open labour market.



#### Figure 2: Overview of Employment Activity Not in the Open Labour Market

**4.5 Approaches to TBI Vocational Rehabilitation in the United States:** It is considered that whilst there is evidence of specialist TBI VR services in the UK having adopted some aspects of American experience, particularly focussing on skill generalisation and transfer, there is still much that can be learned from the experience of practice there based upon research evidence. The American vocational rehabilitation system is described in Rubin and Roessler (1995) and, for the sake of brevity, can only be briefly addressed here. The significant difference between US and UK practice is that in America disabled people are statutorily entitled to vocational rehabilitation services. Hence, there are extensive services. The Vocational Rehabilitation Act amendments of 1986, to the 1973 Act, define eligibility for rehabilitation services and the concept of employability as *"The determination that, with the provision of vocational rehabilitation services, the individual is likely to enter and return, as a primary objective, full-time employment, and when appropriate, part-time employment, consistent with the capacities and abilities of the individual in the competitive labour market or any other vocational outcome the Secretary may determine consistent with this Act."* 

The amendments also require Individualised Written Rehabilitation Programmes (IWRPs) introduced in the 1973 Act:

- (a) Be developed on the basis of a determination of employability designed to achieve the vocational objective of the individual.
- (b) Specify the provision of rehabilitation engineering services where appropriate.
- (c) Assess and re-assess the need for post-employment follow-on services after case closure and to provide a statement detailing how these services will be provided or arranged through agreements with cooperative agencies.

In the United States supported employment has a different connotation to that historically understood in the UK, although it may appear similar. It is defined in the 1986 amendments as "competitive work in integrated work settings for individuals with severe disabilities, for whom competitive employment has not traditionally occurred and who, because of their disability, need intensive, ongoing services to perform such work". The significant differences are in respect of "intensive, ongoing services" and the total commitment to "integrated work settings".

**Stages in TBI Vocational Rehabilitation.** This process is likely to involve a number of steps, initially deciding whether or not there is sufficient information to establish an initial goal and gaining agreement on this target. Corthell (1993) describes the steps in detail with regard to using gathered data for goal setting and dealing with problematic issues which may occur, such as failure to agree on a preliminary goal.

Whilst there will be variation service delivery and achieving employment outcomes are likely to contain some element of the vocational rehabilitation process postulated by Kay and Silver (1988):

#### Stage 1: Pre-vocational preparation

Many TBI vocational rehabilitation programmes consider that even before a head-injured person is ready to take on a vocational evaluation and placement, a process of preparation is required. The purpose of this process is to prepare the person to assume a new employment identify with appropriate aspirations. The goals are ones of awareness and accommodation. Awareness involves recognition of the nature, extent and impact of residual strengths and limitations and the acceptance of these implications for future employment. This may involve a recognition of a 'changed self' that is considered crucial to a positive rehabilitation outcome. Accommodation involves the remediation, whenever possible, of existing cognitive and behavioural deficits and compensation, through modification of both environment and habits, for deficits that cannot be remediated (although, at this stage, accommodation seems a very ambitious target and, without the next stage, involving assessment, it is difficult to see how the deficits can be accurately assessed and appropriate remediation determined). It is argued that failure to recognise the need to go through this pre-vocational process is the main reason why many vocational programmes fail with head-injured clients.

### Stage 2: Vocational Assessment and Work Trial

Even after a period of pre-vocational preparation, many head-injured people are likely to lack a set of consistent work skills and habits tuned to particular work requirements. Hence, the next step in vocational rehabilitation is specialised vocational assessment and intervention. This assessment includes both modification of standard instruments and, more importantly, **an** 

**extended situational assessment or job trial**, during which the client's on-the-job behaviours can be directly observed and addressed. The intervention should consist of "fine tuning" work-related interpersonal behaviours, as well as developing compensation strategies to allow the head-injured person to meet the job requirements and relate appropriately to their peers and supervisors.

#### Stage 3: Vocational Placement and Follow-Up

In the final stage, placement(s) are (said to be carefully) chosen in a working environment that optimises the client's strengths, whilst avoiding demands in the deficit areas. There is often a prolonged period of follow-up with back-up crisis intervention.

It will be appreciated that these stages are idealised and, in practice, how they are delivered will vary.

#### Elaboration of Stage 2:

It will be noted that the second stage of the discussed model involves assessment. In turn, this may rely upon the administration of psychometric tests. In this respect, it is considered that one has to keep in mind the distinction between the purpose and nature of neuropsychological testing and occupational testing. Neuropsychological assessment invariably precedes a vocational assessment and in a clinical setting may be perceived as part of a holistic rehabilitation programme. Those who receive such an assessment within a clinical setting may be more disabled than those subsequently proceeding to a community-based occupational one. (However, such a proposition has not been subject to research-based evidence in the USA or UK).

Evaluation is perceived to be an initial step in a screening process, as such it is conceptualised by Balutanski (1993) as a time limited component and includes screening (for suitability) and gathering medical, psychological, educational, social, vocational and other relevant data. As well as demographic data. A comprehensive evaluation may start with formal and informal measurements of the areas pertinent to work, particularly cognitive and functional abilities as well as such matters as self-concept and adaptability to job requirements.

Corthell (1993) considered that due to the multiplicity of deficits evident in those with brain injury, the tasks and roles of those undertaking a vocational evaluation are more complex than with other disabilities and that effective vocational evaluation requires individualised planning, flexible and variable procedures in actual/realistic job situations and repeated evaluations over time as a consequence of physical, cognitive and behavioural changes steadily occurring.

Hence, whilst it is apparent that not all TBI vocational rehabilitations programmes will be the same it is considered the US approach is reasonably represented by highlighting the significance given to the obtaining of clinical/psychological characteristics alongside occupational factors. In the UK a clinical rehabilitation programme may address such factors as part of a community integration programme, any observations on employment often only made by way of inference and work preparation agencies may or may not have such information made available to them. Another common factor in the USA is that at the assessment stage, not only is there the use of occupational tests to identify abilities, aptitudes and interests, but also ones of learning style and worker personality.

Once the process of evaluation and vocational preparation has been completed a person should be mentally and physically prepared for a work placement. The first step in this process is to identify a suitable work placement.

**USA Supported Employment:** In the USA supported employment theory and technology emerged from a number of research and demonstration projects of the late 1970s and early 1980s (Bellamy et al 1986) and became a vocational rehabilitation option by way of the 1986 amendments to the 1973 Rehabilitation Act. In contrast to rehabilitation alternatives that focus on delivering services before job placement, supported employment concentrates almost all the components of vocational intervention, training, counselling and support, at the job site. This enables the employment specialist, or job coach, to help clients overcome their inability to generalise or retain skills and other major social, behavioural and physical problems that have typically hindered their ability to maintain employment (Kreutzer and Morton 1988, Wehman et al 1989a). The commitment to intensive job-site training and long-term support distinguishes supported employment from traditional vocational placement models. A fundamental feature of the supported employment model is the use of a job coach. The role of a job coach essentially comprises four components; job placement, job site training, continuing assessment and follow-up.

Clients receiving services through supported employment are matched with a real job following behavioural and neuropsychological assessment. Clients are not excluded from consideration for placement, except in the case of medical contra-indications, and a no 'employability rating' is assigned. An assumption of this approach is that all referrals are potentially employable. Before and during initial placement the client is paired with a job coach to assist the client acquiring both task-related and other work behaviours. Cognitive and interpersonal training occurs on the job as the client learns the job tasks. The amount and type of intervention is based on the requirements of the job and the client. This may range from continuous presence

on site during the initial stages to a gradual complete fading from the job site once the client is able to independently perform the job according to standards set and agreed with the employer. 'Follow along' monitoring and intervention occurs that may be increased or decreased as problems are encountered and resolved. It is apparent that a rationale for the development of the *in vivo* approach relates to criticism in respect of the transferability and retention of remediated skills acquired in a clinical setting. Wehman et al made the point that "Clinicians implementing such programs (holistic treatment) often assume that the cognitive skills laid in pre-vocational training were generalised to the patient's employment situation."

Five features of traditional vocational evaluation have been called into question by supported employment practitioners:

- 1. The use of the vocational evaluation process as a screening mechanism to select or reject those considered able or unable to benefit from vocational services. Wehman (1986) considered that supported employment models have been designed to serve individuals who do not necessarily meet traditional criteria for "job readiness" or "employability". It is argued that evaluation designed to accept or reject a person for services have no place in supported work programmes and, indeed, advocates of supported employment consider placement in a sheltered setting as a form of segregation and, therefore, an unacceptable rehabilitation outcome (Rusch, 1986; Brown et al, 1986).
- 2. It is argued that a traditional vocational evaluation relying on psychometric tests, work samples and in-house situational assessments for the purpose of diagnosis, placement or prediction (Rudrud, Ziarnik, Bernstein and Ferrara, 1984) are largely artificial and simulated, bearing little resemblance to actual community jobs.
- 3. Reliability and validity data regarding many traditional assessment tools is said to be either absent or lacking (Botterbusch, 1980).
- 4. It is argued that the settings in which evaluations are conducted have traditionally been closely associated with sheltered work facilities and that many individuals become subtly socialised into the setting and workshop tasks.
- 5. It is maintained that vocational evaluation has traditionally been viewed as a separate and discreet component of the rehabilitation process, with little follow-up data collected to find out where evaluees are eventually placed or how well they do (Pruitt, 1986). In

contrast, evaluation in supported employment is one continuous integrated process, that is, rather than being a discreet component, evaluations occur prior to job placement and throughout the term of employment.

Fawber and Wachter (1987) provided an early description of the move away from a clinical rehabilitation setting to working in situ. They considered that the traditional vocational rehabilitation system in general provided services to the mildly head injured population, since they are more readily able to make the transition from a specialised medical rehabilitation programme to a community without specialised services.

They described the traditional vocational rehabilitation service delivery model as consisting of vocational evaluation, vocational training and job placement, in that order. This model presupposes that the client is capable of transferring what has been learned from one setting to another. Fawber & Wachter (1987) noted that the deficits of many clients included impaired memory, slow information processing skills and impaired ability to generalise newly learned information limiting their ability to transfer information from one setting to another. Hence, compensatory strategies could hold the greatest promise for improving vocational outcomes as they do not rely on the transfer of learning from the pre-vocational to the vocational setting. Fawber and Wachter (1987) adapted the supported work model outlined by Wehman and Kregel (1983) and encompassing four components (1) a paid job; (2) work in an integrated, competitive setting; (3) support for the life of the client's employment; and (4) a disability severe enough to warrant such specialised placement. They considered that the traditional vocational rehabilitation model of vocational evaluation, vocational training and job placement could be modified to vocational evaluation, followed by job placement, then training for the client at the job site to perform that job. Awareness of the implications of deficits and development of appropriate behaviour for community based work were considered critical issues to be addressed during the evaluation and placement process. Fawber and Wachter considered one advantage of the 'place-train' model is less concern with generalisation, since the training occurred at the job site. Another is that the client does not have to be as 'work ready', since certain work adjustment issues can be dealt with on the job. It was also considered that such an approach appealed to the clients, since there was movement from the rehabilitation facility to a real-life setting in the community. They also found that in the `real world', clients displaying inappropriate work behaviour more readily accepted supervisory criticism from someone outside the rehabilitation facility.

Fawber and Wachter recognised that, whilst competitive employment is ideal, in reality many people sustaining TBI are incapable of such activity. They broadened the definition of

placement to include community re-entry, not only in competitive employment but sheltered and volunteer employment. It was considered that no single placement technique was the best for all clients, considering the heterogeneity of the head-injured population. Examples of preparation included task rehearsal and the use of video taping to illustrate slowness. It was further considered that job coaching was vital for successful placement.

Fawber and Wachter advocated an incremental approach to job placement, based on the notion that the demands of a competitive job are significantly greater than those found in most rehabilitation facilities and represented "almost a quantum leap" for many head-injured clients. In certain circumstances, it was considered appropriate to initially seek volunteer positions on a part-time basis, gradually transferring the client to a part-time and, ultimately, a full-time job.

In summary, the following steps are recommended by Fawber and Wachter (1987):

- 1. *Selectivity.* Any placement must be consistent with the client's cognitive, physical and psychosocial strengths and weaknesses. In addition, the client's interests, abilities and aptitudes must also be taken into account.
- 2. *Job analysis.* The demands of the job can then be compared with the strengths and weaknesses of the client prior to placement.
- 3. *Placement site education and training*. This also includes advice to the employer and supervisor.
- 4. *Staff support.* Effective use of the supported work model assumes the availability of a knowledgeable staff member to function as a liaison between the employer and the rehabilitation facility.
- 5. Family support.

Although there are a number of variations to the supported work model, two of the most popular are the train-place, train-follow up (Lagomarcino, 1986) and the place-train-follow up (Wehman, 1986) approaches.

# Train-Place, Train-Follow up (TPTF)

This approach has been described as having four major components:

- 1. Surveying potential employers to determine important vocational and social survival skills that need to be trained;
- 2. Training individuals to perform such skills;
- 3. Placing training clients into competitive employment; and
- 4. Providing long-term follow-up training.

# Place-Train, Follow up (PTF)

The place-train, follow up approach also contains four major components:

- 1. Job placement;
- 2. Job-site training (and advocacy);
- 3. On-going assessment; and
- 4. Job retention.

In respect of developing this model major aspects of component 1, the job placement process include:

- i. matching job needs to client abilities or potential;
- ii. encouraging employer communications with the client;
- iii. encouraging parental communications if applicable;
- iv. establishing travel arrangements or providing travel training; and
- v. analysing the job environment to verify all potential obstacles that may arise.

There are several key points. Firstly, effective placement is based on an analysis of work requirements. This process has been variously referred to as ecological analysis (Wehman, 1983), top-down curriculum (Brown et al, 1979), or job analysis (Van Der Groot & Worrell, 1979). Details in respect of job requirements, characteristics of the work environment, and other features that may influence job retention are considered essential for matching job requirement with client abilities.

The second key point is that job placement can take place with clients who do not possess all the necessary work, cognitive or social skill competencies for immediate job success. The strength of the supported work model is that whoever is making the placement knows that the job site help will be available once the placement formally occurs. This is a significant departure from traditional placement approaches that require the client to be "job ready".

A third important element is that travel, financial benefit, job interviews and other non-work

related factors are actively managed in the job placement process. Within a more traditional placement framework, it is often accepted that the client or parents handle most of these concerns if a job is made available.

Job placement is frequently conducted not by a specialist in placement but by a job coach, who handles not only placement but all aspects of the supported work model process. A virtue of this approach is its continuity across all components of the model.

Component 2, job site training and advocacy, is an essential feature of the PTF model. Two major processes are involved: (a) behavioural training of skills, and (b) advocacy on behalf of the client. There is a limited amount of research literature in respect of the application of behavioural training to vocational skills in the supported work model. Rusch has undertaken research in respect of selected work skills (Schutze, Joste, Rusch & Lamson, 1980), time-telling (Sowers et al, 1980), time-on task on the job (Rusch et al, 1980a), reducing inappropriate behaviour (Rusch et al 1980b), as well as selected communication training (Karlan & Rusch, 1982).

Advocacy or promotion of the client is the other principle feature of this component. In some cases, head injured workers will need less time spent on training and more time spent on orientation to the new job site. Orientation might involve such activity on the part of the job co-ordinator as locating the cafeteria or vending machines, working out communication problems between client and co-workers, communicating with parents about job progress, and counselling with the client on improving general work behaviours (e.g. getting to work on time, appropriate appearance).

Component 3 of the PTF model differentiates the supported work model from more traditional approaches to job placement is by providing continuing assessment and/or monitoring of client performance.

There is a recognised need to gauge the employer's perceptions of the worker's performance once a placement is made. There are usually two major indicators of performance: supervisor evaluation data and client data. Although quantifiable data are most desirable, in some instances verbal feedback to an on-site staff person is considered sufficient. The amount of assessment data collected is related to variables such as the ability level of the client, amount of staff available for data collection, and above all the specific need for data to evaluate a certain problem. In the final part of the PTF model follow-up is consistently referred to in the literature, yet it is unclear how much follow-up by way of frequency of employer contact, communication with clients, and replacement into an alternative job is provided.

In one of the few papers addressing follow-up, Hill, Cleveland, Pendleton, and Wehman (1981) list regular on-site visits to employers, phone calls, periodic reviews of supervisor evaluation, client progress reports, and parent evaluation as ways in which to promote retention.

**4.6 Job coaching:** In the USA a feature of the supported employment approach is a reliance on job coaches. They may undertake the following tasks:

- i. Prior to the client commencing work, the job coach has to learn about the job itself, and the rules and procedures of the workplace in order to model these for the client. Initial training and supervision is undertaken by a job coach, and does not rely on the availability of a foreman or other members of staff. In some jobs, typically in production work, the job coach has to be responsible for maintaining productivity whilst a client is acquiring basic job skills.
- ii. The job coach liaises with other members of the workforce, acting as an advocate for the client when necessary, as well as modelling the appropriate interpersonal skills relevant to workplace. This may mean that, prior to the trainee starting work, the job coach has to familiarise the supervisors and other employers with the nature of the client's difficulties likely to be encountered once the client starts work.
- iii. The job coach provides feedback to the client to promote awareness of interpersonal behaviour, speed and quality of learning and any other information required to develop the work role. This may involve the job coach being aware of: a) stamina; b) mood (to prevent emotional outbursts) or c) other characteristics displayed by the client which might interfere with the work role or adversely influence other employees.
- iv. The job coach provides an additional pair of eyes and ears for the trainee and, more importantly, monitors the behaviour, helping the clients evaluate information in the workplace essentially to develop not only work skills but also appropriate interpersonal ones.

In the UK job coaches are primarily involved in pre-placement activity whereas in the USA they are used more to work *in situ* with placed clients on employers' premises. This approach would appear to address issues relating to the generalisation and transfer of skills from a clinical to a vocational setting, deal with any matters relating to appropriate social skills and provide advice and guidance to co-workers and employers. Its efficacy is maintained by advocates such as
Wehman and colleagues (1988 a and b; 1989, 1990a,b,c, 1993a, 1995). The development of job coaching in the UK mirrors the early use of employment specialists/job coaches in the USA where they were initially employed during the 1970s and 1980s to assist the placement of people with learning or psychiatric disabilities, later moving into the brain injury sector. Initiatives in the USA were first identified in the UK by local authorities and voluntary organisations recognising the value of being able to move their clients from segregated sheltered workshops into work activity integrated within mainstream open employment.

In 1997 the Enham Trust, based in Hampshire, and the Papworth Trust in Cambridgeshire, participated in a European Union funded Employment-Horizon initiative to produce manuals providing training for job coaches and a best-practice workbook (Deal & James-Brown, 1997; Morritt & Clark, 1997). These manuals give some indication as to the work of job coaches in the UK, lately increased in number by the introduction of the progression system into the Supported Employment Programme.

Consideration of the manuals leads one to conclude that the primary activity of job coaches in the UK is one of placement, although Deal and James-Brown (1997) define a job coach as "an employment specialist who facilitates disabled people in accessing and functioning and integrating in work settings through training, development and support within the employers' environment." There is an emphasis on placement, as opposed to the development of compensatory strategies, in the Papworth Trust workbook (Morritt & Clark 1997). It is recognised that job coaches work with clients with a range of disabilities. The issue for this study is in respect of whether or not the unique needs of people with TBI are being fully met within the general provision of 'training, development and support'. Deal and James-Brown define the job coach functions as follows (Table 4.3):

#### Table 4.3: Job Coach Functions

	Function
а	Identifying and analysing national and local labour market trends
b	Identifying job vacancies suitable for client group
С	Obtaining/creating profile of client
d	Making contact with employer
е	Learning and analysing jobs and identifying appropriate training method in line with company culture
f	Training and coaching clients using 'natural supports' where possible
g	Supporting the client to become integrated into the workforce
h	Giving feedback to client and employer
i	Producing appropriate documentation
j	Monitoring client progress long-term in a manner acceptable to client, employer and Supported Employment agency

Deal and James-Brown (1997)

This list begs the question as to what extent 'support' involves the development of compensatory strategies other than the use of 'natural supports'? There is no recognition that people with an acquired brain injury may need additional training to, say, people with learning disabilities and mental health problems. (On the other hand, it is acknowledged that there are limits to the extent a manual of this nature can address the needs of specific disabilities.)

Traditionally job coaches in the USA have worked with clients in low-skilled occupations although Brantner (1992) describes job coaching for TBI subjects employed in professional and technical occupations. The coach's skill is not so much in respect of being able to learn the tasks of the job but being able to use a number of specialised instructional techniques to teach the job to the client in the workplace. They may spend a number of weeks or months doing this and, over a period of time, often work with the same client in a number of different jobs with different employers.

The Papworth coaches noted that clients on their programmes tended to go into 'medium to high skilled jobs' (Morrit and Clark, 1997) that, by definition, contain tasks that cannot be performed by a person untrained in that job. As such, they suggested that it is unreasonable to expect anyone to quickly acquire a working knowledge of such activity and, as a consequence, they experienced rarely being called upon to do *in-situ* job coaching. They further noted that once a programme is completed they would rarely see the clients again. They described their role as being primarily one that places the emphasis on coaching clients *into* jobs (Table 4.4),

starting with an advisory role and moving on to facilitating placement. They also stated that "discussion with other job coaches working in the UK and EU have shown us that in some areas the skills we practice do not differ greatly from those practised by people working with other client groups".

	Activity
а	helping clients enhance existing skills and acquire new ones
b	helping clients re-learn their employability skills
с	discussing changes in the labour market and how they could affect the type of work the client is aiming for
d	training in job search skills
е	training in job application skills
f	interview preparation training

#### Table 4.4: Into-Job Coaching

Morrit and Clark (1997)

Other activity, not directly working with the clients, involved approaching employers, arranging work experience placements, soliciting information about job vacancies, arranging outside placements (involving access and job analyses), preparing clients for placements, monitoring, evaluating and record-keeping. They also added that they were frequently asked about benefits and legislation.

Deal and James-Brown (1997) recognised a need to take a pragmatic approach to the level of job coaching likely to be provided (in the UK), noting that "whilst in the ideal world, job coaches should provide ongoing support to the client in the work setting, in a manner appropriate to the individual, with daily contact of a one-to-one nature (if that is right for the client), the reality is often very different to this. Most Supported Employment agencies will simply not have the funding to provide intensive, permanent support and will therefore expect, after an initial time-limited period, the client in the workplace to take on a degree of autonomy." They added "Natural supports from the client's workplace are vital to this process and must therefore be included as soon as possible in the process of support for the client." They suggested that the role of the job coach is basically to support the client's work placement through a process of learning about how best to work with the client and secondly, to identify what natural supports are easily accessed and can be used long-term.

There is American literature that lends support to such an approach. Fabian & Luecking (1991) considered that the reliance on a job coach may create problems for both employer and

employee as a consequence of intrusiveness, a presence which is said to raise the issue of stigma in the workplace and questions the eventual attainment of integration (Nisbet & Hagner 1988); fading the job coach from the work environment and the related issue of dependency (Nisbet & Hagner 1988); retraining and subsequent promotional opportunities when the job coach has to re-enter the site and the issues of intrusiveness and fading emerge again and job coaching possibly being a high cost means of facilitating employment opportunities (Lamb 1986).

Fabian & Luecking (1991) reported that such problems have given rise to alternative models of support incorporating the use of natural workplace supports, such as co-workers as job trainers (Shafer 1986), promoting mentoring relationships between the supported employee and others in the work environment (Nisbet & Hagner 1988) and using environmental cues as a means of sustaining new behaviours by the supported employee.

It is suggested that the employment of job coaches and the use of such methods are not exclusive activities - and that job coaches working *in situ* may deploy such approaches if feasible. Summarising the work and *potential* work of job coaches one has the following activities.

a) Marketing Clients to Potential Employers: In all organisations employing job coaches a fundamental work activity is placing clients. In turn, this involves an appropriate marketing strategy. Whereas the training recommended by Deal & James-Brown (1997) offers support in respect of approaching employers it does not consider how to explain the specific problems created by TBI (although not designed to do so).

**b)** Employer Contact and Training: There are reasons why an employer of someone sustaining brain injury may retain an interest in their employment. The Disability Discrimination Act (1995) requires employers to make 'reasonable adjustment' to facilitate employment (and there are unlimited penalties), besides which, many brain injured employees retain skills, knowledge and experience that can continue to be utilised, and recruiting more staff can be both time-consuming and expensive. Although there is a need for a vocational agency to establish a good working relationship with an employer intervention may occur so long after injury in the UK, and after the termination of an appointment, that rarely occurs. There may also be limited resources to do this. Client support needs to be focussed on the nature and needs of the employer and the particular problems of the employee. As the majority of individuals sustaining TBI do not have visible signs of disability, it is likely that their employment capability will not be

understood. Employers' experience of injured or ill workers returning to work is likely to be one of them 'getting better'. Few employers of a brain injured person are likely to be aware of the need for continued monitoring.

c) Developing compensatory strategies: A significant issue is considered to be the way job coaches working with clients doing an actual job can use appropriate compensatory strategies to enhance their performance. Compensatory strategies refer to a group of techniques, procedures and devices that allow an individual to overcome a cognitive, physical or emotional impairment and successfully perform a specific task or behaviour (Parenté and DiCesare, 1991). Wehman et al (1989a) provided a list of compensatory strategies that they considered helped them improve the employability of their clients, for example:

- Using visual cues, such as charts and check-lists.
- Using written instructions as a supplement to verbal ones. Additionally, it is stated that a client will often learn a task more efficiently if it is demonstrated rather than simply explained.
- Verbal rehearsal, to be initiated before a problematic situation. An example provided by Kreutzer and colleagues (1988) is, in respect of the client's difficulty keeping himself from swearing to co-workers. He was talked through rehearsal of appropriate behaviour with the employment specialist.
- The use of notebooks for recording important information.
- Attention may be improved by reducing distractions in the work environment, taking rest breaks and getting sufficient sleep each night.
- Watches and electronic devices with alarms can be used as reminders of important daily events.

Compensatory strategies are suited to vocational applications because they can be designed and implemented at the job site and may result in an immediate improvement in production and self-esteem. To be effective, compensatory strategies must be developed on an individual basis with a knowledge of the work environment. Typically, the first step in developing compensatory strategies is reference to a neuropsychological evaluation to determine the client's strengths and weaknesses with regard to areas having a direct implication for potential work performance. The second step is a job or task analysis; that is an evaluation of the work setting and the step-by-step process necessary for work completion. The next step involves the development of a series of specific instructions and/or materials to be utilised by the client.

At least four categories of compensatory strategies have been used in vocational settings:

	Category
1	job analysis (Callahan and Garner, 1997)
2	environmental engineering (Parenté et al, 1994; Hirsch et al, 1996; Sachs and Redd, 1993)
3	prosthetic aids (Kirsch, 1987; Parenté and DiCesare, 1991)
4	cognitive orthotic devices (Parenté and DiCesare, 1991)

Table 4.5: Categories of Compensatory Strategies Used in Vocational Settings

'Slotting' strategies into a specific category is not a constructive activity and one it is suggested that some interventions can go in more than one distinct bracket. To the list this study one can add: (5) cognitive remediation (Kreutzer et al, 1988) as an appropriate intervention and support strategy although many would perceive such intervention as a pre-placement activity.

It is beyond the scope of the study to develop Table 4.5 in respect of the strategies to be deployed with commonly presenting problems but this information is available in the literature on denial (Johnson, 1987; Najenson et al, 1980), behaviour and work adjustment training (Ballack and Hersen, 1988; Lewis and Bitter, 1991), communication difficulties (Isaki and Turkstra, 2000; Curl et al, 1996), memory (Van den Broek et al, 2000; Sohlberg et al, 1994; Glisky and Schacter, 1986; Isaki and Turkstra, 2000; Burke et al, 1994; Phillips et al, 1991), executive functions (Burke et al, 1991).

Nisbet & Hagner (1988) noted that one support model (the job coach) will not be appropriate for every person's needs and that a series of different options are required that may include:

- (a) Mentoring.
- (b) "The training consultant option" (understood to mean bringing in the company's training provider to provide *in situ* support rather than the job coach doing this).
- (c) Job sharing.
- (d) The attendant option.

Table 4.6 summarises the approaches:

Option	Support person/role		Responsible to	Agency role
	Initial	Ongoing		
Job coach	Job coach trains	Coach fades; worker is presumed independent	Agency	Direct: training and follow-up
Mentor	Job coach trains; supervision is transferred to mentor	Mentor remains on- site, providing support and supervision	Company	Indirect: matching and support for mentor
Training Consultant	Job coach trains with the co-workers/supervisor	Co- workers/super visor provider support, supervision, and additional	Company	Indirect: consultation
Job sharing	Job coach identifies job sharer, then trains and assists	Job sharer remains on- site	Agency and Company	Indirect: matching; support for job-sharer
Attendant	Attendant trains and assists (may need some assistance from job coach)	Attendant remains on- site at worker's discretion	Worker	Possibly initial training; afterward little or no intervention

#### Table 4.6: Community Employment Support Options

Nisbet & Hagner (1988)

**4.7 Summary and Main Points:** A purpose of this chapter has been to provide an understanding of the nature of current disability employment services for people with TBI in the UK as a basis for understanding the experience of the study sample. A second aspect has been to develop some understanding of TBI VR practice in the United States with a view to informing UK practice and a third to introduce job coaches.

In response to the questions asked at the start of this Chapter in respect of how the TBI population are identified in the UK and how employment services are delivered for them it will be apparent that development of employment services for people with TBI have substantially developed without reference to their specific needs, only during the 1990s have specialist services been established but these remain limited.

TBI vocational rehabilitation has developed in the UK outside the NHS (with the exception of Working Out). The provision of specialist TBI vocational services in the UK remains limited,

particularly in England and Wales. The Working Out programme at the Aylesbury NHS Trust was the first to incorporate specific vocational rehabilitation, including occupational trials, alongside clinical rehabilitation. A similar approach to Working Out has also been developed by Rehab UK at its Brain Injury Vocational Centres (but without the same intensive clinical services, hence, to a degree, acting as a "follow-along" vocational service to clinical intervention). A distinguishing feature of the approaches of these service providers is the arrangement of sequential activities beginning with clinical rehabilitation/treating cognitive deficits, then progressing to supported occupational trials. The provision of specialist vocational rehabilitation services for people with TBI in the UK remains limited. Generic work preparation programmes may not meet their needs. NHS Trusts have not taken up recommendations made by the House of Commons Select Committee on Health (2001) to promote the Working Out model. On the other hand, this may be explained by the complexity of the model, the duration of courses and costs.

The government has recognised that there is a problem with regard to the growing number of people in the UK in receipt of incapacity benefits and a response is to develop condition management programmes. However, at the time of writing there are no specific proposals for people with TBI.

Supported employment would appear to offer a suitable vehicle for *in situ* assessments and the vocational rehabilitation of people with TBI but there is no evidence in respect of the TBI population participating in this programme in any great numbers. Recent funding changes may work against this but this is a speculative matter without up-to-date evidence in respect of the characteristics of current participants.

The equivalent development of the supported employment approach articulated by Kreutzer et al (1988) has not occurred in the UK. Whilst aspects of such an approach have been adopted by Rehab UK, particularly using job coaches to develop in-situ compensatory strategies, this is not undertaken in the same way. Rather than job training beginning before employment (although this can occur) in the USA job coaches accompany the TBI client to the work site and provide the necessary cognitive and behavioural interventions on the job. Job coaches provide on-going assessments and problem-solving to facilitate retention of employment. This model appears well suited for individuals who have good awareness of their deficits, few neurobehavioural problems and are amenable to learning job skills. Other people with TBI may have relatively intact job behaviours but need psychological support for themselves and consultation with the employer on how best to manage the employee with TBI.

(Whilst time and costs issues can not be ignored there are a number of reasons as to why job coaches are considered invaluable, albeit the strictures of Deal and James Brown (1997) in respect of resourcing raise practical and ethical issues. A significant issue is the amount of time to spend on clients. The work of Wehman and colleagues (1993) suggest that in their programmes job coaches were spending more time with clients likely to fail than succeed at work).

A brief review of TBI VR practice in the USA indicates that it is underpinned by legislation requiring Individual Written Rehabilitation Plans (IWRPs). On the face of it there is a focussed approach on assessing and ameliorating common variables affecting employment (as opposed to clinical services facilitating general community re-entry) and there are different placement strategies, particularly relying on the development of in situ compensatory strategies and 'follow-along' services supported by job coaches.

One approach developed in the USA to overcome the problems of generalisation, transfer and maintenance of skills from a pre-employment setting, for example clinical rehabilitation, to a 'real' job is the supported employment approach.

There are four major assumptions behind this supported employment model:

- i) Vocational intervention, job site training and counselling should occur at the place of employment, as contrasted to a therapeutic setting.
- Rehabilitative intervention such as cognitive retraining, work adjustment and social skills training required to obtain and sustain a placement are best provided at the job site when the person is initially employed.
- The job setting should involve paid employment for productivity based on the same standards that are applied to non-physically or mentally disabled co-workers.
- Supported employment interventions should be long-term, preferably permanent, means of achieving and sustaining job stability for a person with severe disabilities who are, or likely to be, unemployed.

Of interest is the fact that VR practice in the USA is based upon research-based evidence. Because of differing legislation, health-care systems, cultural, social security and vocational rehabilitation systems and resourcing it is not possible to simply 'copy' US practice in the UK but it is considered sensible to recognise good practice. In this respect it is particularly noted that extensive research has drawn a distinction between trying to predict the future employment of people with TBI to focussing on individual barriers to employment and developing compensatory strategies, enhanced by *in situ* job coaching and/or the use of 'natural supports'.

# Part 2

# METHODOLOGY AND RESULTS

Chapter 5	Research Methodology and Practical Issues	153
Chapter 6	Questionnaire Construction and Data Collection	175
Chapter 7	Results: The Relationship Between Commonly Found Variables Reported in the Literature and a Return to Work Amongst the Study Sample	191
Chapter 8	An Analysis of Three Case Studies From the Study Sample (Annex 9) and an Evaluation of Working Out's Vocational Rehabilitation Strategy	221
Chapter 9	Revisiting Back to Work	266
Chapter 10	Addressing Job Retention Issues and a Framework for Mapping Employment Outcomes Following TBI	276

#### **CHAPTER 5**

#### **RESEARCH METHODOLOGY AND PRACTICAL ISSUES**

5.0	Overview	153
5.1	The Choice of Methodology	154
5.2	Realistic Evaluation	161
5.3	Identification of the Study Sample	171
5.4	Summary and Main Points	173

**5.0 Overview:** The main purpose of this chapter is to explain the reasons for selecting the chosen methodologies, a survey evaluating the post-injury employment histories of the study sample and the application of a realist approach applied to three case studies. It builds on the literature review in Part 1 through applying methodologies that allow for the consideration of variables reported to influence outcomes whilst taking into account factors unique to the UK labour market (with an underlying premise that an in-depth understanding of the histories of members of the study sample will positively contribute to a model TBI VR programme).

Chapter 5.1 commences with a review of the methodological approaches used in employment and disability studies and describes how the decision to adopt the pluralist approach was made. This includes reference to the use of a randomised controlled trial (RCT) in the Back to Work (BtW) pilot condition management (VR) programme for Jobcentre Plus customers with chronic pain conditions. (Back to Work failed to recruit and retain a sufficient number of subjects to deploy regression techniques and justify the choice of methodology. This illustrates the fact that it is not just a question of choosing "the best methodology" for establishing relationships but one of taking into consideration practical issues with regard to the recruitment and retention of the study sample, a matter highly relevant to the 'rolling-out' of any VR programme).

Chapter 5.2 considers the application of the realist approach and Chapter 5.3 the identification of the subjects.

In such a fashion Chapter 5 commences the investigation of the employment experience of the study sample, including factors influencing outcomes and the role of Jobcentre Plus, by addressing the answers to such questions as:

'What is the 'best choice' of research methodology for meeting the aims and objectives of this

thesis?'

'What is the case for methodological pluralism, what approaches are both 'workable' and should be used?'

'What can be learned from experience, and other research, what sort of issues are likely to emerge?'

**5.1 The Choice of Methodology:** When there is data collection in UK RTW services, it is invariably driven by a requirement for funding or a need to evaluate an experimental approach. The driving force is the need of the service provider rather than the participant. The concept of social validity highlights the need to consider service outcomes in relation to the individual. What is often heard (in the UK) are claims to place a certain percentage of clients in employment without any reference to how many may have spontaneously returned to work and how many continued to maintain employment. There is never any reference to how many improved as a consequence of their own efforts or that of the family, friends or employers, or how the level of employment may contrast with the pre-injury position. Invariably the emphasis has been on evaluating a service and not on individual benefits. Such matters were considered at an early stage important to this study if a programme was to be designed for the benefit of individuals.

Any categorisation of the more commonly used research methodologies in employment and disability studies is likely to be subject to debate. It is considered that practice can be subsumed under the following broad perspectives:

- Empirical practice. Such practice concentrates on evidence-based outcomes, relying on such approaches as the application of reliability and validity tests in randomised controlled trials (RCTs), for example the Back to Work (BtW) programme, to be discussed, or single-case studies (Target et al, 1998).
- Pragmatism or methodological pluralism. A significant amount of employment and disability research is pragmatist, based on non-experimental quantitative methodologies including surveys. Through a methodological pluralist stance data can be gathered using triangulation, that is in more than one way, for example by interviews, surveys and statistical analyses. Effectiveness, in respect of the influence of any intervention, is reflected by drawing a distinction between the intervention and its effects, these being tested both quantitatively and qualitatively.

In the early days of RTW studies, evaluation, following an empiricist or pragmatic approach, utilising quantitative univariate analyses, relying upon data collected before and after intervention (experimental and/or survey), was often used. This approach has the appeal of apparent simplicity. The classic multivariate approach deployed in later RTW studies, for example, Crepeau and Scherzer (1993), rely upon multiple/logistic regression techniques in which the specific contributions of individual variables can be identified. There is a concentration upon one or a few small components within a field of enquiries. In an academic context, this sometimes means that the components within a systemic issue, such as the importance of neuropyschological test indicators, or the clinical severity of injury, have been carefully analysed, researched and studied over a prolonged period of time. Whilst such an intricate study of one or a few components of the larger picture is valuable - if only for providing one or two pieces of the jigsaw - it is apparent that even when regression techniques have been used to consider the relationship of a particular factor with others, using the studies for predictive purposes, there has still been an absence of reference to factors which might otherwise have influenced the eventual outcome, for example the influence of the external environment, such as family support. Such matters have not been considered within standardised approaches to programme evaluation.

Hence, despite regression techniques having the advantage of identifying many potential relationships, effectively predictors in many RTW studies, there remains the problem that in a situation in which many independent predictors can be used and in a situation in which independent variables are highly inter-correlated, and influence the outcome, there is a risk that, in the final analysis, one may not identify the important connections. Apart from variables inter-correlating too closely to distinguish their respective significance, it may not be a continuous variable that influences the outcome in one particular case but a discreet one. An example might be someone returning to work because the employer is a relative. It might not be possible to ensure that all participants answering a questionnaire would make reference to such a situation, but it may be the most significant issue affecting the outcome in a particular case. There are also issues in respect of how many variables go into the equation, and when to stop asking questions and, indeed, what sort of statistical analyses to use. (In this study, it was decided to restrict the study variables outlined in Chapter 6 to ones that repeatedly feature in RTW studies).

It is not possible to find other approaches (to empiricist/pragmatic) adopted in RTW research although in the wider context of employment and disability studies interpretivist approaches can be found, for example based on a social model of disability (Oliver, 1991) and there is one example in the UK of realistic evaluation, or "scientific realism", being used (Pilling and Garner, 2000).

Despite possible analytical limitations, including the application of the results to specific individuals, it is considered that in an ideal world research evaluating employment outcomes following TBI would be based on comparable groups experiencing differing degrees of support, and no support.

Such an approach was never feasible in this study. When there are large data sets and hypotheses in respect of relationship between several variables, one can use multivariate analysis to test each hypothesis. The process of determining the exact sample sizes for different size effects is complex and a working rule is often adopted when performing analyses, such as multiple/logical regression, that to detect anything of statistical significance one should use at least ten subjects for every variable to be used in the analysis (Tabachnik and Fidell, 1997). In this case, power analysis suggested that the study would require around 70/80 subjects in employed and unemployed categories (a matter that could not be predicted, hence, in reality, one would need many more than 150 subjects). In addition, in view of the number of other variables used in this research, there would be a need for several hundred subjects to use multiple/logical regression. It was impossible to predict the number of subjects who would receive clinical and/or vocational rehabilitation, never mind have any control over these processes. Further, evaluation based on the assignment to alternative forms of rehabilitation, and a control group, would be compromised by difficulty, indeed improbability, of obtaining matched individuals, never mind matched samples. There would also need to be a non-random pattern of referrals to alternative settings.

An example of empirical practice is the Back to Work research programme , introduced in Chapter 1.1. The significance to this study is in respect of:

- 1. The choice of research methodology and the assessment of the number of subjects required to run an RCT.
- 2. Limitations on evaluation.
- 3. Practical difficulties to be faced when 'rolling out' a vocational rehabilitation programme.

During 1999/2000, the Back to Work vocational pain management approach was developed at the Hope Hospital, Salford, to assess the feasibility of a collaborative venture with the Employment Service and a private sector vocational trainer (effectively providing a job club service) as part of the current government's determination to tackle long-term reliance on incapacity benefits. A second centre, the Frenchay Hospital in Bristol, was further instructed in its delivery. Unemployed customers with back pain and in receipt of Jobseekers Allowance, or incapacity benefits, were recruited onto the programme. Customers received a programme incorporating physical rehabilitation, psychological interventions and vocational advice and assistance. Eighty-six customers were recruited onto the programme in the two centres (59 males and 27 females) from an initial referral of 152. Customers had not worked for a mean time of 38.1 months (range 2 to 204 months) and had a mean back pain history of 103 months (range 9 to 600 months); 95.5% of customers completed the programme. At 6 months, 87% of the initial cohort was followed up; 39.5% of customers who started the programme were employed. A further 25.7% were participating in job training, education or voluntary work. The results suggested a potential model for developing rehabilitation services for this customer group.

The number of customers entering employment was greater than the 30% prediction in the initial contract. Combining employment, work placement, education and voluntary work as outcomes, then the programme had a success rate of 70.5% in Salford and 64.2% Bristol.

The success of the 1999/2000 programme led to further research managed by myself from the Department of Health Sciences, Leicester University to run from 2003 to September 2005, with recruitment taking place between April 2003 and March 2004.

Two further contractors were added from the voluntary and academic sectors (the Shaw Trust in Neath and the Queen Margaret College in Edinburgh), the number of participants was increased from 80 to 400, eligibility was extended to 'chronic pain' and a randomised controlled trial (RCT) was introduced to determine what aspects of the intervention best worked with whom. The 1999/2000 study demonstrated the *efficacy* of BtW. If the programme was to be extended, there remained a need to determine the optimum allocation of scarce resources, test the applicability of the intervention with a wider range of disability, broaden the potential range of contractors and demonstrate the capacity to deliver the programme to a larger number of Jobcentre Plus customers. In particular there was a need to identify:

- Customers likely to return to work with little or no assistance.
- Customers only likely to return to work given appropriate support.
- Customers unlikely to return to work in any circumstance.

157

In addition, information was required on the type of appropriate assistance.

Recruitment to this research study did not run to plan. None of the four sites was able to recruit a sufficient number of subjects to meet research targets, although 22% of the incapacity benefit registers are said to have musculo-skeletal complaints (DWP 2002). By March 2004, the research programme had 46 customers in the intervention group and 7 in the control group (target 200 each) with the uneven numbers reflecting the suspension of randomisation for a period. The total number of referrals stood at 494. The fundamental problems were an insufficient number of appropriate referrals and an inability to retain them once identified. Because some customers would not be suitable over 800 referrals are likely to have been required relying upon the 1999/2000 take up rate, and the low take up rate. With only 96 of the referrals participating there was a take up rate of 19.5% (in contrast to the previous 53%) followed by a high level of 'drop-outs'.

In the event the research programme was curtailed although a qualitative review was undertaken into the take up rate. This is summarised in Chapter 9 because of its contribution towards the practicalities of rolling-out a VR programme.

At this juncture the significance for this thesis is in respect of recognising the reasons why an RCT was recommended (initially at the insistence of the Treasury) and in seeking to address the limitations and objections to such an approach.

The National Disability Development Programme (NDDP), part of Jobcentre Plus, advocated randomisation on the grounds that the allocation of customers to control and treatment groups results in more valid data than other approaches, given a sufficient number of subjects confounding variables can be expected to balance out across the two groups. It will be recognised that NDDP sought to favour the collection of perceived objective scientific data using a research methodology familiar to clinicians well represented on the Steering Group.

Although there were objections to NDDP favouring RCTs, principally from disability organisations on ethical grounds, few questioned the rationale that an RCT offers the most robust research evidence for identifying those customers most likely to need and benefit from support. An RCT has the apparent virtue, and appeal, of providing evidence on the effectiveness of intervention. However the Royal National Institute for the Blind (RNIB) did bluntly warn that 'the crudeness of the methodology in relying on a laboratory model, which is irrelevant to complex social interventions, will offend and alienate the very people whose co-

operation is needed for the social intervention being proposed to have an effect'6.

(The academic researcher might also note that the programme was being undertaken on four sites, each producing two groups. In many ways each group could not be expected to be homogenous. The independent variables (pain management and vocational training) could not be applied in anything like the systematic way that would apply in a true experiment (despite the controls exercised in the contract. For example, the vocational trainers had to vary the programme to make it locally relevant and, because of staff availability, on some sites the vocational training was offered in between the clinical sessions and, at the other sites, following on from the treatment. Selection bias could also occur as a consequence of the way Jobcentre Plus staff and other referral agents 'sold' the RCT to potential customers).

In addition, any disproportionate negative reaction, possible drop-out and non-compliance on follow-up amongst the control group would, in any event, result in research of a quasi experimental nature rather than a true experiment when there is a control over the variables).

The rationale for randomisation is ultimately driven by financial considerations, that the results will lead to an analysis of what intervention works best with whom and, thereby, lead to a future judicious allocation of resources. However, this assumes that sufficient numbers of people will volunteer to participate in both groups and complete the follow-up enquiries, when the chosen methodology may make this an uphill task. Secondly the data will not necessarily lead to information resulting in the capacity to deliver individual programmes.

Whilst the Treasury and DWP may advocate RCTs as the 'ultimate' research design they have to be able to recruit a sufficient number of subjects to justify the choice of methodology. In the event of this not being possible there is a need to consider alternative approaches to answer the research question that is almost always the same in rehabilitation studies, 'Does the therapeutic intervention, compared to standard care, make a worthwhile difference to the outcome?'

Such practical considerations as the number of subjects that can be recruited to a research programme leads to limitations in respect of any quantitative analysis. In particular, it was recognised that the sample size likely to be obtained for this stuidy would cause difficulties in

<sup>&</sup>lt;sup>6</sup> Correspondence made available to me by the RNIB.

respect of constructing any "employability index" for measuring "distance travelled". Whilst it might be possible to establish the relationship between variables and outcomes using a 2x2 design (see Annex 7) such an approach could not 'weight' the respective significance of variables potentially achievable through logistic regression. Whether or not univariate analysis would aid the development of an index identifying subjects only likely to return to work following VR remained to be seen.

Hence, there was a need to consider alternative methodological approaches for analysing the post-injury histories. it became evident that the survey data , identifying the variables influencing the outcomes of the study sample, would need to be supplemented with more than group data. In any event data collection proceeded on the basis that a number of subjects would receive rehabilitation although because numbers were unknown, the extent to which statistical analyses could be used was not known until the data was collected. As the research developed the position with regard to the final number of subjects began to clarify confirming the need for methodological pluralism in order to meet the aims and objectives of the research.

The first 18 to 24 months of the time allowable for this thesis was spent on undertaking the literature search using the British Library Document Centre. In the meantime consideration was given towards the identification of the study sample. At the time there were grounds for considering that it would be possible to obtain a larger study sample than was ultimately possible. Approaches to staff at an NHS Trust and one large disability organisation were initially received with enthusiasm. In addition, the Papworth Trust in Cambridgeshire, contracted to run work preparation courses, offered to collect data. It was hoped that a sufficiently large study sample would produce a substantial amount of data, that if not dividing in the same fashion as an RCT (control/experimental group), would at least have enough subjects spontaneously returning to work and participating in various VR programmes to establish a data base to analyse the variables bearing on post-injury activity.

In addition sometime previously I had asked subjects, and their families, on whom I had reported in personal injuries litigation if they would consent to participation in a research programme investigating their post-injury employment history.

In the event I was left to entirely rely upon my own subjects, creating a number of potential methodological and practical problems:

Whilst my experience of Back to Work meant that for practical reasons it was considered appropriate to take on board alternative approaches to the control/experimental approach, robust statistical analysis was still favoured. Although an RCT was impracticable it was hoped that there would be sufficient subjects for an analysis of the major variables identified in the (primarily American) literature as potentially having a bearing on a return to work. As the research proceeded, and when 'eyeballing' the returned questionnaires, it was recognised that whilst the lack of any obvious emerging patterns supported the view that a return to work following TBI may follow a random pattern, it was seemingly so random that the responses were not going to lend themselves to the development of any scale distinguishing subjects likely to spontaneously return to work from subjects never likely to work again, never mind identify those only likely to return to work following VR.

Again, as the questionnaires were returned, it became evident that the 'quality' of a number of vocational interventions needed to be reflected. Whilst this lent support to the view that Jobcentre Plus services were failing many people with TBI the widely varying nature of vocational services also compounded any meaningful analysis of the impact of VR as a single entity.

There was, therefore, a need to reconsider how to account for the experience of the study sample. In the event, following the presentation and discussion of the statistical findings, it was decided to apply realistic evaluation (RE) to selected case studies. In turn it was recognised that whilst the application of RE could possible facilitate an understanding of the employment experience of the subjects studied there was a question as to how this was to be applied. It raised ethical questions in respect of identifying the subjects and reporting a sufficient number to support the methodology. (Whilst the first point could be addressed the latter one remains an issue).

Nobody in the UK has previously endeavoured to record the post-injury employment experiences of subjects sustaining TBI from outside a group of their own patients and the extent to which difficulties could have been anticipated is conjectural.

**5.2 Realistic Evaluation:** It is considered that realism potentially offers an additional means of evaluation that can be used to analyse the circumstances of an individual and *modus operandi* of a VR programme (subject to available data). The purpose of using realism in this study is to

facilitate a greater understanding of the statistical findings by developing the employment outcome of the three case studies and the Working Out programme in Chapter 8.

Rather than just concentrating on linking the variables, for example in this study between demographic and clinical variables and outcomes (cause and effect relationships) realistic evaluation seeks to address the questions of why a programme works, for whom, and in what circumstances. As such it is considered particular pertinent for examining rehabilitation programmes. It is possibly unique for RE to be applied to individuals (as opposed to programmes) but there are no obvious reasons as to why it cannot be used in this way. RE is based on an approach to the construction of models of intervention summarised as 'causal outcomes follow from mechanisms acting in context', presented as a formula:

Outcomes = Mechanisms + Context

The effectiveness of the mechanism is therefore contingent on the context in which it is introduced. As such it is considered that starting out with the individual as the context and the mechanisms as the responses to injury it may be possible to establish outcomes resulting in empirical uniformities, albeit three studies (limited by wordage) is likely to be insufficient for this purpose.

Feinstein (1998) made the point that "it might be more appropriate" to express the formula in functional form, with outcomes (o) not necessarily depending in an additive way on both the mechanisms (m) and the context (c): O = f(M, C).

The realist approach differs from experimental design, in which the experimenter manipulates one variable and looks for resultant change in a second one, by putting an emphasis on systems, looking at which mechanisms trigger the outcomes. Pawson and Tilley (1997) indicate that it is possible to carry out a realistic evaluation using quantitative and qualitative approaches, small or large samples, the central aspect being that the choice of method has to fit the hypotheses developed earlier in the cycle. The cyclical nature of the enquiry being based upon theory-hypotheses-observations and programme specifications being revisited, a working 'backwards and forwards'. Ultimately, it is claimed, one arrives at causal explanations, that is a statement of the context in which a particular cause leads to a particular effect.

Pawson and Tilley maintain that to be of value, evaluations must be oriented to cumulation. Cumulation involves "deepening, specifying, focussing and formalising" the understanding of context-mechanisms-outcomes (CMO) configurations. A CMO is defined as "a proposition stating what it is about a programme that works for whom and in what circumstances".

Context refers to "the spatial and institutional locations of social situations together, crucially, with the norms, values and inter-relationships found in them." Pawson and Tilley define mechanisms as "what it is about a programme which make it work".

The enquiry cycle (theory-hypotheses-observations-programme specifications) helps the construction of the CMO configuration and leads to a cumulation of programme knowledge. It is through this enquiry cycle that CMO configurations can be tested. There can be multiple CMO configurations to take into account the different aspects of the context and different types of mechanisms (Pawson and Tilley, 1997, Chapter 5).

Fundamental to Pawson and Tilley's approach is a view that there are embedded levels of social processes, with underlying generative mechanisms that result in observed regularities. Using these core ideas Pawson and Tilley build their realistic evaluation around CMO configurations. It is not enough to evaluate or describe a programme. Evaluators need to analyse the elements of a programme that the programme intends to tackle. These elements form the causal mechanisms that would, in the appropriate context, produce the intended outcome. Mechanisms may also be triggered to produce unwanted, unintended consequences that should be analysed accordingly. In this study, Feinstein's view (1998) that outcomes can be expressed as functions of mechanisms and contexts, not in an additive way, is the basis for discussing the experience of subjects not being offered or choosing any supportive intervention. In respect of application the distinctive aspect of realistic evaluation is the content depicted in the cycle below (Fig, 3):



#### Figure 3: The Realist Evaluation Cycle

The theory, the starting point, needs to be understood in terms of propositions about how mechanisms (in this case the inconsistent pattern of support services) produce the outcomes. The conjectured CMO configuration is a starting plan for an evaluation, the refined CMO configuration is the finding of an evaluation.

Phase 1 of implementation involves qualitative preliminaries, that is the identification of variables under consideration. The development of CMOs necessitates a certain amount of theorising in the form of generative causal propositions relating the contexts, mechanisms and outcomes within the analytical framework and focussing on programme ideas.

Phase 2 involves establishing the recognition of an 'outcome' enquiry with reference to context (c), mechanisms (m) and postulated outcomes (o). As previously stated this is achieved through the process of cumulation - a progressive refinement of the CMOs.

The identification and testing of CMO configurations is central to Pawson and Tilley's task of realistic evaluation. " *The basic task of social inquiry is to explain interesting, puzzling, socially significant regularities (R). Explanation takes the form of positing some underlying mechanism (M) which generates the regularity and thus consists of propositions about the interplay between structure and agency has constituted this regularity*". Pawson and Tilley are concerned with very specific prescriptions for practice (and, in this respect, pay only passing reference to pluralistic theories that endorse virtually all possible evaluation activities).

Following multi-method data gathering there is the development of CMO configurations and the identification of empirical uniformities leading to the establishment of a realistic evaluation cycle. This should ultimately enable the practitioner to make intervention programmes more specific by defining what may work for whom and in what context. As such CMO configurations are considered potentially helpful for answering some of the following questions:

- When examining individual circumstances can any relationship be established between clinical and demographic factors and a return to work?
- Does such information enable one to assess the likelihood of a return to work following TBI?
- Does vocational rehabilitation influence participation in the labour market/return to work and, if so, in what way?

• How can vocational rehabilitation programmes ensure they meet identified need and optimise the prospect of subjects returning to work?

Such questions need placing into hypotheses within a theoretical framework.

**Design:** Designing a realistic evaluation study goes through a number of phases beginning with the evaluator entering the programme with a theory or theories that form an explanatory blue-print to be tested out with CMO configurations.

Developing realistic evaluation relies upon a conceptual framework addressing:

purpose(s) theory research questions methods sampling strategy

purpose(s)		theory
	research questions	
methods		sampling strategy

#### Figure 4: An Overview of Realistic Evaluation

Pawson and Tilley (1997)

In respect of this study, the purposes are set out in the aims and objectives in Chapter 1 - in summary, to identify factors influencing the employment outcomes following TBI with a view to identifying the "best intervention" that could form the basis of an NHS/Jobcentre Plus service. The aim is not to discover if rehabilitation 'works' (albeit it could be seen as such). Ultimately the aim is to identify approaches likely to produce the best employment results considering the specific needs of the subjects within practical organisational constraints.

Pawson and Tilley maintain that "Realism's key feature is its stress on the mechanics of explanation, and its attempts to show that the usage of such explanatory strategies can lead to a progressive body of scientific knowledge". They postulate that a pre-requisite to a reliable evaluation is the carefully enunciated programme theory based on a model of generative causation. It is not entirely clear from the literature what Pawson and Tilley mean by 'generative causation' but this is taken to have its roots in classical treatment/control group methodology - with any differences in outcomes being ascribed to the treatment - with generative causation allowing the researcher to make sense of a real connection between the treatment and outcome (as opposed to it being inferred). In this respect it is not just the treatment (the internal mechanism) that needs to be taken into consideration but also external influences, such as the interest of stakeholders. There is a need to understand how and why social programmes have the potential to cause change. Hence, causation is not to be understood in terms of X producing Y but in terms of the action of stakeholders in making the programme work. The crucial issue in this study is not so much whether intervention 'works' but what aspects of intervention are best suited to the resettlement needs of the subjects (and others broadly like them) and how and why do subjects respond to support.

Pawson and Tilley (1997) emphasise the importance of utilising the immense amount of knowledge held by various stakeholders in any project. They point out that much of the knowledge will not be readily available or must be "teased out" by the researchers. Simply taking mechanisms as interventions is unlikely to lead to adequate explanations and there is likely to be a need to go beyond such a process to examine the role of stakeholders and the response of users to the availability of any service.

By way of illustration, it was considered possible that some of the study sample would return to work following a vocational rehabilitation programme but others would not do so.

By way of preliminary theorising the VR programme may be considered to be the mechanism<sup>7</sup> that results in the outcome (a matter initially subject to statistical analysis). However, the "real issues" are what is it about the nature of the intervention that results in the outcome and what is

<sup>&</sup>lt;sup>7</sup> A reading of the literature on scientific realism may lead to an initial view that mechanisms reflect the process of intervention (or project activities) and this study commenced on this basis. As the research has progressed it has become apparent that it embraces concepts such as a subject's response to an intervention/project, that is more intangible matters (see Julnes, Mark and Henry, 1998). It is understood that Pawson and Tilley are planning a second edition to 'Realistic Evaluation' in which this issue is addressed.

it about the nature of the subjects (the variables under consideration) that may produce different outcomes although experiencing the (notionally) same intervention (mechanisms).

Linking the variables and outcomes requires a recognition of the social mechanisms influencing the choices that people make. The first activity needs to be understood in terms of the context of decision making and seeing beneath the surface of available inputs and outputs of any intervention (described as ontological depth). For example, reference has already been made to the fact that in the Back to Work programme had recruitment problems. Whilst all of the study sample did not have the choice (as to whether or not to go on a rehabilitation programme), the question arises as to whether or not subjects going on rehabilitation programmes somehow differ, for example being better motivated, than subjects who do not. Whilst there may be no obvious statistically significant differences between subjects undertaking rehabilitation and those not doing so, seeing below the surface requires a recognition of what factors influence choices in the first place, of which availability may only be one.

Returning to the evaluation strategy, for hypotheses to be derived from the theory (in turn reflecting the aims and objectives of the research) there is a need to draw together such matters within a conceptual framework, hence all research activity is theory-driven. This stage requires specifying the variables to be included in the study and the procedures to be followed. The theory underpinning this study is presented figuratively within a theoretical framework (Fig. 5) and relies on the premise that the TBI study sample is likely to experience a random pattern of employment, that is one not always directly related to the severity of injury and consequential clinical sequelae, although one in which a search or return to 'normality' often features and one in which the process of labour market entry can be positively influenced by appropriate vocational services. The CMO variables are derived from the literature review.

167

#### Figure 5: Basic Framework for Researching TBI Vocational Outcomes

#### Contexts



One can considerably add to this framework, such as including psychological factors such as self-esteem and duration of employment to the outcomes. However, this is a framework and not an all inclusive model. It is also recognised that many people would perceive (a return to)

education or training as a positive outcome. Whilst one might ultimately hope that such outcomes would ultimately lead to paid activity they are not included in this framework on the grounds that:

- it is considered that, ultimately, the aim of vocational rehabilitation should be work.
- if a subject is in education or training at a final follow-up (and it is suggested that post VR they should be monitored for as long as possible) there is the spectre of using education or training as a substitute for an inability to return to the labour market.

It is accepted that many people in the VR sector would not agree with such propositions, maintaining that any structure to a person's life is likely to be beneficial.

The framework forms the basis for examining the experience of the study sample, in particular the three case studies and forms the background against which the efficacy of Working Out is examined. This is in order to develop a VR programme within the context of condition management programmes.

Returning to, and expanding the theory, it is considered that, in general, those who sustain anything but the mildest TBI may face some employment difficulties, ranging in severity and consequences. The provision of clinical and vocational rehabilitation services in the UK is patchy (the latter being a responsibility of Jobcentre Plus). Hence, many people sustaining TBI are unlikely to receive appropriate support to enable them to successfully resume employment (on the assumption that, somehow, rehabilitation 'works'). It is postulated (theorised) that the inconsistent provision of appropriate support services in the UK is likely to be reflected in irregular patterns of return to work rates. In other words, irregularity and inconsistent return to work rates (in respect of clinical and demographic variables) are *consistent* features of observing the return to work of people with TBI in the UK. However, it ought to be possible to identify and address many of the barriers to employment through the use of appropriate compensatory strategies. Such theorising leads to a number of hypotheses:

#### Hypotheses

- The severity of injury can be related to successful labour market participation/return to work, even if the relationship is not always a strong or consistent one (the more severe the original injury then the chances are that the consequences will be more severe than a lesser injury).

- Other clinical and demographic factors, such as neuropsychological sequelae, domestic support and pre-injury employment history, may also have a bearing on outcomes.
- The provision of clinical and vocational rehabilitation is 'patchy' and that there are likely to be difficulties establishing a relationship between rehabilitation and vocational outcomes with a small study sample.
- Any search for a model predicting employment in the UK amongst people sustaining TBI may be confounded by:
  - the difficulties in isolating clinical variables and measuring their specific input (because of the practical difficulties in collecting such information and, even when it is available, the close collinearity);
  - determining the influence of demographic factors (such as whether or not a partner is supportive) and;
  - (iii) the inconsistent provision of appropriate support services.
- Whilst quantitative approaches may be helpful in establishing group relationships they lack ontological depth and a methodology such as realistic evaluation may be more helpful in vocational rehabilitation research for explaining the experience of individuals.
- Moving on from realistic evaluation it is possible to plan individual vocational rehabilitation intervention by looking at the barriers to employment for people sustaining TBI and developing a vocational rehabilitation approach, including matching identified neuropsychological and other clinical deficits with compensatory strategies to facilitate resettlement.
- An examination of the variables influencing outcomes ought to enable the researcher to establish how far any person sustaining TBI is away from entering the labour market. Further, it ought to be possible to identify specific outcomes, thereby providing a basis for measuring 'distance travelled'.

Such hypotheses need to be tested within the mechanics of realistic evaluation and CMO configurations. Besides reference to Working Out it will be noted that the use of realistic evaluation in this case differs from the application advocated by Pawson and Tilley in another

major respect. Pawson and Tilley apply realistic evaluation to actual community programmes. If all the subjects in this study were offered and undertook vocational rehabilitation programmes then one could apply realism in their prescribed fashion. However, this was never likely to be the case. Hence the application to individuals, as opposed to programmes, to address the question as to what is it about the contexts (the TBI, clinical and demographic variables and choices made) and mechanisms (possibly including VR programmes) that contributes to the employment outcomes.

**5.4 Identification of the Study Sample:** When undertaking research with TBI subjects, researchers have invariably used clients within their own service. As Brooks (1989) put it "...... writers are more commonly restricted to their own local specific population, being reluctant .... to face the practical and other difficulties inherent in identifying new samples."

A number of organisations were asked to participate in this research with regard to providing data:

- 1. Rehab UK considered that it did not have the resources to provide the data required for this study.
- 2. The Disability Trust, incorporating the Brain Injury Rehabilitation Trust, provides residential clinical rehabilitation in a number of locations, including Leeds and Milton Keynes, and it has the longest established brain injury job coaches in the country. The Chief Executive expressed enthusiasm for this research and an initial interview with a job coach was conducted to establish available variables. Unfortunately, a new Chief Executive decided that the organisation did not have the necessary resources to commit to collecting data.
- 3. The Nottingham Traumatic Brain Injury Team, City Hospital, participated in the National Traumatic Brain Injury Study (NTBIS) (Stilwell et al, 1997) and, as such, it was considered a good source for providing data on those receiving only clinical rehabilitation (for comparative purposes). Initially, the Team Leader expressed support and contact was made with the appropriate Ethics Committee. However, when the amount of work was realised by the team, enthusiasm waned and the Team Leader's secondment to complete his own PhD ended any further involvement.
- 4. The Papworth Trust in Cambridgeshire agreed to provide data, but during a twelve months follow up period it was only able to collect data on three people meeting the

necessary criteria (and this information has not been used).

5. The Employment Service declined on the strange ground that work preparation agencies were likely to feel particularly vulnerable to any criticism. No reason for assuming criticism was ever given.

Hence the data on 54 traumatically brain-injured people on whom I reported in personal injuries litigation has been used (from 82 who originally consented to participate. Either questionnaires were not returned or the subjects had moved away). Whilst there was one common factor uniting them, all had personal injuries litigation claims settled at the time of follow-up, they were, otherwise, a random group varying in age, severity of injury, education, employment histories and the amount of support received. It is recognised that the history of personal injures litigation may not make this group so random in contrast to TBI subjects unable, or possibly unwilling, to pursue civil damages ( inasmuch as what drives people to pursue damages may in some way make them different).

The inclusion criteria were:

Having sustained a traumatic brain injury of mild/moderate, severe or very severe status.

Being of working age (18 to 50 years) on follow-up.

Because of the size of the study sample it was recognised that this would place restrictions on the nature of statistical analyses, although there remained a need to use other relevant strategy by moving away from group analyses towards explaining what happens to whom and why.

With two exceptions (because of the quality of available information) data was collected a maximum 12 years post-injury. As time after injury increases, so does the difficulty in identifying unequivocal causal relationships between the original injury and the current clinical and social situation (Brooks et al, 1987b).

As indicated all of the subjects were first interviewed for reports in personal injuries litigation. Clinical data was made available for the initial interview and demographic data was also collected at that juncture. Subsequent to the interview consent was sought for the subject's participation in this research study and to be allowed to use this data for research purposes. The follow-up rehabilitation/employment data was collected at the second stage when information was specifically gathered for this research. Some of the subjects were seen for a further interview, either for litigation or data collection for this study, but all the subjects were sent the questionnaire (Annex 3) and a number further followed-up by telephone. In theory the telephone interviews should have followed a set format taking the subjects through the questionnaire to complete any missing data. In practice it was often difficult to keep the subjects to the point and discussions were invariably peppered with benefits issues and family problems arising from the brain injury.

**5.5 Summary and Main Points:** All research methodologies have their advocates and critics. The issue is not in respect of whether or not one method is 'better' than another but one of selecting the most appropriate approach(es) to answer the research question(s). In some quarters there remains an argument that the positivist quantitative approach produces 'superior' research outcomes. It is often considered that multiple regression techniques have the advantage of identifying many potential relationships, effectively predictors in this case, for variables with a particular variance. It may seem that many of the research objectives could be addressed in this fashion. One might choose to model the collected data to answer research questions. For example, one could test for the strength, direction and reliability of any intervention and its effect on the outcome measures. A fundamental purpose in this case would be the construction of an 'employability' or 'vocational rehabilitation index'. However it was also recognised that many RTW studies have been unable to answer the questions for which they were designed because of inadequate sample sizes and in 'simply' relying on statistical analyses there was a danger that this study would have the same failing.

In addition, in a situation in which many independent predictors may be used such as age, length of unemployment and nature of treatment there may be problems caused by both multicollinearity and, for operational purposes, limiting the number of variables. In the final analysis it may not be a continuous variable, which influences the outcome in a particular case but a discrete one. In vocational rehabilitation practice an employment placement may be a consequence of a family member being able to make appropriate arrangements, or a failure due to other external factors, such as the influence of a litigation case. Whilst it may be reasonably maintained that given a sufficiently large sample such instances will not affect the overall statistical outcomes, it does mean that such outcomes may not relate to individual experiences. Given that in the UK we do not have the equivalent legislation to America, where the 1992 Amendments of the Rehabilitation Act provide for an Individualised Written Rehabilitation Program (IWRP), nor the infrastructure to offer such services (in terms of accredited practitioners and organisations capable of offering a case managed approach to the resettlement of a large number of people), it may be argued that this does not matter and that group analysis favours variables most frequently involved in return to work. If so, it also needs to be recognised that results may be too general to apply to individual cases.

In addition, whilst the classic quantitative approach may be essential in some research, for example establishing the efficacy of a particular drug, when the range of influential variables cannot be controlled, the methodology itself may skew results or it may not be ethically or practically acceptable. Whilst group analyses favours variables most frequently involved in return to work, in so doing, they minimise more rarely observed sequelae in TBI that may compromise re-integration into the work force. Reported correlations and associations in the literature cannot represent a definitive response concerning the validity of the specific predictors and indicators of work status. The prognostic value of certain variables is limited by the distribution of variables within and between samples, for example, age, gender, duration of PTA. Undoubtedly, a lot more work could be done in order to improve data collection in relationship to understanding outcomes following TBI and this is discussed in the Conclusion. In such circumstances alternative approaches may have to be considered. The use of realistic evaluation in this study is not to deny the validity of other approaches but one of seeking to add to the knowledge and understanding of what happens to people with TBI in the labour market. The literature review leads to a view that the search for an all-embracing predictor of RTW following TBI (reflecting an understanding of those unlikely to work in any event, those who may spontaneously return to work and those only likely to work given support) is unlikely to be found through quantitative evaluation relying upon regression techniques (if at all). In the circumstance it was decided that the only feasible way forward would be a survey of the postinjury employment experience of the study sample. In addition to reporting group findings using description and association statistics, this study applies the realist approach (Pawson and Tilley, 1997) to evaluate the post-injury experience of three members of the study sample and the Working Out VR programme.

Pawson and Tilley (1997) are critical of control group methodology. They maintain that RCTs are linked to a discredited view of positivism. They say little on why an intervention has failed and they can not yield an accumulation of findings that help to build up an understanding. They argue that allocation removes choice, but 'choice is the very condition of social and individual change and not some sort of practical hindrance to understanding that change'. However in recognition of what Julnes et al (1998) describe as "commonsense realism", this study makes reference to Working Out. This should be viewed as providing a comparison contributing to an understanding of the contexts (of the study sample) and mechanisms (to be discussed) influencing the outcomes.

The fact is that running an RCT (particularly a multi-site one) in employment and disability

studies is an extremely difficult matter. In the absence of any mandatory rules on participation it would appear that customer preference has to be given considerable importance. One can hardly enforce clinical intervention. Strategy based on a view that large numbers of incapacity benefit recipients will voluntarily participate in work intervention programmes may be misplaced. The (potential) reasons for the difficulties in recruiting and retaining Jobcentre Plus customers are considered as part of the findings in Chapter 9 because of the implications for rolling out any joint NHS/Jobcentre Plus VR programme for people sustaining TBI. At this juncture it is considered significant to say that the failure of this approach in the BtW programme to recruit sufficient subjects for regression supports the reliance on a combined methodological strategy.

Of necessity the study sample in this research are 54 people with TBI on whom I first reported in personal injuries litigation and whom subsequently consented to participate.

#### **CHAPTER 6**

# QUESTIONNAIRE CONSTRUCTION, DATA COLLECTION AND APPLYING THE METHODOLOGY TO THE DATA

#### **Contents**

6.0	Overview	176
6.1	Items for Inclusion in the Survey Questionnaire	176
6.2	Questionnaire Construction and Data Collecting	181
6.3	Problem Issues in Recording the Data	182
	a) Classification of Occupations	183
	b) Clinical Data	183
	c) Validity of the Data	186
	d) Intervention Processes	187
	e) Outcome Measures	187
6.4	Applying the Methodology to the Data	188

#### 6.5 Summary and Main Points

**6.0 Overview:** The aims and objectives of this thesis (Chapter 1.2) required subjects to be identified and selected clinical and demographic data to be collected. The realist approach required both the context of subjects' employment status to be identified and mechanisms bearing upon this status to be defined. Chapter 6.1 outlines the data collected for this research, Chapter 6.2 the questionnaire on which this information was recorded, Chapter 6.3 discusses issues and limitations that arose during the data collection and Chapter 6.4 how the methodology is to be applied to the data.

**6.1 Items for Inclusion in the Survey Questionnaire:** The questionnaire (Annex 3) was prepared with the experience of already having interviewed this group once, and having started the literature review, but with the expectation that more subjects would be forthcoming. A lack of certainty as to the responses that would be received, and a concern lest there should be insufficient data, contributed to listing too many variables, albeit there were also omissions. A

189

factor influencing outcomes may be local economic circumstances but this had to be omitted because the subjects were drawn from various parts of England and Wales and there were too few subjects in some regions for any meaningful analysis. Staff at the Papworth Trust in Cambridgeshire assisted in a trial of the questionnaire.

Based upon the issues considered significant in the RTW studies, and experience, it was decided to incorporate the following items into the survey questionnaire representing the major research variables (Tables 6.1 and 6.2).

Because of the number of subjects in this study, it was considered that the recording of ethnicity would not be helpful, as the number was likely to be too small for any meaningful analysis.

#### Table 6.1: Summary of the Research Variables

1	Demographic	2 Severity of Injury	3 Rehabilitation	4 Clinical	5 Outcomes
	Gender	ΡΤΑ	Clinical	Physical	Open Employment*
	Age		Vocational	Sensory	Supported* Sheltered*
	Age at Injury			Psychological	Therapeutic <sup>8</sup>
	Domestic Circu	imstances		Executive	Voluntary*
	Education/Qua	lifications		Emotional	Not employed
	Employment Hi	istory		Other *	full-time and part-time

The data was further sub-divided as indicated in the categorisations.

**Categorisation of the Variables:** for analytical purposes the following categorisations were used (Table 6.2). Given the size of the study sample, 54 people, it was considered there are too many variables. However, it was recognised that not all of the variables would apply to every subject and the frequency of many variables, such as the clinical symptoms could not be predicted.

<sup>&</sup>lt;sup>1</sup> During this research Social Security rules changed and therapeutic work became part of Permitted Work.

# Table 6.2: The Categorisation of the Variables

### Personal Data:

- 1. Male
- 2. Female
- 3. Current age
- 4. Age at time of injury
- 5. Chronicity (years from injury)
- 6. Living with partner
- 7. Living with partner and children
- 8. Single living with child(ren)
- 9. Single living with parent(s)
- 10. Single living alone
- 11. Other living arrangements e.g. living with carer or in residential accommodation

# Education History (for those injured after entering the labour market):

- 12. Age left full-time education
  - Highest level of pre-injury qualification
- 13. No qualifications
- 14. O levels/ GCSEs or equivalent
- 15. A level or equivalent
- 16. HND, degree or higher degree
- 17. Trade qualification eg City and Guilds
- 18. Professional qualification

# Education History (for those injured before entering the labour market):

Level of schooling at time of injury

- 19. Injured prior to starting school
- 20. Infant or Junior School
- 21. Senior School
- 22. College or University

# Highest level of qualifications obtained post-injury

- 23. O levels/|GCSEs or equivalent
- 24. A levels or equivalent
- 25. HND, degree or higher degree
- 26. Trade qualification
# 27. Professional qualification

# **Pre-injury Employment Status:**

- 28. History of regular employment (that is, as far as could be ascertained, in employment for at least 2 years prior to injury and with no history of frequent unemployment). Occupational status: For this research the social classifications (from the British Standard Occupational Classifications) were recorded as follows:
- 29: Professional occupations
- 30. Skilled occupations
- 31. Partly skilled occupations
- 32. Unskilled occupations

# **Post-Injury Employment Status:**

- 33. Return to paid employment at any time
- 34. No employment of any description
- 35. A maintenance of regular full-time employment (defined as not having any breaks of 3 months or more)
- 36. History of irregular employment
- 37. Return to pre-injury employer in same position
- 38. Return to pre-injury employer in different position
- 39. Found position(s) with other employer(s)
- 40. In regular ft employment at time of follow-up
- 41. In regular pt employment at time of follow-up
- 42. Recorded adjustments made by employer
- 43. Supported Employment at time of follow-up
- 44. Sheltered or therapeutic activity at time of follow-up
- 45. Voluntary work at time of follow-up
- 46. Pre-morbid activity no longer open but no suitable alternative activity found

# Rehabilitation received:

- 47. Clinical rehabilitation, that is attendance either as an in or out-patient or at a specialist brain injury service providing such treatment as cognitive rehabilitation, speech and occupational therapy and with a focus on community re-entry (although some clinical rehabilitation teams have a work input, generally as part of an OT programme, they were not classified as vocational rehabilitation agencies as this is not their main activity). Treatment in the immediate post-acute stages of injury is not classified as clinical rehabilitation.
- 48. Vocational rehabilitation, that is consultation with a DEA resulting in placement on a

work preparation course, attendance at a specialist brain injury vocational centre and/or other supported employment arrangement organized by an employment specialist. Activity may have included an occupational assessment, a work trial and/or the development of *in situ* compensatory strategies. Whilst some brain injury case managers and/or carers made work arrangements, for example, for therapeutic activity, as work was not the major focus of intervention support, such a service is not classified as vocational rehabilitation.

#### **Clinical variables:**

## Physical

- 49. Balance
- 50. Lifting
- 51. Walking
- 52. Spinal cord injury

#### Sensory and Motor

- 53. Visual
- 54. Hearing
- 55. Pain perception
- 56. Anosmia
- 57. Epilepsy
- 58. Co-ordination

#### **Psychological**<sup>9</sup>

- 59. Memory
- 60. Attention/Concentration
- 61. Communication
- 62. Visual-Spatial difficulties

<sup>&</sup>lt;sup>9</sup> Whilst a reduction in Full-Scale IQ was recorded on a number of occasions, albeit sometimes relatively small, it was never reported by the examining neuropsychologist as a major critical factor affecting the subject's employability, in contrast with other neurological sequelae. This is a common feature in the literature. When it was discussed in respect of employability it was almost always as a factor to be taken into account when considering placement prospects, that is a reduction in employment status, alongside other factors considered even more significant, rather than as a factor affecting employability *per se*. On many occasions, not all of the sub-tests of the WAIS-R, measuring IQ, were administered nor the National Adult Reading Test (NART) used to measure pre-morbid intelligence.

- 63. Speed of information processing
- 64. Organization and planning

# **Executive Functions**

- 65. Dysexecutive syndrome reported as such
- 66. Sequencing problems
- 67. Unable to initiate motor acts
- 68. Planning /directing goal directed behaviour
- 69. Loss of self-monitoring ability
- 70. Inability to analyse social situations and adjust.

# Emotional

- 71. Depression
- 72. Anxiety
- 73. Anger/irritability
- 74. Emotional lability
- 75. Reported personality/behavioural change

# Length of PTA

- 76. Very severe
- 77. Severe
- 78. Moderate

# Other

79. In practice this category, when completed, invariably referred to fatigue and/or headaches

The early returns of the questionnaire showed the need to revise some of the clinical categories that did not emerge during trialling (hence a change in two categories of Executive Functions between the form in Annex 3 and the classification indicated above).

**6.2 Questionnaire Construction and Data Collection:** The process of preparing the questionnaire (Annex 3) was as indicated in Figure 6:

#### Figure 6: Steps in Questionnaire Design

- Deciding the 1 information sought
- Deciding type of
   questionnaire
   to use (open/closed questions/check list)
- 3 Writing first draft
- 4 Re-examining following consultation with staff at the Papworth Trust and revising
- 5 Piloting the questionnaire
- Editing and 6 specifying first draft for usage

Whenever possible for ease of completion, closed questions were used, including simple categorical answers (yes/no) and check lists, because of the ease of conversion to a numerical format required for the Statistical Package for the Social Sciences (SPSS). The responses to open-ended questions were summarised into categories for entry into SPSS. It will be noted that sometimes a combination of both closed and open-ended questions were used. This involved providing the respondents with a number of defined responses and an additional category to record any further details.

In an ideal situation, a follow-up interview (to the one for litigation purposes) with each subject would have been desirable. However, the collection of data was restricted by research practicalities including the availability of the subjects/family members and distance. Hence, the reliance upon the postal questionnaire (in some cases followed up with a telephone discussion and interview) completed by reference to the available clinical reports. It is recognised that with a postal questionnaire there is always a potential sample bias, but the 66% rate of return is considered to go some way towards excluding this. Nunally (1978) maintains that a 70% response rate is a good one and sufficient to exclude bias.

**6.3 Problems in Recording the Data:** Issues arose during the establishment of the variables and recording of the data in respect of:

Recording occupations.

- Determining what and how best to record some of the clinical data.
- Recording intervention processes.
- Recording outcome measures.

a) Classification of Occupations: Annex 8 makes reference to the British Standard Occupational Classification System. It was initially decided that it might be useful to adopt the social classification of jobs on the basis that (i) such categories are well understood within the UK, (ii) the British occupational classification system (OPCS 1980) allows for the ready classification of jobs into such groups. In practice, it proved difficult relying upon these categories and for analysis positions were simply dichotomised into manual and non-manual activity.

Whilst reference to the OPCS is useful when considering classifying subject occupations, subjects regularly moved between jobs falling within different occupational classifications and their position at the time of injury did not necessarily reflect their 'real' status. For example, at the time of injury one former sales representative was a student at Oxford University studying to become a teacher. To simply make reference to the economic position ignores the specific type of work and this could be an important research issue. In addition, whilst the dichotomy 'employed/unemployed' so often used in RTW studies does not reflect current working patterns, a matter also reflected by the National Traumatic Brain Injury Study (1998), the OPCS lacks an economic category particularly germane to this study, economically active but prevented by a <u>long-term</u> health problem from seeking *any type of* employment. In the circumstances the survey questionnaire was designed to elicit information that covers a broad range of activity, to be classified by response.

b) Clinical Data: The fundamental issues with regard to the collection of clinical data were:

- i) The reasons for collecting it;
- ii) The nature of the available information.

Throughout the collection of data it was recognised that the recording of the clinical data (for predictive purposes) is a different matter to collecting such information for the purpose of vocational rehabilitation. This is not surprising considering that a return to work may be influenced by factors rehabilitation can not influence, such as age and the pre-injury intellectual ability. Rehabilitation clearly needs to concentrate on the factors that can be positively influenced.

One has one of the first factors that needs to be collected with regard to a 'starting point' is the severity of the injury and the nature of the subsequent sequelae as they affect vocational rehabilitation and employment (two different issues). The obvious difficulties are in respect of deciding exactly what factors to include, and how one collects this information. For instance, Crepeau and Scherzer's meta-analysis suggests that cognitive deficits symptomatic of frontal lobe damage, with specific deficits in executive functions (planning, organisation, selfmonitoring) and lack of flexibility might be the basis for loss of autonomy (considered a significant issue in respect of a return to work). Such a finding confirmed Ben-Yishay et al (1987) who postulated that executive dysfunctions interfere more with adaptations, other cognitive deficits and motor problems. However, the importance of executive functions in the RTW process has only been weakly associated. Lezak (1989) suggested that such deficits are difficult to evaluate and it is possible the weak correlations can be explained, at least in part, by measurement problems. In the circumstance it was considered important to record the frequency of executive dysfunctions for planning vocational rehabilitation (that is frequency in respect of the number of different aspects that may have been recorded as opposed to how often each aspect was seen).

Besides executive functions it was considered important not to neglect other sequelae that are likely to have a significant bearing upon any outcomes and reviewed in Part 1. It was decided to keep matters relatively simple by:

- including only the commonly reported clinical items (but allowing an opportunity for the inclusion of additional evidence should this emerge);
- allowing the opportunity for a further analysis of clinical data should anything considered significant emerge from the first review.

In addition to the indices of severity of injury, such as PTA, reported clinical factors covered include:

- physical problems;
- sensory motor problems;
- cognitive sequelae;
- executive dysfunction;
- emotionally related problems;
- social and behavioural problems;
- other significant injuries accompanying the head injury.

In additions to the deliberations in respect of what to include in the clinical data difficulties occurred in recording the clinical data as a consequence of:

- i) Inadequate medical reporting. The period of post-traumatic amnesia is invariably estimated, although given the classification of PTA (see Introduction) this is not considered a significant problem. For research purposes it does not matter if a member of the study sample sustained two or four weeks PTA, they would both be recorded as a 'very severe injury'. The problem occurred when neurosurgeons or neurologists incorrectly used expressions such as 'mild' or 'severe' not in accordance with clinical definitions. Whilst it was necessary to read all the available clinical documentation in order to establish the period of PTA, this was still not possible in two cases because of conflicting evidence.
- ii) Varying practices in respect of reporting symptoms. A few psychologists did not attach test results to their reports (understood to be on the basis that they considered there was a risk of unqualified interpretation). A difficulty subsequently occurred when, for instance, they would report a memory problem, without differentiating between verbal and visual memory. This would extend to not saying if the problem was a short or long term one. As a consequence memory had to be recorded as a unitary concept, when it is not, and it may require different compensatory strategies in vocational rehabilitation practice. For example, there is little point in colour-coding an object for someone with a visual memory problem. Such a person may be capable of following verbal instructions given appropriate prompts. Because of the insufficient recording, all memory deficits are simply recorded under 'memory'.
- iii) Similarly, the deployment of different approaches to assessment, including the use of different psychometric tests to measure the same symptoms, seemingly not only contributed to clinicians reaching different conclusions with regard to the nature of presenting problems but an inability to establish any valid comparisons with regards to the reported severity of symptoms between members of the study sample. The use of differing assessment material was particularly noticeable.. For example, in one case, a neuropsychologist using BADS (Behavioural Assessment for the Dysexecutive Syndrome) concluded that the subject did not have executive problems but another psychologist, using an observational rating scale, that he did. Whilst there is a possible explanation for the difference of opinion, without further information, it was difficult to decide what to record. (Executive difficulties are not unitary phenomena. An individual

may show reasonable planning, sequencing and organizing ability whilst showing poor psychosocial insight, regulation of emotion and social behaviour). Tests tend to be more based around planning, organizing and flexibility of thinking. The recorded response, in the case in question, was to consider both clinical reports and observations from other sources.

On other occasions, (neuro)psychologists recorded a 'dysexecutive syndrome' (whilst at other times, simply noting a deficit that could be part of such a syndrome). Whilst the majority went on to say what they meant by this description, this was not always the case (as surprising as this may seem). Hence, in some instances, it was difficult to know if a reported symptom was part of a dysexecutive syndrome (invariably because of frontal lobe injury). Aside from the implications for vocational rehabilitation planning, the immediate problem was how to record such reporting. To simply record a dysexecutive problem (under executive skills) without detailing the further specific deficits could lead to an under-recording of the other categories used in the executive skills section. On the other hand, when full details were provided, there would be possible distorted recording, by identifying a dysexecutive syndrome and going on to delineate the other categories (when only recording a dysexecutive syndrome in some other cases). In the circumstance, pragmatism was used. When a dysexecutive syndrome was reported this was recorded but no further symptoms were then recorded in this section under 'Executive Functions'. When specific symptoms are recorded/reported in this section they have not been specifically noted as part of a dysexecutive syndrome. Whilst this measure may have resulted in some underrecording of the frequency of the categories in this section, this measure does have the merit of consistency and, given the frequency of symptoms in this section, any under-recording only confirms that the most common problems following TBI are likely to fall within the province of neuropsychologists.

Reporting mood and behaviour are particularly problematic. There are few tests of mood designed specifically for the brain injured population and a lack of awareness of behavioural impairment (at least in the more severely brain injured) is commonly reported (Prigatano et al 1994). Hence, many measures rely on reports by staff and relatives

 TBI primarily results in diffuse injury. This not only results in a wide range of symptoms but, as a number of correlation studies have demonstrated (Crepeau and Scherzer 1993) an inability to identify the respective importance and contribution of various symptoms to the post-injury employment status. Variables such as attention and concentration deficits correlate too closely to enable one to do this. Consequently, whilst it is possible to record the frequency of the major recorded deficits, no attempt is made to rank these factors, although, on occasions, one factor alone could be responsible for the post-injury employment status, such as the development of severe post-traumatic epilepsy.

c) Validity of demographic data: It was not possible to validate information in respect of such matters as educational qualifications and employment histories. Subjects were sometimes vague or confused issues, for example being unable to recall whether they obtained CSEs or GCSEs. There was even difficulty in describing the nature of the work they undertook, for example whether skilled or not, for example, "It was skilled I suppose, I learned on the job" (a roofer). Whilst in some cases an inability to remember detail or confusion may have been a consequence of the neuropsychological sequelae, family members were not always more informed. Hence, for categorisation and analysis, it was decided to dichotomise responses, for example whether a job was manual or not, and to put together various broadly comparable qualification levels, CSEs, GCSEs and equivalent NVQs.

There was a reliance on the subject and/or members of the family for the reason(s) why, postinjury, subjects lost their positions. In an ideal situation it could have been useful to check responses with former employers.

#### d) Intervention Processes: These refer to:

clinical (cognitive) rehabilitation; the opportunity for work trials/return to former employer;. vocational rehabilitation job coaching.

Whilst subjects were aware of returning to hospitals for 'some treatment' they were often vague as to how long they attended or what treatment they received. Hence, unless records indicated a specific course of cognitive rehabilitation, this process was not recorded. Vocational rehabilitation was only recorded when there was specific evidence a subject had undertaken a course. Any specific reference to job coaching had to be excluded because subjects were often vague as to the nature of received support.

e) Outcome Measures: These include: current status: hours worked; productivity, quantitative and qualitative; amount of structure required to sustain work; temporal aspects; external influences; work-related variables such as salary and time in the work force.

The inclusion of all these categories was over-optimistic, and it was impossible to collect all this information. Although the research aimed to avoid relying on the dichotomy employed/unemployed, it soon became apparent as to why so many RTW studies have had to rely on these categories. Subjects would need to be continuously tracked over a period of years if all this information was to be accurately recorded.

**6.4 Applying the Research Methodology to the Data:** The thesis relies upon a combined methodological strategy. Application is essentially a question of how best to apply the strategic threads to meeting the aims and objectives of the study (Chapter 1). Many pertinent aspects were covered in Chapter 5 including the need to recruit sufficient subjects to justify the choice of methodology. In this respect it is considered that a review of the Back to Work RCT explores the practical difficulties in not only relying on this methodology but in rolling out a large scale VR programme for a specific group of disabled people. There remains a need to explain the potential reasons as to *why* the RCT failed to recruit sufficient subjects and this is covered in the qualitative review described in Chapter 10. The lessons to be learned from this RCT are applied to the development of the theoretical model VR programme outlined in Chapter 12 when 'building in' mechanisms to address subject identification, engagement, recruitment, compliance and retention.

The application of the statistics to the survey data (Chapter 7) is a recognition of the need to identify significant relationships between the selected variables and a return to work and to find explanations for the results (as a response to the question as to what works with whom and why, and what to include in any TBI VR programme).

This process is enhanced by the in-depth analysis of the histories of three members of the study sample and the Woking Out *modus operandi*. In particular the process of applying realistic evaluation identifies the contexts within which decisions on the future and factors influencing choices, such as domestic, clinical and rehabilitation circumstances, are made. During this process the role of critical stakeholders is identified.

Again the lessons to be learned from this process are applied to the development of the theoretical model programme. This is reflected in the way barriers to employment are identified and addressed, and the way compensatory strategies are introduced.

It will be noted how the overall methodological strategy is applied to the development of the model programme. It starts with reference to the RCT for lessons in respect of customer identification, engagement, recruitment, compliance and retention to the statistics, originally designed to develop an 'employability index' (Annex 8) forming the basis for a discussion on the results, enhanced through applying the realist approach to the case studies to examine the contexts and mechanisms accounting for the outcomes in these cases. This is supplemented by applying the same approach to the Working Out programme. All this information is used to develop a framework for understanding employment outcomes following TBI (Chapter 10) and the model VR programme in Part 3, the specific methodology varying according to the research needs when examining a particular aspect of the RTW process and devising a VR model to meet the identified needs.

**6.5 Summary and Main Points:** Concern in respect of collecting as much perceived relevant data as possible, and over- optimism as to what could be achieved, contributed to establishing too many variables. With hindsight, it is recognised that the data collection could have been more focussed , for instance, there was no need to ponder over the occupational classifications. However there are more general lessons in respect of:

- Achieving some consensus in respect of the main clinical variables to be used (and how these are to be measured ). For the purpose of collecting and organising a large amount of clinical data this study has adopted PTA as a measure of injury severity and categorised symptoms by clinical groupings although some potential disciplinary 'overlap' is recognised, particularly between the neurological and (neuro)psychological domains. Whilst no study appears to have previously adopted this approach it is considered that a manageable means of sorting a large amount of clinical data for occupational purposes is essential if, for example, staff on VR programmes are to seek appropriate medical guidance.
- Validating data. When interviewing the subjects and collecting the data it was often difficult collecting basic information such as educational qualifications and work history. Whilst this may have been a consequence of the injury, family members were often

equally vague.

Other researchers have not reported such limitations in respect of the potential consistency of their data, perhaps because of a reliance on collecting data from their own work sites, although meta-analytic studies have seemingly extracted data without considering the means whereby it was recorded. If multi-site TBI RTW studies are to be undertaken there is a need for some consensus in respect of the data is to be collected and how this is to be validated.

In this instance the literature has been used extensively to identify the variables; there has been a reliance on the word of the subjects and their families; clinical data has been measured with different instruments and, apart from the severity of injury, only frequency is recorded and pragmatism has entered the equation with regard to classifying occupations for analysis. This brings with it research limitations. There is no attempt to 'weight' the clinical data. Other than PTA no attempt is made to assess the relative impact of specific symptoms on the employment histories of the subjects.

Equally critical is the reliance on the word of the subjects, and their families, as the outcomes measures, particularly the reasons for losing jobs.

Answers affect outcomes when the data is analysed. When the response was not clear, for example, whether or not a rehabilitation course was attended, that particular subject was excluded from that part of the analysis.

Finally, this Chapter has described how the combined methodological strategy has been applied to the data in order to meet the aims and objectives of the thesis. In the VR sector methodological pluralism is considered to have advantages over any single approach, for example whilst group data cannot address the circumstances of a specific individual realism can do so.

#### **CHAPTER 7**

# RESULTS: THE RELATIONSHIP BETWEEN COMMONLY FOUND VARIABLES REPORTED IN THE LITERATURE AND A RETURN TO WORK AMONGST THE STUDY SAMPLE

#### **Contents**

7.0	Overview	191
7.1	Results of Description and Association Statistics	191
7.2	Discussion of the Findings from the Study Sample	201
7.3	Study Sample Experience of Jobcentres	215
7.4	Summary and Main Points	217

**7.0 Overview:** Chapter 7.1 reports on selected demographic and intervention variables and outcomes in respect of:

- age
- gender
- domestic circumstances
- qualifications
- pre-injury level of education
- socio-economic status
- pre-injury work history (regular/irregular employment)
- nature of a return to work
- influence of clinical/vocational rehabilitation
- severity of injury

It further reports the frequency of clinical symptoms. Description and association statistics are relied upon for comment on group relationships. The purpose of this exercise is to identify factors to be taken into account when planning vocational intervention. The statistical approach is considered adequate for addressing the Aims and Objectives of the research in respect of the study sample when supplemented by further investigation. Discussion on the statistical data is saved for Chapter 7.2. It will become clear that the statistical findings resulted in the direction of the thesis being reconsidered. Chapter 7.3 is a review of the study sample experience of Jobcentre Plus. This stems from the preceding sections identifying limited contact and

, generally, unsatisfactory outcomes.

7.1 Results of Description and Association Statistics: It will be recognised that with the

study sample located throughout England and Wales, and differing dates when the original injury occurred, data could not be collected at exactly the same points in time post-injury. Data are reported at two stages, firstly referring to a period between the injury and when the follow-up data was collected, reported as "any time" (post-injury), and, secondly, the position when this information was collected , what may be regarded as the final follow-up. It was considered that collecting data at two stages might reflect any change in circumstances, so, for example, drawing a distinction between when a subject may have returned to work at some stage post-injury but was not in employment when the data was finally collected. The final position is ordinarily reported unless otherwise stated.

#### Demographic

**Age:** The mean age on injury was 25 years, with a standard deviation of 10.4 years. The mean age when the final follow-up data was collected was 32.7 years with a standard deviation of 9.39 years.

The mean number of years between injury and the follow-up data being collected was 7.67 years (range 4 to 22 years, SD 3.096)<sup>10</sup>.

There was a significant difference in age at the time of injury between those who returned to work at any time post-injury and those who did not ( $x^2 = 2.44$ , df = .52, p = 0.018), younger subjects being more likely to subsequently have some work experience. (For analysis the subjects were grouped into those injured prior and subsequent to entering the labour market).

The mean age, on injury, of those who joined the labour market any time post-injury was 21 years in contrast to 29 years for those who did not do so.

**Gender:** 40 members of the study sample (74.1%) were male and 14 female (25.9%). There was no significant difference between gender and a return to work at any time post-injury ( $x^2 = .026$ , df = 1, p = .872) or on the final follow-up ( $x^2 = .106$ , df=1, p = .708 <sup>II</sup>).

<sup>&</sup>lt;sup>10</sup> The range was particularly extended by one subject injured before starting school, included because of the quality of data on him.

<sup>&</sup>lt;sup>11</sup> Fisher's Exact Test used for small sample sizes.

**Domestic Circumstances:** Many of the study sample continued to live at home with their parents:

	<u>_</u>
	Frequency
Married/living with partner Married/living with partner and children Single, living with dependent children Single, living with parents Single, living alone Other	4 9 2 19 11 9
Total	54

	Table 8.1:	Domestic	Circumstances	on	Follow-L	Jp
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On dichotomising domestic circumstances (living in a family group as opposed to living alone), analysis showed no significant relationship on returning to work at any time post-injury ( $x^2 = 2.619$ , df = 1, p = 0.106)<sup>12</sup>.

Despite a mean age of 32.7 years on follow-up, nearly 54% of the study sample remained single with a third continuing to live with their parents. This percentage excludes the 'Other' category, in the main subjects either living in their own accommodation with a carer or in sheltered accommodation, in one case a residential community and, in another two cases, sharing rented accommodation. One member of the study sample, living at home with her husband and children, required a live-in carer.

**Education:** Most of the study sample left full-time education at the minimum school-leaving age (68.5%, 37 members), 24.1% (13 members) left aged 18. Generally members of the study sample were not well qualified:

	NVQ 1/2 CSE, GCSE	31	57.4
	A-levels/equivalent	4	7.4
	HND/degree	3	5.6
	Vocational		
	qualification	6	11.1
	No qualifications	10	18.5
	Total	54	100.0
1			

#### Table 7.2: Highest Level of Qualification of Study Sample

<sup>&</sup>lt;sup>12</sup> Return to work is defined as paid activity including open, supported, sheltered and therapeutic/permitted activity.

Dichotomising, 44 people with educational qualifications, 25 (57%) worked at some point postinjury (any time) as did 3 (30%) of those without vocational qualifications. This difference is not significant ( $x^2 = 2.347$ , df= 1, p = .169) although, clearly, this finding could be confounded by the small number in the latter group.

**Socio-Economic Status:** In respect of socio-economic status at the time of injury the Standard Occupational Classification (SOC) system does not lend itself to analysis, excluding students. Hence, a simplified classification system has been used including students (Table 7.3).

# Student/Working Age at Time of Injury: Dichotomising the pre-morbid status

(employed/working age: student/pupil) there was no significant relationship between pre-morbid status and either a return to work/participation in the labour market at any stage between injury and follow-up nor when the follow-up data was finally recorded (respectively  $x^2 = 1.763$ , df = 1, p = .184 and  $x^2 = 1.736$ , df=1, p = .287)

	Frequency	Percentage
Manual worker White	23	42.6
Collar/Professional* Student/pupil**	8 22	14.8 40.7
Total	53	98.1
Not included**	1	1.9
Total	54	100.0

 Table 7.3: Socio- Economic Status on Injury

\* One housewife included in this category because of her employment history and stated intention to resume work at the time of injury.

\*\* Injured prior to starting school but included because he otherwise met inclusion criteria.

**History of Regular Employment:** Twenty-two (22) members of the study sample (71% of the working age group at the time of injury) had a pre-morbid history of regular full-time employment from 31 in the labour market (one about to start seeking work) at the time of injury.

There was no significant difference in respect of future labour market participation at any time post-injury whether or not the study sample had regular or irregular work histories ( $x^2 = 2.695$ , df=1, p = .132).

**Nature of a Return to Work:** Of the 14 members of the study sample injured as adults going on to have some post-injury work history, 10 returned to work on a full-time basis and 4 on a part-time basis, including therapeutic activity.

All bar one of the nine subjects who returned to the same employer also returned to the same job, but not always initially on a full-time basis. Whilst it is possible that the means of collecting data (questionnaires, telephone calls and interviews) resulted in missing some salient data, it appears that job modifications ('easier' work or support) were rare. One subject and his wife reported that he was given "an easier job" for two weeks, before being expected to resume his former occupation (he could not cope and his position was subsequently terminated). Another subject was provided with reduced hours by his father.

For those who returned to work at some stage post-injury (45% of those of working age at time of injury) there was a pattern of short-lived activity and job changing so that at follow up only 4 remained in regular employment, a final return to work rate of 13% in this group when reported as a 'snap-shot'. When those injured as students/pupils are included (plus the one injured before starting school) there is a follow-up return to work rate of 18.5% in this study. Whilst lower than other reported UK studies, for instance Brookes et al (1987) at 29%, one has to consider the overall severity of injury as measured by PTA reported later in this section.

It was not possible to establish the number of jobs one member of the study sample may have had nor was it possible to establish for how long others may have held their positions. Subjects and relatives were often vague or disagreed over such matters. Hence, data in respect of job duration and the number of positions held, is limited. Excluding the one member of the study sample for whom the data was notably unreliable, 10 members had had one job on follow-up, 2 had had four jobs and 3 had had three or more jobs. Two members of the study sample had held continuous employment for more than one year, two for more than two years and one for nearly five years. It would appear that following the injury, a number of the subjects who returned to work for a short period never worked again when one or two jobs failed.

For those in education at the time of injury (and one injured before starting school), the pattern of limited labour market experience, short-lived employment and a fall-off in the final number employed similarly emerges. Of the 23 members of the study sample within this group, 14 went on to subsequently have some work experience (61% of this group). Whilst it is not unusual for young people to change jobs, on follow-up, 2 had had one job, 1 had had two jobs, 2 had had three jobs, 3 had had three jobs and 3 had had more than three jobs at the time the data was collected. In respect of the status at that juncture, only 6 remained in regular paid

activity including one part-time and 3 in supported and therapeutic activity.

In respect of the discussed outcome categories, the final follow-up return to work figures are given in Table 7.4:

	Full-time (defined as a minimum of 22 hours per week.)	Part-time
Open employment	6	1
Supported employment	2	
Sheltered employment		
Therapeutic activity		1
Voluntary work		
Unemployed/in receipt of incapacity benefits	44	

Table 7.4: Final Return to Work Figures

Overall, therefore, 52% of the study sample had some post-injury work related experience, but only 18.5% remained in some form of paid activity, on average, 7.67 years post-injury.

Return to Work Following Rehabilitation: The number of subjects receiving clinical/cognitive rehabilitation may be under-recorded and, consequently, data referring to this intervention cannot be considered reliable. The information from two subjects on receiving clinical rehabilitation was so confused that they were excluded from this part of the analysis.

Table 7.5 :Return to Work (Any Time) Following Renabilitation				
		Receiving Rehabilitation	No Rehabilitation	
Return to work	Yes No	12 13	16 11	

\* Clinical and/or vocational rehabilitation.

By the follow -up, the numbers maintaining employment had fallen away.

		Receiving Rehabilitation	No Rehabilitation
Return to work	Yes	6	4
	No	19	23

Table 7.6 :Return to Work Following Rehabilitation on Follow-Up

Half of the subjects receiving rehabilitation remained in employment at the follow-up stage compared to a quarter of those receiving no rehabilitation. An initial analysis showed no statistical significance between receiving clinical and/or vocational rehabilitation and a return to work at any time between injury and the follow-up ( $x^2 = .662$ , df = 1, p = .416). There was also no significant relationship between rehabilitation and a return to work on follow-up ( $x^2 = .705$ , df = 1, p = .401) nevertheless the number of subjects not receiving rehabilitation and maintaining employment will be noted.

In respect of the subjects receiving vocational rehabilitation alone:

		Vocational	No
Return to work	Yes	7	21
	No	7	19

Table 7.7 :Return to Work (Any Time ) following Vocational Rehabilitation

By the time of follow-up, the numbers maintaining employment had fallen away.

		Vocational Rehabilitation	No Vocational Rehabilitation
Return to	Yes	4	4
Work	No	10	36

The most obvious feature is the way that the subjects not receiving vocational rehabilitation subsequently failed to maintain employment. However, there was no significant statistical relationship between those receiving vocational rehabilitation and a return to work at any time post-injury ( $x^2 = 0.26$ , df = 1, p= .872) or on follow-up ( $x^{2} = 2.834$ , df = 1, p = .183).

**Severity of Injury:** The study sample was a particularly severely injured group (Table 7.9). The figures contrast with Fraser et al (1988)( see Introduction) indicating the following general figures in the American population (UK not available). It is recognised that an explanation as to why the study sample may not be representative, that is a particularly severely injured group, is because they all had substantial claims for compensation:

Mild/moderate head injury 95% Severe/very severe 5%

Frequency	Percentage			
7	13			
13	24			
32	59			
	Frequency 7 13 32			

 Table 7.9: Frequencies of PTA Severity

The data for two subjects was too unreliable to include (although one made an initial return to work). On dichotomising the severity (minor and severe/very severe) the following picture emerges.

Table 7.10 : Return to Work at Any Time Post-Injury by Severity of Injury

RTW	Minor	Severe/VS
Yes	4	23
No	3	22

Table 7.11: Return to Work Position on Follow-Up by Severity of Injury

RTW	Minor	Severe/VS
Yes	1	9
No	6	36

Whilst there is no statistical significance in either case ( $x^2 = .088$ , df = 1, p = 1.0 and  $x^2 = .127$ , df = 1 and p = 1.0) between the severity of injury and the inability to return to work and maintain employment (follow-up), it could be the case that the small number of subjects receiving minor injuries is confounded by exceptional circumstances.

# Frequencies of Clinical Symptoms

In respect of other injuries, it is reiterated that because of the way this information was assessed and reported by clinicians the *severity* of each variable could not be recorded, only the frequency (Table 7.12). This is a common problem in rehabilitation studies.

# Table 7.12: Clinical Frequency of Injuries

Problem	Frequency	Percent
PHYSICAL		
Balance	10	18.5
Lifting	16	29.6
Walking	12	22.2
Spinal cord injury	6	11.1
SENSORY AND MOTOR		
Visual	4	7.4
Hearing	1	1.9
Pain Perception	7	13
Smell	4	7.4
Seizures	15	27.8
Taste	1	1.9
Co-ordination	7	13
PSYCHOLOGICAL		
Memory	48	88.9
Writing	5	9.3
Attention/concentration	33	61.1
Organisation and Planning	17	31.5
Communication	15	27.8
Visual-Spatial	7	13
Speed of Information Processing	10	18.5
EXECUTIVE FUNCTIONS		
Dysexecutive syndrome	18	33.3
Unable to initiate motor acts	4	7.4

Planning/executing goal		
directed behaviours	1	1.9*
Sequencing difficulties	1	1.9**
Loss of self monitoring ability	7	13**
Inability to analyse social		
situations and self-adjust	7	13
EMOTIONAL		
Depression	14	25.9
Anxiety/stress	7	13
Frustration	8	14.8
Anger/irritability	19	35.2
Behaviourally out of control	8	14.8
Mood Swings	11	20.0

\* With the exception of one case, this deficit was always reported as part of a dysexecutive syndrome. This particular problem is considered to be much more common than this figure records.

\*\* These particular deficits are considered under-recorded for the same reason.
 The most commonly reported 'other symptoms' included "personality changes" (5, 9.3%), and headaches (3, 5.6%).

Whilst a large number of return to work studies correlate symptoms with vocational outcomes there is a (surprising) absence of recorded frequencies.

In ranked order of this study's findings, the most common deficits are:

# Table 7.13: Ranking of Reported Symptoms

		%
1.	Memory	88.9
2.	Attention/Concentration	61.1
3.	Anger/Irritability	35.2
4.	Dysexecutive Syndrome	33.3
5.	Organisation and Planning	31.5
6.	Lifting	29.6
7.	Seizures	27.8
8.	Communication	27.8
9.	Depression	25.9
10.	Walking	22.2
11.	Speed of Information Processing	18.5
12.	Balance	18.5

**7.2 Discussion of the Findings from the Study Sample:** Chapter 7.2 addresses the following variables and issues:

demography

family and accommodation

pre-injury level of education, occupational status at time of injury, and post-injury qualifications

the high level of post-injury job loss

regularity of pre-injury employment

return to work and injury severity

rehabilitation

#### Demography:

The fact that so many of the study sample were young at the time of injury, either in education or at the start of their working lives, is consistent with other studies (Brooks et al, 1987a).

Whilst those injured as pupils/students generally had a better prospect of returning to work than older subjects, the pattern is not consistent. Whilst the small study sample is recognised the figures challenge a view that is sometimes referred to as the 'Kennard Principle' (1940) that brain damage in childhood causes less damage in children than adults and little or no observable functional loss in long-term outcomes (Smith, 1983). One can still see such opinions reflected in medical reports for personal injuries litigation, namely:

- 1. That young people sustaining TBI go on to make good recoveries and successfully participate in the labour market.
- That obtaining and maintaining a job for a period is indicative of the capacity to carry on doing likewise. It is clear that a period of labour market participation on leaving school, or an early return to work following TBI, are no measures of continuing capability.
- 3. That following the settlement of personal injury claims, claimants sustaining TBI go on to make recoveries sufficient to allow them to return to work. In this study none of the subjects improved their employment status following the conclusion of their claims. The converse was true, two subjects lost their jobs, both following the onset of late posttraumatic epilepsy, although one case was further complicated by the breakdown of his marriage.

Factors that were considered likely to positively contribute to a return to work, such as the level of domestic support, level of qualifications (considered to reflect intellectual ability), and previous work histories have not proven statistically significant. In a small study sample, random factors may influence the findings. Other possible explanations for the lack of statistical significance are as follows:

- The fact that someone has a partner, or lives with their parents, does not necessarily mean that they are receiving appropriate encouragement to return to work.
- Whilst it was considered that those with educational qualifications are more likely to return to work, the pre-injury level of qualifications held by the study sample is low. Hence, the 'real' comparison is between a low level of educational/vocational achievement and no qualifications at all, rather than a contrast with higher level qualifications/vocational attainment.
- The situation with regard to pre-morbid work history is difficult to explain. It was considered that those with established work histories were more likely to return to work than those with irregular work histories. However, this was not the case. Whilst it is recognised that in a small study sample other variables may become more significant, such as the particular neuropsychological sequelae, in respect

of this study sample there is no support for a commonly held view that pre-injury work histories are a reliable indicator of a potential return to work.

#### Family and Accommodation Circumstances:

It is apparent that TBI can have a significant adverse impact upon the capacity to enjoy and sustain 'normal' social relationships. The effects domestic circumstances have upon the capacity to return to work have not been fully investigated in RTW studies. It is considered reasonable to suggest that when planning vocational rehabilitation programmes, and a return to work, that the nature of domestic support needs to be investigated, and, in the absence of appropriate support, suitable alternative measures need to be implemented.

In this study, the data were collected on the premise that those subjects living in a family group, with a partner and possibly with children, are likely to receive more support and be more motivated to return to work than those living on their own or in other circumstances (although a risk of being caught in the 'benefits trap' is recognized).

In the event it is apparent that it is unwise to make this assumption. A surprising number of single subjects in their 20s and 30s continued to reside in the parental home, leading to the postulation that it is a *consequence* of deficits in coping within the community, including obtaining and maintaining employment, that contribute towards continuing to live in the family home and not necessarily a case of residence in a family home supporting a return to employment.

One subject reported that although he continued to live with his wife and children, his wife was petitioning for a divorce as a consequence of his changed behaviour. (Although not a focus of this study another subject also attributed his divorce to a changed personality and behaviour and a further subject reported that his partner had asked him to leave her and their two children for the same reason).

One potential subject was excluded from this study because it was considered that her family conspired with her to maximize potential civil damages by claiming that she was less capable than *all* the examining experts considered her to be, and, hence, could not attempt to undertake any work activity. This threw into doubt the accuracy of much of the recorded clinical data because of accusations of exaggeration.

In another case it was suggested by some clinicians that a wife was (inadvertently) reinforcing her husband's poor self-image and low esteem by doing everything for him and, thereby, not encouraging him to return to work. This subject was included in the data because, in my view (and two visits were made to the home), such observations were not justified. This situation illustrates the difficulty in determining whether or not a person with TBI is, or is not, receiving positive support and encouragement to return to work and the fact that it is unsafe to make assumptions just because of domestic arrangements.

In respect of findings on follow-up:

- 19 (35%) of the sample continued to live in the parental home
- 11 (22%) lived on their own
- 9 lived with their partner and children (including one supported by a live-in carer)
- 4 lived with their partner alone
- 2 lived with their child(ren) alone
- 9 had some other living arrangement. Of these 3 lived in shared accommodations, 3 in sheltered/residential accommodation and 3 had live-in carers.

It has been explained why this information is not entirely reliable for analysis in respect of the reason for which it was collected. Nevertheless one employment related issue is noted. Nobody considered incapable of living independently in the community made a successful return to the open labour market. Whilst the sample size is too small to lead one to a conclusion that this would always occur, it is possible that independent living skills may be a necessary pre-requisite for labour market entry, although, as noted in Chapter 3.1, there are *levels* of employment and observing that a person with TBI may not be capable of work in the open labour market is not necessarily the same as saying they are incapable of some work related activity and have no earnings capacity. One of the subjects lived in a residential rural community where he had undertaken various activities, such as car washing, that had provided him with an (irregular) therapeutic income.

# Pre-injury level of education, occupational status at time of injury, and post-injury qualifications:

Thirty-one (31) members of the study sample were injured after leaving full-time education; 22 were injured whilst still in education and one was injured before entering education.

It was surprisingly difficult collecting the educational qualifications of the subjects in the labour market at the time of injury and a trial differentiating between O levels, CSEs, and GCSEs, grades A to C and below, had to be abandoned in favour of grouping together qualifications at this level, including one Scottish Certificate of Education. A number of the subjects were confused as to the exact nature of their qualifications, for example whether or not they held CSEs or GCSEs. One subject was a mature student at the time of injury. Because he had work experience he was included within the employment group.

Similarly, whilst Table 7.3 groups pre-injury status, it was not easy to classify pre-injury occupational status in line with the SOC socio-economic status and some judgement had to be used in respect of the <u>main</u> activity. The main problems were that members of the study sample held jobs that did not lend themselves to one classification, for example running a business but often working in a 'hands on' manual capacity, jobs in IT not (yet) covered by the SOC, and difficulty in determining the skill level. More than one respondent insisted his job was skilled, although he had undertaken no specific training, other than 'on the job', and held no qualifications. In the circumstance, it was decided that the only practical solution for analysis was to opt for manual and non-manual titles (main activity). Most members of the study sample had manual backgrounds. Typical jobs held were in service industries, the building trades and factories. Non-manual jobs included sales representative and legal executive.

In respect of post-education and pre-injury qualifications and occupational status for the study sample employed at the time of injury.

- 17 had undertaken vocational training, for example part-time attendance at College to obtain craft or secretarial training (this category also included the acquisition of a Large Goods Vehicle and a Fork-Lift driving license)
- 6 had undertaken professional or higher technical training (two as adults)

By socio economic status at time of injury (SOC):

17 were in skilled occupations

- 9 were in unskilled occupations
- 7 were in Intermediate occupations
- 5 were in partly skilled occupations

1 was a housewife (included in the non-manual group for analysis because of her previous secretarial work history)

It will be noted that only four subjects from this group made a successful long-term return to a job in the open labour market. There is modest evidence of deskilling, one subject held a managerial/supervisory position in MacDonald's and returned to work as a crew member, but the lack of substantial evidence on deskilling may only reflect the nature and status of the preinjury employment. It should be further noted that there is not necessarily a relationship between the level of qualification and occupational status. For example one person with modest educational qualifications, leaving school aged 16, had risen to a managerial position in a large organization at the time of injury. Another person had trade qualifications but worked in an unskilled capacity whilst, conversely, two others, both in the building trade, undertook skilled jobs although possessing no qualifications. One had learned 'on-the-job' and the other had been trained in a family business.

For information, the following post-injury qualifications were obtained by the group employed at the time of injury:

#### 1 degree

- 2 National Vocational Level 1 qualifications (whilst there are difficulties equating this with a low grade GCSE, because it is competency and not examination assessed, this is probably not an unreasonable approach).
- 2 other members of the study sample started Level 1 courses but failed to complete.

The subjects injured as students/pupils obtained a range of qualifications at GCSE level or equivalent. It has not been an objective of this study to discover whether or not the qualifications are lower than pre-morbid estimates. There were frequent anecdotes from subjects and their families in respect of difficulties experienced in resuming courses.

It is considered that the skills required to successfully obtain educational qualifications postinjury are not necessarily the same skills required for successful labour market participation. Educational courses may contain a significant element of continuous assessment. For instance, a student can take work home and prepare assignments in his/her own time; there may be little requirement for the maintenance of appropriate interpersonal skills; there is rarely a need for a consistent 8 hours application during the day and there is often the opportunity to deploy useful compensatory approaches, for instance obtaining lecture notes or taping lectures/seminars.

Overall the picture post-injury is one of substantial inactivity. Amongst the adults, apart from the one person who pursued a degree, the only subjects to undertake any accredited training post-injury were those in vocational rehabilitation case management programmes (and one supported by a brain-injury case manager). It is noted that both subjects who did not complete a course were supported by their DEAs and placed with generic training providers. One reported that 'the course was for people with physical disabilities and was not suitable for me'. On the other hand one subject who did complete a course was offered extensive support by his DEA, attending no less than 3 work preparation/employment rehabilitation courses.

On follow-up, two of the subjects undertaking training undertook therapeutic and voluntary activity. One subject with a young child at home, did some occasional unpaid work for her self-employed husband. None had resumed open employment.

The different RTW rates between study samples in education and employment raises the question as to whether or not they manifest different labour market entry problems and/or require the different vocational strategies.

On the face of it, the problems manifest by those subjects injured as young people were not substantially different to the ones experienced by the adults (although they did not have the same pre-injury work experience to draw upon). As younger people have the rest of their working lives ahead of them it may be considered both morally and financially sensible to put resources into addressing their employment needs. This begs the question as to what can be done to further enhance their prospects.

Job retention. Why did so many of the study sample fail to maintain any degree of continuity of employment?

The collection of data for this study necessitated a reliance upon accepting the word of the participants and their families. In practice, it was difficult to establish why so many of the study sample lost or left their job. Replies were often vague, for example "*I don't know, I thought I was doing alright....*", or possible rationalisations, for example, "*I don't think they liked me*". Examples of given reasons are:

Factory worker, "I couldn't stand the noise .... "

Shop assistant, "I got muddled and tired."

Laboratory worker, "I started having fits, I couldn't drive to work any more...."

Care-assistant, "She was having arguments....." (mother)

Factory worker, "He was making suggestive comments to the girls at work...." (mother)

Delivery driver, "He was getting the orders wrong and damaged the vehicle three times..." (employer in Court evidence)

One subject finished her part-time position for (seemingly) reasons unrelated to her injury, deciding to concentrate on a full-time education course.

Nobody has reported the reasons why people with TBI lose their jobs in the UK, possibly because nobody has previously noted such a significant retention problem. "The 'snap-shot' reporting of figures can be misleading. For example, even if RTW rates are reported at 12 and 24 months, consecutive figures of, say, 30% and 25% may seem to suggest that 5% of the subjects failed to maintain employment. However, if half of the 30% of the study sample returning to work at 12 months lost their jobs in the next 12 months but another 10% of the study sample found jobs, then the 'snap-shot' report at 24 months will only indicate a 5% 'fall-off' in retention when the actual rate is three times that level.

MacKenzie et al (1987) suggested that transport difficulties, form filling, lack of encouragement as well as unrealistic expectations and benefits issues contribute to initial low RTW figures but whilst such factors may overspill *into* a job there is seemingly something else going on. It will be evident from the research findings that few of the subjects received any assistance towards finding a suitable job. When asked how the positions were obtained, typical responses related to returning to the former employer, responding to newspaper advertisements and Jobcentre vacancy displays. Silver, Piasetsky and Rattok (1987) suggest that poor self-awareness and unrealistic expectations are the primary contributors to high post-injury unemployment rates. What is clear with the study sample is that with the exception of the three subjects who attended Rehab UK Brain Injury Vocational Centres, there was little or no discussion with the employer in respect of the nature of TBI and the likely problems to be encountered. Even in one case when an occupational physician made constructive recommendations to the employer, this was not accompanied by any discussion or follow-up so that when the subject returned to work, he was expected to resume normal duties within two weeks.

#### Regularity of pre-injury employment:

An assumption a reader could sometimes make is that when return to work figures are published they reflect a notional comparison that in the ordinary course of events 100% of the subjects could be expected to be in employment, unless pre-injury employment rates are specifically included. This position can be reflected in reports on the efficacy of vocational rehabilitation (see Rehab UK's submission to the House of Commons Select Committee on Health, March 2001).

As the National Traumatic Brain Injury Study reported (Stilwell et al 1997) such an approach does not reflect the reality of current patterns of labour market participation, and it is considered such reporting does the rehabilitation sector no favours when considering the fact that some clients may have had pre-injury employment difficulties.

Reference to RTW studies does not help establish an identifiable operational definition of 'regular employment'. Whilst there is some confidence that regular employment is accurately recorded, with the subjects of working age at injury reporting continuous employment in the 2 years prior to injury with no lengthy or frequent periods of unemployment in their working lives, it is recognised that converse may not necessarily reflect 'irregular employment', is it reasonable, for instance, to describe someone returning to full-time education or staying at home with young children as being in 'irregular employment'? However, for research purposes, an operational definition was required albeit the situation illustrates the need for a standardisation of such matters in VR research and the need for accurate employment data, and how to obtain it, is discussed in Part 3.

#### **Return to Work and Injury Severity:**

Of the 54 members of the study sample (40 men and 14 women) 28 (52%) undertook some work-related activity post-injury. This is considered high, especially when one considers the overall injury severity of the group compared to the figures cited by the National Traumatic

Brain Injury study (Stilwell et al, 1997) and Stambrook et al (1990). Typically 5% or less of the population are likely to receive a severe or very severe injury. In the study sample 32 sustained a very severe injury, 13 a severe injury and 7 a minor or moderate injury. It was not possible to establish the period of PTA from the clinical records for two people.

The definition of 'work-related activity" is a broad one, incorporating open employment, supported employment, sheltered and therapeutic activity. Of the study sample 20 (37%) undertook activity in the open labour market and 8 (15%) in supported or therapeutic activity. It will be noted that 26 members of the study sample (48%) undertook no work-related activity.

Disappointingly, of the 28 (52%) undertaking some work related activity post-injury only 10 (18.5%) were able to maintain any continuity of activity, that is not punctuated by breaks of 3 months or more. Of the 10, 3 were in supported and therapeutic activity, leaving just 7 people (13% of the study sample) able to maintain continuity of employment on the open labour market. The percentage of the study sample unable to maintain a job (33.3%) is close to double the percentage able to maintain work (18.5%).

There is nothing remarkable about the final resettlement figure, particularly bearing in mind the degree of injury severity (the lack of statistical significance between severity and RTW may be confounded in this study by a small number of subjects with minor/moderate injuries sustaining significant secondary damage). In a UK (Glasgow) study Brooks, et al (1987a and b) found that 29% of individuals who were employed prior to experiencing a brain injury were working 7 years following their injury. The suggestion was that the number of subjects losing their jobs was probably balanced by the number of other subjects obtaining work during the study period. hence the overall resettlement figure remained fairly constant, however this is not backed up with data. Jacobs (1987) in a follow-up study of 142 people who were employed at the time of injury found that 27% were employed 1 to 6 years post injury; 13% had returned to work but lost their positions before the follow-up interview. Another study of 78 individuals in a supported employment programme in the USA (Sale, et al, 1991) reported 38 'job separations'. Whilst more recent data suggest more optimism for RTW potential (for example Rehab UK's submission to the House of Commons Select Committee on Health, 2001, indicating a 60% return to work rate following vocational rehabilitation and a further 12% in therapeutic activity) definitions of employment and gainful activity vary widely between studies making comparisons of relative outcomes difficult.

The fact that only 10 people were able to maintain any continuity of work related activity means that 18 (33%) members of the study sample were either unable to build on supported or therapeutic activity (5 people) or (13 people) to hold down a job in the open labour market.

**Full-time or part-time work activity:** unfortunately (in view of the frequency with which fatigue is reported) it was not possible to establish exact data on the number of hours participants were able to work when they did work. One respondent, working for his father was allowed to 'come and go', another that he worked full-time but that 'it isn't really, it is just called full time'. Another person reported that she worked part time, but had she not also been attending college part time she could "probably work longer hours". Further, another member of the study sample reported that she worked part time because only part time hours were available to her. One of the study sample member's wife commented that when her husband was working full-time he would come home 'ranting and raving' and go to bed early. Hence, even if working full time there is a possibility of paying a social price for this. The issue of collecting reliable employment data is further discussed in Part 3.

#### **Rehabilitation:**

A fundamental problem when assessing the influence of rehabilitation on a return to work was the confusion amongst the subjects (and their families) as to whether or not they had received clinical rehabilitation, as opposed to treatment (see glossary for the operational definition of clinical rehabilitation). Clinical rehabilitation is only recorded when there is evidence of attending a clinical/cognitive rehabilitation programme as an outpatient.

The lack of any association between rehabilitation and return to work has been found by other studies (in particular the National Traumatic Brain Injury Study 1998) but it is, nevertheless, disappointing, in particular, the lack of any association between vocational rehabilitation and a return to work. Possible explanations are not hard to find. The quality of some vocational rehabilitation programmes left much to be desired. For instance, a young man in West Yorkshire was referred by his Disability Employment Advisor to a residential programme in Surrey. He had significant behavioural problems and his course was almost inevitably terminated after a number of weeks. In another case, a former ex-Policeman in the Potteries was referred to a generic work preparation provider. He reported that "nobody understood my problems" and he quickly terminated the course. Not all experiences of the Employment Service was negative. In another case in the West Midlands a DEA spent a considerable amount of time finding suitable work experience placements and providing the

trainers/employers with appropriate guidance. However, the subject simply could not cope with even reduced work demands. In another West Midlands case, it was apparent that the young man received an excellent assessment and guidance by Rehab UK but the local DEA could not find a suitable part-time supported employment position for him. At the time of follow-up for this study both he and his mother had "given up".

**Employment outcomes and rehabilitation:** twenty-five members of the study sample (46%) received either clinical and/or vocational rehabilitation. Eleven (20%) of the study sample received clinical rehabilitation alone (9 with a very severe injury, one with a severe injury and one with a mild or moderate injury), 7 (13%) vocational rehabilitation alone, and only 7 (13%) both clinical and vocational rehabilitation. Only 19 people were provided with clinical rehabilitation (by the definition above<sup>13</sup>) including 15 (from 32) with a very severe injury, 2 (from 13) with a severe injury and 3 (from 7) with mild or moderate injuries. Notwithstanding the small sample sizes the figures appear to suggest that those receiving a very severe injury are more likely to receive clinical rehabilitation than those receiving a severe injury (particularly bearing in mind the relative distribution in numbers). It is apparent from a study of the 3 cases of mild or moderate injury receiving clinical rehabilitation that this was only provided after being expected to spontaneously make a full recovery but failing to do so.

**Employment outcomes of those receiving clinical rehabilitation alone.** Of the 11 people receiving clinical rehabilitation alone, 4 subsequently had some work–related experience (of these 2 had sustained very severe injury, 1 severe and 1 is not known) but only 2 went on to maintain continuity of employment, both with very severe injuries although 1 subject continued to report significant sequelae he returned to a sympathetic pre-injury employer. His work required a level of organizational ability he had lost. The other subject made a remarkable recovery and illustrates the danger of using the severity of injury alone to forecast prospects.

It is considered noteworthy that in a number of cases clinicians recommended clinical rehabilitation on the grounds that it would assist the patient back to work, for example in respect of one of the above cases a neurologist prognosticated that 'a course of neuropsychological treatment' would lead to 'some form of sheltered employment. I think this is possible...'. Six years following injury and following intensive cognitive rehabilitation, this

<sup>&</sup>lt;sup>13</sup> 11 and 7 clearly makes 18. The figure 19 includes one person on whom the VR data was unreliable and, hence, could not be described as receiving clinical rehabilitation 'alone'.

member of the study sample was not considered fit for any work by other examining and treating clinicians. On only one occasion did a consultant (a pain specialist) specifically say that *'treatment will not make any difference* (to employment prospects)'.

(Although the 'accuracy' or 'inaccuracy' of clinical opinion in respect of the employment prospects of those sustaining TBI is not the subject of this report, the relationship between clinical symptoms and subsequent occupational status and advice given to patients is a matter which does need to be considered.) In another case, in which the member of the study sample unsuccessfully returned to his pre-injury employer, a forensic psychologist (not a neuropsychologist) opined that a course of cognitive behavioural therapy would enable him to return to his pre-injury employment. Recommendations made by myself for a gradual return to work, preceded an appropriate job analysis and matching of the subject's capabilities against available work, and continuing *in-situ* support were ignored in favour of clinical treatment. Only when this treatment failed, and seven years following injury, was vocational support proposed by an insurance company, although, at the time of follow-up, this had still not been implemented. In the meantime the subject had returned to work and lost his job.

Employment outcomes of those receiving vocational rehabilitation alone: only 7 members of the study sample received just vocational rehabilitation (although another one received financial support to attend a Rehab UK Brain Injury Vocational Centre he declined to take up a position because of the travelling distance, over 30 miles each way, and the fear of a seizure on the train). Another subject was taken by her care worker to a DEA for an assessment for the Supported Employment Programme. According to both a neurologist and neuropsychologist she was capable of this. The DEA declined to take any action because, in her opinion, and without referring for a vocational assessment, this subject lacked the stamina to meet the necessary performance targets. Another subject also attended a Jobcentre with a view to seeing a DEA and a referral to an employment rehabilitation course. This young man could present well, although there remained profound cognitive and behavioural sequelae. Post-injury he had had three jobs but lost them for reasons associated with his injury. He reported that instead of being referred by Jobcentre staff to the DEA he was sent to see a Personal Advisor (PA) from the New Deal programme. According to an accompanying family member the PA apparently said words to the effect that she could see 'nothing wrong' with the person concerned and that she did not understand why he should need additional support. Whilst it has not been possible to verify this anecdote the subject was referred to mainstream services rather than the specialist disability service. He did not take this advice and, on follow-up, remained assessed as unfit for work by the Benefits Agency, now Social Security and part of Jobcentre Plus. In another case (unusually) a clinical rehabilitation consultant described a vocational model she wanted the subject to undertake (it mirrored Rehab UK provision). Unfortunately in the locality there was nothing available. (It is noted that this consultant had sat on a British Society for Rehabilitation Working Party on vocational rehabilitation).

Of the 7 members of the study sample receiving just vocational rehabilitation support (13% of the study sample) 4 had sustained very severe injury and 3 severe injury. Three received support from a private sector vocational rehabilitation company, 1 with very severe injury and 2 with severe injury. Five undertook work placements in open employment and 4 went on to hold down a job, 1 in supported employment negotiated with by his DEA, brought in by an employment specialist to facilitate this process. Two people attended a Brain Injury Vocational Centre run by Rehab UK; both had sustained very severe injury. One undertook work experience placements and he went on to hold down a job in the open labour market. The other was referred to the Employment Service with a view to a supported employment placement but he was not found a placement. Two people were referred for employment rehabilitation/work experience courses by DEAs, one severe and one very severe injury. Neither was considered employable.

**Employment outcomes of those receiving clinical and vocational rehabilitation:** only 7 members of the study sample received both clinical and vocational rehabilitation (11% of the study sample). Of this group 4 sustained very severe injury, 1 severe injury and 2 mild or moderate injuries. Only 1 person (with a very severe injury) returned to regular employment in the open labour market (part-time work in the family business). The vocational rehabilitation received by 3 other people would not appear to have been suitable:

- one person was referred by his DEA to a residential centre over 200 miles from his home (on a course not offering any *in situ* supported work placements).
- a further member of the study sample reported being sent by his DEA on an IT course that was for people with physical disabilities, "It didn't help me".
- the third person had two weeks generic assessment arrangements made by a private sector employment consultant.
Two people appear to have been extensively assisted by DEAs without a positive outcome. G, the subject of case study and a complaint from a member of her clinical management team, was offered no further support by a DEA when a work preparation placement broke down (on the basis that no further regional funding was available for another placement). With the assistance of a case-manager effectively doing the 'spade-work', finding an employer, another DEA arranged three work placements for their client. Whilst this person was not employed at the time of the follow-up there was some optimism that he would be at least capable of therapeutic or voluntary activity.

**Employment outcomes of those receiving neither clinical nor vocational rehabilitation:** 28 members of the study sample (52%) received neither clinical nor vocational rehabilitation. It was expected that a higher percentage of those receiving a very severe injury would at least receive clinical rehabilitation but this did not occur (16 subjects did so, 50% of the 32 known to receive very severe injury).

In this group of 28, 15 received a very severe injury (28% of the study sample), 10 (18.5% of the study sample) a severe injury and 2 (4%) a mild or moderate injury. The severity of injury in one case was not established. Of all these subjects 16 went on to undertake some work-related activity but, on follow-up only 3 had a history of maintaining activity. The 2 people sustaining mild or moderate injury and receiving no rehabilitation both went on to have regular work histories.

Of the 45 members of the study sample known to receive a very severe or severe injury only 4 (9% of this group) made a successful spontaneous return to the labour market although 16 (36% of this group) did have some work related experience, 14 of them of them in the open labour market. Any 'snap-shot' study of their employment status could, at any one point, have identified these people as successfully resettled, when this was clearly not the case.

**7.3 Study Sample Experiences of Jobcentres:** An objective of this research is to develop a potentially efficacious theoretical vocational rehabilitation model (with a view to a condition management programmes for TBI subjects now being developed by Jobcentre Plus). Efficacy is not just a matter of getting the programme context right ( identifying and meeting customer needs) but, in the first instance, identifying, engaging, recruiting and retaining these customers. Chapter 7.3 relates the study sample experience of Jobcentre services with Chapter 10 further considering the lessons to be learned from Back to Work in respect of customer identification,

engagement, retention and compliance.

Members of the study sample consulting their local Jobcentres had mixed experiences.

**East Midlands.** A subject referred to her local DEA for an assessment at the Papworth Trust, case study KW, was told that because clinical evidence indicated fatigue this was likely to adversely affect her availability for work and, as such, she could not be assisted. (As a psychologist for the Defendant pointed out she had managed to attend College some distance from home on a full-time basis. Notwithstanding the different demands between College and work, stamina is not something likely to *decrease* over time. On the contrary it is often possible to gradually increase stamina. It is considered that the impact should have been monitored).

**South West.** A hospital-based Head Injury Rehabilitation Team wrote a letter of complaint to the local DEA over the 'odd dynamics' on a work preparation course, considering the patient's rehabilitation had been set back (case study G). In short, the agency did not understand the nature of brain injury and the difference between presentation and capability. The subject was given tasks beyond her capability, took her work home to revise and ended up 'breaking down'. A request for a more suitable placement brought the response that funding was not available.

**West Midlands.** In contrast, a DEA in this region arranged three work preparation courses for her client and visited all the agencies to discuss the nature of his symptoms and what she hoped the placement would achieve. The plan was to assess him for suitability for supported employment. Whilst this was not achieved it was not for the want of trying.

**West Midlands.** A former policeman was placed with a work preparation agency undertaking clerical/computer work. Whilst praising the work undertaken by the agency he reported that the staff did not understand his problems and he was making no progress. He terminated his course.

West Midlands. One subject was referred to Rehab UK in Birmingham. He was given a great deal of personal support, including a supported occupational trial in his home area. It was hoped that this would lead to a part-time supported placement. On completion of his course the DEA could not find a suitable placement. Contact was maintained for three months whilst the search continued but, at the time of the follow-up for this research, there had been no further contact for over two years. The subject, and his mother, had 'given up' the idea of

returning to work.

**North East.** A subject told to 'see the DEA' by his solicitor endeavoured to arrange an appointment at his local Jobcentre. The DEA was not available and he was referred to a Personal Advisor (PA). His partner accompanied him to the interview and reported that the PA said words to the effect she 'could see nothing wrong' with the subject. He presented well but, amongst other symptoms, he had significant memory and organisational problems. They did not return to the Jobcentre on the basis that 'they don't know what they are doing'. (It needs to be said that this experience is in contrast to the findings in Loumidis et al (2001), a study of the New Deal for Disabled Persons Personal Adviser Scheme. Most of the scheme's clients interviewed felt that it had made a positive impact on their prospects of returning to work although Loumidis also found a low level of 'joined-up' approach between Personal Advisers and other potential support services, such as health and social security).

**Yorkshire.** A subject with behavioural problems (disinhibition) was referred by his DEA to a residential vocational course. It lasted a matter of weeks before it was terminated because of his unacceptable behaviour.

Although one subject found a place in supported employment through the DEA (the initial contact and advocacy for this position having been undertaken by a case manager) most of the subjects had no contact with their local Jobcentres at all. They remained in long-term receipt of incapacity benefits and in the 'stock' of IB claimants, even though many had attempted a return to work only for it to fail. A noteworthy fact is that of the seven cases cited above *six* of the subjects were only contacted, or were put in touch with, their local Jobcentres once an attempt to return to work had failed.

**7.4 Summary and Main Points:** This chapter has addressed the relationship between a number of variables identified in the literature as positively influencing employment outcomes following TBI and their significance with regards to the study sample. Had there been a number of statistically significant relationships it would have been possible to have developed an employability index (although one requiring prospective development) identifying those unlikely to return to work in any event, those likely to require vocational rehabilitation and those able to spontaneously return to work (see Annex 8). It also needs to be remembered that geographical factors, such as the level of local employment may influence outcomes (a matter not factored into this study because the location of the members, from the North-East to South Wales, meant that there would be insufficient numbers for regional analysis).

Whilst a lack of statistical significance between the variables and a return to work (other than age) has been reported in other studies this was still not anticipated to the extent this occurred. The inference is that other factors (than the variables used in this study) were more significant in influencing the final outcome. The question is what were these factors?

For reasons previously discussed it was not possible to record the *degree* of severity of continuing individual clinical sequelae, only the frequency. The one factor that does give some indication as to the overall group severity of injury is PTA and, contrasted with the evidence in Chapter 2, suggests that the study sample was a particularly severely injured group.

But whilst severity of injury can account for a failure to return to work, it does not satisfactorily explain (repeated) attempts to return to work nor the apparent failure of rehabilitation programmes in this respect.

A high percentage of the study sample sought to join the labour market (over half of them), an activity described as a 'search for normality'. The inference is the subjects, their advisors and/or families must have thought they were capable of undertaking some work-related activity and, if the subject failed, they must have been either wrong in their opinion, the subject was in the 'wrong job' or else, *there was inadequate preparation and support*. It is recognised that, possibly, some of the subjects may have been pressured , or felt pressured, to return to work by either their own legal team or the defendant's legal advisors, but this still leads to the same observation. There is a need to take on board a number of important lessons

**1.There is a need for an assessment of 'work readiness' before attempting to return to work.** This is addressed in Part 3 when developing the model VR programme.

**2.There is a need to consider the reasons for the high level of RTW failures.** Unless the subjects were colluding in a return to work only to fail (an implausible explanation), there could be a number of potential explanations:

- They were not able to undertake any work (related) activity. In other words either the subject, or those around him/her, had unrealistic expectations.
- They were not yet ready to undertake work (related) activity. Again, there were unrealistic expectations.

(Such points bring us full circle back to the need to be able to distinguish the unemployable

from those only likely to return to work given appropriate support).

- Something went wrong at work.
- There was inadequate or inappropriate support at work for the subject *and/or* the employer and work colleagues.
- They were in the 'wrong job'.

**3.** Relating to the previous point it is apparent that the issue of job retention requires further investigation, and this is further addressed in Chapter 9. (Because the size of the retention problem was not anticipated Chapter 9 was not planned at an earlier stage in the study). This is a separate matter to point 2 because it may also embrace other perspectives/explanations than the subjects' position, such as the benefits system.

4. The fourth issue requiring consideration is the lack of significance between rehabilitation and a return to work. Whilst only the more severely disabled subjects tended to be offered clinical rehabilitation (the lesser injured ones received clinical rehabilitation only many years after the injury and following a failure to successfully return to work) and this may go some way towards explaining this finding, the lack of a relationship between vocational rehabilitation and a return to work is more disconcerting. The nature and 'quality' of vocational rehabilitation programmes on offer to the subjects is an issue.

The frequency of the clinical symptoms requires little comment. The figures lend support to the view that most clinical problems affecting a return to work are likely to fall in the neuropsychological domain but that reports from other disciplines, particularly neurological, can also be of paramount importance in individual cases when planning a return to work.

**5.** The nature of the symptoms raises a question as the relationship between VR mechanisms and a return to work. The discussion on job coaching in Part 1 introduced the application of in situ compensatory strategies but, it will have been noted, that job coaches generally do not work in such a fashion in the UK even when they are employed in specialist brain injury services. The *modus operandi* of VR practitioners in the UK was described in Chapter 5. In addition to these issues there remains a need for:

- More understanding of individual experiences than can be reflected by group statistics.
  A greater understanding of what actually goes on when a subject returns home from hospital (or leaves school). What prompts work considerations? What are the stages of a return to work? How is this process managed if at all?
  - The process whereby employers (or work preparation agencies) take people on

(thereby explicitly considering them potentially capable) only to see them fail?An understanding as to why so many people failing an initial attempt to return to work appear to subsequently 'drop out' of the labour market?

Clearly no efficacious VR programmes can be developed without an understanding of such issues.

The number of subjects in this study receiving support was disappointingly low. If intervention programmes are to identify people on the IB registers with TBI then there is a need for a greater understanding of what happens to such people in the labour market. Arguably some of the subjects in this study who returned to work and maintained employment were less disabled than a number who never returned to work or failed to hold down a job. In addition, whilst the expression 'failed to hold down a job' seems to imply a failing on the part of the person this need not be the case if insufficient measures are in place to facilitate continuing labour market participation.

# **CHAPTER 8**

# AN ANALYSIS OF THREE CASE STUDIES FROM THE STUDY SAMPLE AND AN EVALUATION OF WORKING OUT'S VOCATIONAL REHABILITATION STRATEGY

# <u>Contents</u>

8.0	Overview	221
8.1	Developing CMO Configurations for the Case Studies	222
8.2	Working Out	249
8.3	Drawing together the Findings: What Produces Changes to the	
	Status of a Subject with TBI ?	258
8.4	Summary and Main Points	263

# 8.0 Overview:

The purpose of Chapter 8 is to supplement the group findings discussed in Chapter 7 with an in-depth analysis of the experience of three subjects (the number of subjects limited by space). Whilst science may not be concerned with the individual case, to plagiarize an unattributed quote from Bromley (1986) and cited in Robson (2002), this must be the focus of any intervention to facilitate a return to work for the brain-injured client/patient. In addition the chapter seeks to further an understanding of factors influencing a return to work by applying the same evaluation process (as applied to the case studies) to data from the expert Working Out programme (see Chapter 4).

In this fashion Chapter 8 seeks to answer such questions as:

Why did the Jobcentre network not offer support to potentially employable subjects?

What went wrong when support was offered (why did it not materialise into permanent employment)?

What are the dynamics of the return to work process?

Chapter 8.1 applies the realistic approach to the three case studies and the Working Out programme to address such questions. The procedure involved in collecting the data for the three case studies was the same as for other members of the study sample with a reliance on

interview notes from the subject and members of the family (with the exception of V who lived alone).

The three case studies were selected on the basis that i) they should have had some postinjury contact with Jobcentre Plus (in order to describe the nature of this experience), ii) they should have returned to work at some stage post injury (to determine how this came about and what happened once they had returned) and iii) they should come from different sectors of the labour market (to see if they were any common factors affecting their experiences).

Neuropsychological reports were available for all the subjects and, in the case of KW, other medical evidence was available to which specific reference is made. In respect of Working Out, Dr Tyerman (the programme director) supplied the data and I was able to have a discussion with him on the content and structure of the service.

It is recognised that case studies can be seen as a 'soft option' (Robson 2002) in the absence of an ability to develop the statistical data. It is maintained that the application of realistic evaluation to the case studies represents a strategic approach to the evaluation of empirical and other data. The issue is the extent to which it contributes towards the aims and objectives of the study. Because of the limitations in drawing empirical uniformities from just three case studies Chapter 8.2 also revisits the modus operandi of Working Out to apply the realist approach to examining what it is about this programme that produces positive outcomes (defined as work, voluntary work or education).

# 8.1 Developing CMO Configurations: Case Study 1: KW

At the age of 13, in April 1996, KW sustained a very severe brain injury when she was kicked on the left side of her head by a horse. Investigations identified a depressed skull fracture with underlying contusion to the left temporal lobe of the brain. PTA is reported as being "of at least four weeks duration". As she recovered, KW was noted to have some physical weakness affecting her right side. Initially, she also lost the capacity to speak. She was discharged from hospital two months after her injury in June 1996 and made good physical progress but she was still mute and showed difficulties in understanding what was said to her. In September 1996 she had a Grand Mal fit and, subsequently, continued to be prescribed medication for epilepsy. When reviewed as an outpatient one year after her accident, KW had regained her ability to speak but showed considerable difficulties in expressing herself and understanding language. There remained a mild weakness on her right side. Following injury KW was unable to re-integrate into her usual school. She attended a boarding school, where she obtained GCSEs in Art (E) and Pottery (C). She left school in 1999 to attend a Child Care Foundation course at a local college, being taken by a taxi four days a week.

The subject was first seen by me in October 1999, for a litigation report on her employment capability, and followed up in February 2002. It was noted that KW had supportive parents. Her father was employed as a supervisor of car service mechanics and her mother produced a specialist publication for horse enthusiasts.

By Easter 2000, KW was reported to be "struggling" at college due to fatigue. She was subsequently allowed to work at home and earned credits towards a Level 1 in Caring Services.

On leaving college in the summer of 2000, KW was taken by her support worker to see the local DEA. However, no support was forthcoming. (I recommended that the DEA was consulted in respect of making a referral to the Papworth Trust, see Chapter 4). Unfortunately, the DEA declined to offer support on the basis that the level of reported fatigue contra-indicated future employability.

In September 2000, with the assistance of her mother and support worker, KW obtained a position as a care assistant working two afternoons a week from 2.00pm to 5.00pm. Whilst it was reported that KW was able to maintain an appropriate relationship with the residents of the old people's home, she apparently had difficulties with the staff. It was reported that when KW was told to do two or three tasks she would forget what she had to do or muddle her instructions. Responses were described as "inappropriate". She left after a period of three months.

KW then obtained a position as a volunteer classroom assistant working two afternoons a week. Her job was to support the children at play times and listen to them reading. An attempt was made to increase the number of hours worked by KW by attending school a further two mornings a week to assist the children with mathematics and English. However, KW could not answer the questions asked by the children and this attendance was dropped.

Because KW was only attending the school two afternoons a week during term time, KW's mother and support worker looked for alternative positions.

In November 2001, KW was offered a position as an assistant caretaker at a local Study Centre, totalling six hours per week. At the time of my second interview in February 2002, KW was still waiting to have the appointment confirmed following a medical examination. Subsequently, the local authority accepted KW as a permanent member of staff but subject to her not lifting any heavy objects and always having a support worker present, and she has continued to work there. This position has been recognised as therapeutic (now 'permitted') work.

#### **Clinical Information**

Over the years KW was seen by a wide range of specialists who made various observations in respect of her employability:

#### Consultant Neurosurgeon (December 1999):

"At the present time, I think there remains some uncertainty about her employment prospects. She clearly could not work in any capacity which required reading, writing or any significant element of communication. This means that very few forms of employment would be open to her. Even if something appropriate of a practical and straightforward nature could be identified, I think it quite possible that she has sufficient problems with memory, problem-solving, possibly in her behaviour, to prevent her working successfully. (Her best option in the long-term may prove to be some form of sheltered or supported employment).

(In my experience, it is unusual for members of the medical profession to know the distinction between sheltered and supported employment. My own report, dated October 1999, was made available to the neurosurgeon. It contained a discussion on possible employment options.)

#### Occupational Therapist (June 2000):

"..... I have concerns about her (KW) ability to obtain or sustain either of these positions (KW had applied for posts as a child care assistant and classroom assistant). I cautiously raised this with KW at interview but it was apparent that she had little awareness of the potential demands of the sort of work she was applying for and her abilities to undertake this work."

#### Psychologist (July 2000):

"With regard to employment I believe that KW would be capable of undertaking a range of low

level positions that do not place any great demands on her memory. Although KW complains of fatigue, she has been able to attend a college some distance away. This necessitated her leaving home at approximately 7.00 am and not returning home until approximately 5.00 pm. I would, therefore, anticipate that she should be able to work full-time or at least near full-time hours."

#### Consultant Neurological Surgeon (March 1999):

"I would advise that she has a vocational assessment as to what occupations or avenues of employment may be open to her in the future. She has not only suffered a compound fracture, but has also developed late post-traumatic epilepsy......."

Consultant and Professor in Neurological Disability (February 2001): "In the long-term she is certainly not going to recover fully, and her chance of working is uncertain......."

At interview in February 2002, KW's mother continued to report that KW had problems with:

fatigue memory planning disinhibition mood swings irritability/temper

In August 1999, a neuropsychologist, with substantial experience of brain injury and employment, administered a number of neuropsychological test measures and concluded that KW was "probably of at least average ability" before the injury but her principal difficulties were then:

- severe impairment in language skills adversely affecting both verbal expression and comprehension as well as the level of reading and writing. In addition, KW showed problems with immediate repetition of verbal information and mental arithmetic.
- difficulty remembering and reporting verbal information. Whilst it was considered this could be due principally to the language difficulties, it was possible that memory function was also

impaired (visual memory is probably affected little, or not at all, by language impairment but this area was also problematic).

 reduced visual spatial reasoning and visual motor speeds (suggesting that intellectual difficulties may be wider than those relating to language skills).

The neuropsychologist concluded that, "........ under the relative undemanding circumstances of a conversation, she (KW) appears to express herself reasonably well. However, she cannot reliably follow what is said to her and fails to cope with complex instructions or a large amount of verbal information. If she has to find specific words and names of particular things, or needs to explain things in any exacting way, then the extent of her expressive language impairment becomes evident. In association with these symptoms she shows very limited ability to read, or to understand what she reads, and she has problems in written work with defective spelling and difficulty in finding her words. Her ability to repeat verbal information immediately after she has heard it is also impaired. Her ability to calculate, even at the level of simple additions and subtractions is very poor and this too is probably symptomatic of her left temporal lobe brain injury.

Formal assessment of KW's abilities also suggest that she may have some difficulty in her ability to process information or solve problems where there is little or no demand on language skills. Her verbal memory is severely impaired. This is because of her limited ability to assimilate verbal information and problems in finding appropriate words when attempting to recall it later. Thus her ability to retain verbal information is not only weak but she is also vulnerable to reporting a distorted version of what has been said to her. It is probable there is also some direct affect of her injury on memory function......

KW tends to understate the extent of her own difficulties. She denies problems with memory or any other problems of a neuropsychological nature apart from her language difficulties.....

In respect of employment, the neuropsychologist concluded:

"At the present time I think there remains some uncertainty about her employment prospects. She clearly could not work in a capacity which required reading, writing or any significant relevant communication. This means that very few forms of employment would be open to her. Even if something appropriate of a practical and straightforward nature could be identified, I think it quite possible that she would have sufficient problems with memory, problem-solving, and possibly in her behaviour, to prevent her working successfully. I suspect her best option in the long-term may prove to be some form of sheltered or supported employment."

Before developing a number of specific CMO configurations in respect of KW, it is considered appropriate to present an overview of contexts, mechanisms and vocational outcomes following TBI. In turn, this is likely to inform the preliminary theorising and the qualitative preliminaries in respect of the use of such case studies. The heart of the evaluation is an outcome enquiry. Realistic evaluation, as Pawson and Tilley (1997) point out transforms the "does it work?" question to one of "what is it about the programme that works for whom?" (or, in this study, what is it about the nature of choices made and/or intervention that explains the circumstance of the case studies). It will be noted that there is a reliance on the same variables used in the statistical analysis but, instead of trying to identify significant group relationships with the outcomes, they are used within the context of CMO configurations to explain an individual circumstance and employment outcomes.

#### Table 8.1:

#### An Overview of Contexts, Mechanisms and Vocational Outcomes following TBI

#### Contexts

Demographic	Age at Injury
	Domestic Circumstances
	Education/Qualifications
	Employment History
Severity of injury	ΡΤΑ
Sequelae of injury	Physical
	- Balance

- Dalario
- Lifting
- Walking
- Spinal Cord Injury

Sensory and Motor

- Visual
- Hearing
- Pain Perception
- Smell
- Seizure
- Taste
- Co-ordination

#### Psychological

- Memory
- Writing
- Attention/Concentration
- Organisation and Planning
- Communication
- Receptive
- Expressive
- Visual-Spatial
- **Executive Function** 
  - Dysexecutive Syndrome
  - Unable to initiate motor acts
  - Planning/executing goal directed behaviours
  - Sequencing difficulties
  - Loss of self-monitoring ability
  - Inability to analyse social situations and self-adjust

#### Emotional

- Depression
- Anxiety/stress
- Frustration
- Anger/irritability
- Behaviourally out of control
- Other

#### Mechanisms<sup>14</sup>

No intervention/support Clinical Rehabilitation Clinical and Vocational Rehabilitation (without job coaching) Clinical and Vocational Rehabilitation (with job coaching) Vocational Rehabilitation (without job coaching) Vocational Rehabilitation (with job coaching Support of Employer Training Education DEA/Jobcentre support

#### Outcomes

Not employed Voluntary work\* Therapeutic (permitted) work (paid) Sheltered Employment\* Supported Employment\* Open Employment\*

\* Full-time and part-time

The hypotheses for this study are set out in Chapter 5.2, namely:

- the severity of injury can be related to successful labour market participation/return to work, even if the relationship is not always a strong or consistent one (the more severe the original injury then the chances are that the consequences will be more severe than a lesser injury);
- other clinical and demographic factors, such as neuropsychological sequelae, domestic support and pre-injury employment history, may also have a bearing on outcomes;

<sup>&</sup>lt;sup>14</sup> As previously indicated mechanisms may not just refer to interventions but, particularly in this context, the subject's and other stakeholders' response to them.

- the provision of clinical and vocational rehabilitation is 'patchy' and that there are likely to be difficulties establishing a relationship between rehabilitation and vocational outcomes with a small study sample;
- any search for a model predicting employment in the UK amongst people sustaining TBI may be confounded by:
  - the difficulties in isolating clinical variables and measuring their specific input (because of the practical difficulties in collecting such information and, even when it is available, the close collinearity);
  - determining the influence of demographic factors (such as whether or not a partner is supportive) and;
  - the inconsistent provision of appropriate support services.
- Moving on from a realist approach it is possible to plan individual vocational rehabilitation intervention by looking at the barriers to employment for people sustaining TBI and developing a vocational rehabilitation approach including the matching of identified neuropsychological and other clinical deficits with compensatory strategies to facilitate resettlement.

It was further considered that the TBI study sample was likely to experience a random pattern of employment, that is one not always directly related to the severity of injury and consequential clinical sequelae, although one in which a search or return to 'normality' often features and one in which the process of labour market entry can be positively influenced by appropriate vocational services, albeit there is currently limited access to such support. Within the realistic evaluation methodology evaluation has a structured process:

- a) Generative causal proposition(s)
- b) Analytical framework (programs as rational choices)
- c) Middle-range theory (Merton, 1968), this is the development of theories that "lie between the minor but necessary working hypotheses that evolve during day-today research and the all-inclusive efforts to develop a unified theory that will explain all the observed uniformities of social behaviour, social organisation and social change"

In respect of KW:

### a) <u>Causal Proposition:</u>

Focussing upon a single causal proposition applicable to an individual subject it is considered that in the absence of expert vocational intervention, brain injured people and their families will seek to establish 'normality', either unaware and/or denying, that the consequences of the injury are likely to adversely influence the prospect of a 'normal' outcome. In turn, this quest for normalisation will lead to an unsatisfactory adjustment.

Context	Mechanism	Outcome

Consequence of an Inability to choose or implement Unsatisfactory adjustment individual sustaining expert vocational support TBI (symptoms, effects on family etc)

# b) Analytical framework:

Contexts	Mechanisms	Outcomes
School-leaver with TBI	Actions of:	Part-time Job placement
symptoms	College course	Part-time voluntary work
Employment as a	Support worker	Therapeutic (permitted) work
symbol of 'normality'	Family	
	Lack of support from DEA	

It is proposed to examine the issues surrounding the above CMO configuration. Why, for instance, when examining KW's post-injury history, did the outcomes involve the loss of one part-time job, undeveloped voluntary work, and finally, therapeutic work, given the degree of support from college, support worker and parents?

Is it a question that the severity of injury, and sequelae, precluded greater labour market participation or is a question that the mechanisms failed to address the issues in context leading to an unsatisfactory adjustment?

The business of making 'generative causal propositions' requires a conceptual framework. In this respect it is considered that one has to be wary of not working backwards - that is taking

the eventual outcome (therapeutic work) and rationalising this outcome by plausibly using the contexts and mechanisms to 'explain' this. There is a need to start with the contexts and examine how factors within this category are mediated by the mechanisms. In this way abstract CMO configurations develop general utility, in the process moving from the working hypothesis towards a systematic effort to develop (or support) a unified theory that explains KW's employment outcome (and potentially other cases).

Whilst the severity of the injury may be related to the outcome, this is likely to be related to specific neuropsychological, other clinical and demographic variables, and the availability of appropriate vocational services. In this respect there is a working 'backwards and forwards' in order to make 'real' connections.

Contexts	Mechanisms	Outcomes
Severity of injury	Actions of:	Unsatisfactory job placement
Sequelae of injury	Supportive family	Undeveloped voluntary work
Employment as a	Support worker	Therapeutic work
symbol of 'normality'	Lack of support from DEA/	
Lack of empl. history	no formal VR programme	
Demographic variables		

To make sense of the Outcomes it is considered that the Contexts and Mechanisms require revisiting - what is specific to their nature that contributed to the Outcomes? In the case of KW it may be maintained that action taken by the support worker, education authority and parents, was reasonable in the circumstances (a rationale choice representing a search for "normality") and that therapeutic work represents a positive outcome (and in the statistical analysis for this study it is recorded as such). However, one is left asking does it represent the optimum outcome? How is the eventual placement explained?

An overview is provided below:

# Overview of CMOs. Case Study - KW

Context	+	Mechanisms	= Outcome
Something about	+	Something about	= (Eventual) therapeutic work
the demographic		the intervention/	
clinical and vocational		support	
factors			

As indicated within the process of a realistic evaluation the search for understanding can often involve revisiting (and further developing) previous CMOs. In this case specifically applying the relevant aspects of Table 8.1 (an overview of CMOs following TBI) to the case study the specific Contexts, Mechanisms and Outcomes are:

# Table 8.2:

# Contexts, Mechanisms and Outcomes. Case Study KW

# Contexts

Demographic

- Age (13 to 18 during study period)
- Age at injury (13)
- Supportive parents
- Low level qualifications (Art E, Pottery C at GCSE)
- No employment history

#### Clinical

- Very severe injury (at least 4 weeks PTA)
- Mild physical weakness affecting right side
- Epilepsy
- Fatigue
- Verbal memory
- Planning difficulties
- Mood swings/frustration/interpersonal behaviour
- Language impairment
- Reduced visual spatial abilities and motor speed
- Problems compounded by denial

#### Mechanisms

- Search for 'normality'/denial (the "choice")
- Influence of: parents

college staff

# support worker

- Lack of access to specialist assessment/VR programme
- Experience of inappropriate placements

#### Outcomes

- Unsuccessful care worker and classroom assistant placements
- Therapeutic work assistant
- Caretaker

In terms of theory development there is a need to go back and look at what happened to KW. There was inadequate career planning at school, KW leaving school to follow a Child Care Foundation course. Whilst it is recognised that KW had retained an interest in such work, it is apparent that her epilepsy, physical weakness, language impairment and intolerance did not make this the wisest of choices. In addition, this step was taken without any relevant work experience placement.

The feedback from the College that by the Easter following the start of the course KW was "struggling due to fatigue" is difficult to understand. Stamina is something that is likely to improve over time, not get worse (and the psychologist reporting for the Defendant did not consider any lack of stamina an issue).

No VR support at all was offered by the local DEA in the summer of 2000, making a judgement based on the medical evidence made available to her and not supported by any objective monitoring nor strategic approach to improving stamina (by gradually building up working hours in a suitable work placement).

Notwithstanding some obvious potential difficulties the move initiated by KW's mother and support worker to obtain her a position as a part-time care assistant (two afternoons a week) may be seen as a constructive move (representing the 'search for normality'). Unfortunately, issues arising from the symptoms were not addressed in-situ, particularly structuring her work activity and advising other staff on appropriate communication/instructions. Not surprisingly this placement broke down.

What followed represents a continuation of KW's aspiration to work with children and/or in a caring capacity, with a voluntary placement as a classroom assistant. It is considered a measure of the lack of realism, and the failure to address denial, that KW increased her hours by attending school an extra two mornings a week to assist the children with mathematics and English, a position that may be considered destined to fail given her difficulties with words.

It will be noted that only through a process of error did KW eventually find herself in a part-time supervised position that did not require a great deal of interpersonal skills.

In the theorising it has been suggested that in the absence of expert vocational intervention, brain injured people and their families will seek to establish 'normality', either unaware and/or denying, that the consequence of the injury are likely to adversely influence the prospect of a 'normal' outcome. In turn, this quest for normalisation will lead to an unsatisfactory adjustment. Such an opinion may be seen to represent a middle range, theory, but how valid is it?

#### c) <u>Middle Range Theory:</u>

As part of the cumulative process, the building of middle range theory, there is a need to go back and 'test' the hypotheses:

The severity of injury can be related to successful labour market participation/return to work, even if the relationship is not always a strong or consistent one (the more severe the original injury then the chances are that the consequences will be more severe than a lesser injury).

Without repeating the extensive sequelae and history that followed a clinically very severe injury to KW, it is considered that there is substantial evidence to support this proposition (but clearly not enough to generalise about the situation applying to other people).

# Other clinical and demographic factors, such as neuropsychological sequelae, domestic support and pre-injury employment history, may also have a bearing on outcomes.

In KW's case her family and support worker were clearly key players. There is also evidence that specific neuropsychological sequelae contributed to ensuing difficulties in two work placements. It is recognised that there is also a need to make specific reference to education.

In this case the *lack of support* from a DEA may also be considered a factor contributing to the eventual outcome.

# The provision of clinical and vocational rehabilitation is "patchy" and there are likely to be difficulties establishing a relationship between rehabilitation and vocational outcomes with a small study sample.

It is considered this case study has demonstrated a difficulty in accessing an appropriate VR programme.

# Any search for a model predicting employment in the UK amongst people sustaining TBI may be confounded by:

# a) The difficulties in isolating clinical variables and measuring their specific input.

Identifying the clinical issues is not a problem in this case although any attempt to rank their respective significance in respect of employment may serve little purpose because this depends upon the employment What is important will vary from person to person and circumstance to circumstance. The issue is one of identifying the problems so that inappropriate employment can be avoided.

# b) Determining the influence of demographic factors (such as whether or not a partner is supported).

This case study illustrates the point in defining the nature of support. There can be no doubt that KW's parents, and support worker, were highly supportive. The question is whether or not it was directed appropriately.

# c) The inconsistent provision of support services.

Again, this case illustrates the point. Ostensibly the DEA was there to provide access to assessment and rehabilitation but declined to do so, arguably for a spurious reason.

Moving on from realistic evaluation it ought to be possible to plan individual vocational rehabilitation courses by looking at the barriers to employment for people sustaining TBI and developing a vocational rehabilitation approach including the matching of identified neuropsychological and other clinical deficits with compensatory strategies to facilitate resettlement. One of the difficulties in understanding Pawson and Tilley's rejection of comparators is that when examining intervention one can not go back and change the experience of the subject. Whilst a detailed explanation of circumstances (using CMOs) may produce an understanding of what has gone on, there is no way of manipulating the intervention (as in an experiment) to see if any change would produce a different outcome.

Whilst it is recognised that repeated applications of the CMOS to other case studies may serve to verify or disprove hypotheses there is an apparent danger of rationalisation.

As matters stand one can not draw any empirical uniformities from the KW study but only point to what *may* have worked for her (in terms of resettlement). Moving between abstraction and specification, one can only suggest how KW's barriers to employment may have been otherwise handled. Firstly, in respect of the aims and objectives of the study there is a need to see what lessons (if any) can be learned from this experience. It is considered that:

- The clinical variables influencing KW's employment capability could be established by a careful examination of the evidence. Family and care support required 'directing'.
- The return to education/vocational training process was not well handled. The 'return to normality' consisted of going along with what KW wanted to do rather than any realistic appraisal of her capabilities.
- There was no systematic adoption of compensatory strategies.
- There was a lack of professional expertise/knowledge from the DEA.

Given that KW had attended College full-time and that she is capable of (suitable) therapeutic work, was she really incapable of (part-time) supported employment?

The fact is KW never received VR support and, without it, the potential outcome remains speculative. However, returning to the hypotheses, as they relate to this case, the proposition requiring investigation is that whilst the severity of injury may be related to the outcome, this is likely to be influenced by specific:

- demographic variables
- neuropsychological and other clinical variables
- vocational factors

In an ideal situation one would then go on to develop a programme for KW that does seek to optimise her capability - in terms of crime prevention (Pawson and Tilley) or even urban development (Ho, 1999) one can develop new programmes in the same location learning from earlier findings - one can not go back and put KW through the type of VR programme that would make a 'real' connection between the contexts affecting her employment capabilities and mechanisms that may lead to a different outcome, for example.

Contexts	Mechanisms
Behavioural difficulties	Address circumstance in which this occurs/Behaviour modification
Language impairment	Consider means and need for communication
Fatigue	Gradually build up working hours
Denial	Address discrepancies in self-concept and actual performance
Aspiration to work in a caring role	Vocational guidance <sup>15</sup>

In addition before any progress could be made it is suggested that the problems of denial would need to be addressed. This is particularly the case given KW's age and the lack of any employment history. It might be assumed that she would have difficulty in assessing (and accepting) her limitations, and without this step there would be difficulty in moving on to appropriate work activity.

The eventual outcome(s) would depend upon the progress made through any VR programme. The options are considered to be (part-time or full-time) supported or open employment.

<sup>&</sup>lt;sup>15</sup> When examining KW's cognitive and physical barriers to employment it is apparent that she could not successfully work with young children. Despite her injury KW continued to ride (in a group of disabled riders). Given her caring nature and love of animals a placement option may have been in a kennels or cattery, involving a daily routine, a limited amount of instructions and no great demand for interpersonal skills/communication.

### Establishing empirical uniformities, outcomes and regularities.

Pawson and Tilley's model of realist cumulation requires moving on to configuration focussing in order to establish empirical uniformities. In this respect there is a need to examine other case studies.

# Case Study 2: G

G sustained an estimated PTA > 4 weeks. Prior to injury she had an excellent work history as an office administrator. Clinical neuropsychological testing showed that G did not suffer any significant deterioration in her general level of intellectual functioning although she showed mild deficits in terms of memory, particularly verbal memory. She did not show any executive-type deficits suggesting damage to the frontal lobes. However, she did show a severe deficit in terms of sustained attention and speed of information processing, particularly with regard to dealing with multiple tasks simultaneously. There was also reported significant emotional disturbance and some fatigue.

Subsequent to injury G received support from the Head Injury Therapy Unit (HITU) at her local NHS Trust hospital. Early rehabilitation focused upon getting up in the morning and developing stamina, independent travelling, improving communication and memory skills and developing self-confidence. This led to a placement on a National Vocational Qualification (NVQ) course in Business Administration at a local Community Education Centre. G attended for up to 20 hours per week over a 13 weeks period. She also undertook a Royal Society of Arts (RSA) Stage 1 in Computer Literacy and Information Technology (CLAIT).

Completion of this training was followed by an extended holiday with relatives in Australia. On her return to the UK G contacted the Disability Employment Advisor (DEA) in her local Jobcentre who referred her for a Placement, Assessment and Counselling Team (PACT) assessment. The assessment concentrated upon clerical skills. It was reported that:

"G's score in this section was a good average compared to the above group, indicating that at this time she can deal effectively with the basic clerical tasks of filing and checking information normally associated with routine aspects of clerical work."

With regard to numerical ability:

"G was able to undertake basic calculations of whole numbers, however she did not

attend to decimal points, which would have occupational implications if not dealt with. She admitted that even prior to her accident she relied on a calculator for working out mathematical problems. We agreed that the most realistic solution was to ask the HITU team to help her refresh her use of calculator skills ....

*G* assimilated the strategy shown her for locating errors in the matrix but her ability for quick mental calculation let her down. Had she had access to a calculator she would probably have had no problems with this task ...

*G* found these sections very hard, which adversely influenced her scores in the numerical section of this test. The latter section involved mathematical problems written in a verbal format which I think was testing her ability to read as well as solve these problems. It could be argued that as such it was not the best measure of her practical problem solving abilities.

Her overall results in the numerical section would indicate a need to use a calculator and double checking strategies to ensure accuracy when dealing with figure work."

With regard to verbal ability:

#### Spelling:

"G expected to find this section hard and agreed that she would probably make use of spell checking facilities when word processing."

#### Vocabulary:

"She did very well in this section showing good commercially orientated vocabulary."

#### Language Use and Comprehension:

"These last two sections were very difficult for G as the tasks required the reading and comprehension of written text. Having realised that she would not be able to read and answer the questions quickly enough she worked out a visual scanning strategy and guessed the correct answers by picking up critical words. I was not only impressed by her ability to adapt and problem solve but the fact that she could do so under such stressful conditions."

The assessment recognised both the limitations of the approach and G's needs and considered the following issues significant for employment:

- fatigue
- memory
- social integration

Supported employment was discussed as a potential option, in the meantime it was recommended that G continue with her rehabilitation and discuss her needs with the DEA.

Further discussion with the DEA resulted in an employment rehabilitation/work preparation course being arranged with a local specialist training provider for people with disabilities. G commenced a placement, initially working on a clerical placement. G reported that she was initially bored with the routine work. However, she gradually developed her activity, including attendance at a Job Club for people with disabilities, during which she began to assist other clients. By this stage, two months after starting this placement and three years after the injury, G had built her attendance up to 12 hours a week. She further went on to 16 hours a week but, within a matter of 3 weeks had her first day off through tiredness. It was during this period that matters appear to have gone amiss. From attending the Job Club she was invited to increase her own input by presenting part of the training programme. By the second week, G reports that she was "shattered" - during the second week. She had also been babysitting for her sister and everything became "too much" for her.

Correspondence from the HITU key worker to the DEA reads:

"G has been on a work placement for much of this term and there has been limited contact from HITU. Regrettably this placement has proved far from ideal as G was not introduced to increasingly complex administrative tasks as had been expected, and there seems to have been some odd dynamics operating amongst the placement staff. G became exhausted and has finished this placement. Whilst not provided what was expected there are some positive outcomes from this experience, in that G managed some difficult incidents with great skill and negotiated her way to broaden her range of experience."

The Key Worker then entered into correspondence with the DEA and the PACT occupational

psychologist, part of which reads:

*".... It would seem that she was given very simple clerical tasks to perform in an office with quite limited work, there was no increasing challenge of task to find the level at which she could still perform effectively, this being the main purpose of the work placement as I understand it.* 

It would seem that her deceptively competent and confident presentation was not seen for what it was, and that she was moved into being a trainer with the minimum of preparation for what for her, since her head injury, would have been an enormous leap, even though, if she had not sustained a head injury, this would have been an appropriate progression, given her previous history.

I am not wanting to make a complaint against (the training provider), merely to ensure that G is given a proper chance in a work placement. Given the nature of head injuries I feel that 10 weeks is an extremely short period to test a client in, I feel it would be more appropriate to go 15 hours and 20 weeks, with slightly shorter hours if appropriate. I realise that this does not fit your guidelines, but there are specific cognitive issues for the head injured which would seem to indicate that the 10 week period is inappropriate."

Unfortunately, it was not possible to identify further placement and the DEA indicated that no further funding was available. Subsequently, G has continued to remain in receipt of incapacity benefits.

In the case of G there is the same causal proposition, namely that in the absence of expert vocational intervention, brain injured people and their families will seek to establish 'normality', either unaware and/or denying that the consequences of the injury are likely to adversely influence the prospect of a 'normal' outcome. In turn, this quest for normalisation (and inappropriate or no support) will lead to an unsatisfactory adjustment.

G.

Context	Mechanisms	Outcome
Attempt to resume 'normality'	Action taken by health authority	Unsatisfactory
	workers, DEA and work	vocational
	preparation agency	adjustment

A clinical rehabilitation team placed G on a part-time NVQ at a local Community Education

Centre. This was followed by a referral to a DEA. At this juncture the team from the Head Injury Therapy Unit could have had a number of options but chose the local DEA on the basis that the service offers expert assistance to enable disabled people to return to work. This may be perceived to be a rationale choice. In this respect the service offered to G becomes the framework for analysis. In the event the DEA referred G to a work preparation course. The agency staff failed to recognise the nature of G's problems (because of her good presentation) and over-loaded her with responsibility resulting in a 'breakdown' and a complaint from a member of the clinical team.

In respect of the placement 'real' connections are required to understand the outcome.

<u>Contexts</u> Deficits in respect of: communication memory stamina self-confidence

Search for normalisation Placement by DEA with a work preparation agency Clerical placement Increased responsibility (assisting in a Job Club) Increased hours

In order to achieve a positive outcome it is considered that intervention mechanisms should have included:

#### **Mechanisms**

Using compensatory strategies for improving communication and memory Gradually building up working hours Giving G tasks she could successfully undertake to build self-confidence

It will be noted that the entire focus of the approach undertaken by the work preparation agency was on increasing vocational "placeability" in a clerical context. There was no attempt to *integrate* G's deficits into the work she was undertaking nor to develop appropriate compensatory strategies.

Context	Mechanisms	Outcome
Failure to address deficits and	Inappropriate course content	Unsatisfactory
barriers to employment	Inability to cope	vocational adjustment

Whilst it is possible to develop further CMOs in respect of the specific neuropsychological sequelae and how those could have been addressed the underlying hypothesis is considered supported, but not to the extent of confirming VR as a mechanism for producing positive outcomes, only, in absence of an expert programme, providing unsatisfactory ones. Hence, whilst the cited two examples provide some regularity, and empirical uniformity, there needs to be more CMO focussing on the VR process to support this part of the equation.

# Case Study 3: V

V was a skilled engineering machinist when, at the age of 31 years he sustained a head injury leading to PTA of at least six weeks duration. Neuropsychological assessment indicated that V was functioning within the low average range of general ability (not significantly below the pre-accident level) but that there was some fall-off in visuo-spatial abilities. In addition, there were some memory deficits, particularly with immediate memory, verbal recall and new word learning ability. His visual recognition memory showed a moderate degree of impairment and there were also deficits with regard to this visuo-motor abilities, divided attention and memory. He was described as having a dysexecutive syndrome.

V was referred to his local PACT for an assessment and the report, produced nearly two years after the injury, reads:

"The head injury caused by the accident continues to affect you in relation to your personality with associated reduced tolerance and patience, memory and recall of information and the absences that last for approximately half a minute ...

"In relation to work you are keen to use the knowledge you have gained from your engineering apprenticeship and work experience. However, you realise that unless the absences (epilepsy) completely stop, returning to a workshop for setting and operating lathes, milling, grinding machines and so on will be inadvisable. Therefore, the assessment looked towards identifying the retained knowledge you have as well as other functional effects of the head injury.

"The results indicate that you are able to solve progressively complex problems very well,

providing you are able to work at your own speed, suggests that you should be capable of undertaking further training. Arithmetic requires a lot of concentration from you too and some revision for decimals, equations, long division and three-dimensional calculations would be beneficial. You realise your spelling is not too good and in the past your language skills were definitely weaker than your non-verbal ability which was also true during the assessment. However, you retain a sound knowledge of mechanical theory and principles. (Skills and knowledge acquired pre-injury are invariably the best preserved). You worked accurately in a typing exercise and with further familiarity and practice you should be able to improve your skills in keyboard operating.

"Lastly, you were also assessed with regard to your memory and speed of information processing. It would appear from this that you are observant, able to encode, immediately recall within 10 seconds and produce accurate delayed recall over a half hour period with material that is presented visually and diagrammatically. In contrast, items that are spoken and continually repeated without being in context showed a cut-off in learning after three trials with the loss of approximately 40% of the material. There is also more information lost over a delay of half an hour with this auditory channel. Your speed of processing information has also observed with the other assessment exercises has undoubtedly been impaired by your head injury but may be liable to improve with continued recovery and stimulation."

The report went on to recommend training in design draughtmanship within engineering ignoring the dysexecutive syndrome and assuming the skills "*to solve progressively complex problems very well, providing you are able to work at your own speed*" are indicative of the capacity to undertake further training in a new area.

In the event V returned to his pre-injury employer for a period of 8 months, commencing almost 2½ years after the accident. However, he was taken off his normal duties, away from the machines, and placed in a brush shop, trimming and packing brushes. V found the reduction in status and activity demeaning. The company then terminated V's employment on medical grounds, writing to V:

"..... as you know, the company closely monitored the circumstances following your unfortunate accident in 1989 and has recently asked for medical opinion to confirm the future prognosis.

"Unfortunately, this prognosis indicated to the company that it would not be wise to allow you to continue working alongside machinery, and further to this we have a situation where there has been work scrapped and, as you have agreed, you are unable to continue with this type of work ......"

In the case of V there is the same causal proposition in respect of a 'search for normality'. In this case V ignored an (inappropriate) PACT recommendation and returned to his pre-injury employer, although working in a brush shop rather than as a machinist. The impression is that allowances were made for his continuing symptoms but V's employment was still ultimately terminated. The area for analysis is clearly in respect of the 'match' between the continuing symptomatology and the requirements of the job.

Context	Mechanisms	Outcome
Fall off in visuo spatial abilities	Placed in brush shop,	Position
Memory deficits	trimming and packing brushes	terminated
Visual recognition deficits		
Reduced visuo-motor abilities/		
divided attention and memory		
Dysexecutive syndrome		
Reduced tolerance and patience		
Epilepsy		
Substantially retained		
IQ and pre-injury knowledge		

Given the epilepsy it is apparent that V could not return to his pre-injury employment as a machinist but, working backwards and forwards between the context and mechanism, was the placement in a brush shop appropriate?

V was a skilled machinist and found such a reduction in status demeaning - given his reduced tolerance and patience could it not be foreseen that V may find such activity boring and make mistakes, particularly given his divided attention? Would it not have been wiser to have tried to build upon V's retained knowledge and skills?

The PACT assessment said that V was "keen to use the knowledge you have gained from your engineering apprenticeship and work experience" and that he was capable of undertaking further training (although a dysexecutive syndrome would need to be taken into account). Given the problems with memory and speed of information processing could not V have been trained to use a computer (structured activity) and been able to use his retained knowledge by making a contribution in the stores?

Whilst it could not have been without some problems, because of visual recognition difficulties, one might have thought that compensatory approaches (the use of coding for instance) would have facilitated employment in such an arena. Whether or not the firm had a vacancy in this area is not known, however what is clear is that this was not tried and, following the PACT assessment, there was no liaison between the Employment Service and the firm. V had gone back to work and that was the end of the matter as far as the Employment Service was concerned.

Where does this leave us with regard to theory development? What evidence is there to support the view that it is appropriate intervention that results in a positive outcome? These case studies only demonstrate that an absence of appropriate intervention has contributed to an unsatisfactory adjustment.

It is considered these studies show that, in general, support fosters a more consistent and systematic return to work (whether or not it is maintained) than relying on this occurring spontaneously, although one can not go so far as to say that appropriate intervention will result in a positive outcome. What uniformities are there?

- In all three cases there could be considered a search for 'normality' KW following the college course she is likely to have chosen in any event (albeit a higher level and without support), KW attempting to return to her previous sector of employment and V returning to his pre-injury employer.
- 2) There are a number of influential stakeholders involved in this process. They include: parents support/care worker DEA clinical rehabilitation team college staff employer
- 3) Apart from the clinical rehabilitation teams none of the stakeholders could be expected to have an expert knowledge of brain injury (I met KW's support worker and whilst she was undoubtedly a caring person and had developed some insight into brain injury she did not appear to have had any formal training on the subject).
- 4) The employment/placements broke down for reasons commonly found amongst the TBI

population:

- a) inappropriate interpersonal behaviour
- b) fatigue/stress
- c) unsatisfactory performance (due to cognitive difficulties)
- 5) In two out of the three case studies the subject 'dropped out' of the labour market once a job/placement had failed.
- 6) The input from the Employment Service was unsatisfactory:
  - declining to take any action
  - no liaison between the clinical team and the work preparation agency
  - no follow up to a PACT assessment and no liaison with the employer
- 7) None of the placement providers/employers sought expert advice when difficulties occurred

Clearly, the example of three cases proves little. For example, when revisiting the middle range theory, that first hypothesis is that *'the severity of injury can be related to successful labour market participation/return to work, even if the relationship is not always a strong or consistent one....'*, whilst KW and V sustained very severe injuries G did not do so, receiving an injury of moderate severity. Whilst this may be considered to support the lack of consistency in practice, as mentioned in Part 1 of this study, there is a recognition that those people sustaining a severe/very severe head injury are likely to experience employment problems the oft heard converse statement, that those sustaining mild/moderate injury will not have such problems, is not true.

All three case studies support factors other than the severity of injury influencing the final outcome. Whilst all three case studies had contact with the Employment Service there is no evidence of expert rehabilitation. In respect of G and V it could be maintained that they received support, but it did not amount to vocational rehabilitation as defined in this research. Three cases are clearly insufficient to establish any sort of empirical uniformity but the information from these studies is used in building a framework for understanding outcomes (Fig. 13).

Chapter 8.0 set out the reasons for selecting the three case studies, namely i) they should have had some post-injury contact with Jobcentre Plus (in order to describe the nature of this experience), ii) they should have returned to work at some stage post injury (to determine how

this came about and what happened once they had returned) and iii) they should come from different sectors of the labour market (to see if they were any common factors affecting their experiences). At the time it was considered that an examination of the modus operandi of Working Out would address the potential reasons as to why TBI subjects may maintain employment.

Whilst this remains the case, the realist approach is considered to offer a potentially productive way of building a model of post-injury RTW experiences and, in retrospect, the study would have benefited from also including reference to a member of the study sample making a spontaneous return to work and one maintaining employment. At this juncture this would represent an attempt to fit the proverbial pint into a quart pot. To reflect that methodological pluralism can produce such developments but limitations on the extent findings can be developed within a given framework, is to wander off the track of this Chapter.

**8.2 Working Out:** If one accepts the findings of other research, particularly Johnson (1998) that a return to work within the first two years post-injury is likely to be most successful, then it is possible to suggest that the support offered by Working Out is likely to result in better long-term outcomes than experienced by the study sample. But does this mean that it is the specific *nature* of the support offered by Working Out that results in the outcomes?

Without individual data from Working Out, in order to make what Pawson and Tilley refer to as 'the real connection', one can not make any direct comparison between members of the study sample and Working Out clients. Whilst it may be the case that given such long term individual subject data one could rely on RE to accumulate a body of evidence to support a replication of the Working Out programme, as matters stand it is considered unsafe to draw any definitive conclusions. Nevertheless, in the interest of Julne's (1998) "common sense realism" a contrast is made with the Working Out outcomes to see to what extent expert intervention may have contributed to the positive outcomes (Table 8.3).

Table 8.3:		Contrasting Study Sample/Working Out Data				
			Study S	ample		
Nos.	of	Intervention	No	Return to Work	In Employment at	
Subj	ects		Intervention	at Some Stage	Follow-Up	
-				Post-Injury	(mean 7.67 years post- injury)	
54	Clinica	al Rehab. 11	29 (54%)	28 (52%)	10 (18.5%)	
	Voc. F	Rehab. 7				
	& Voc	Rehab 7				
	u 100	(46%)				
		(10,0)				
			Workin	<u>g Out</u>		
Nos.	of	Intervention	Νο	Return to Work	In Employment at	
Subj	ects		Intervention	at Some Stage	Follow-Up	
				Post-Injury	(12 months)	
45	Clini Voca	cal Rehabilitatio ational Rehab:	n 0	25 <sup>16</sup> (56%)	23 (51%)	
	Wor	k preparation gr	oup			
	Com	nmunity rehab. a	ctivities			
	Indiv	vidual project wo	rk			
	Reh	abilitation couns	elling			
	Voc	ational counselli	ng			
	Psychological therapy					
	Pers	sonal issues gro	up			
	Cog	nitive rehab. gro	up			
	Brai	n injury educatio	nal			
	prog	gramme				

Pawson and Tilley's censorious criticism of control methodology would be justified if any attempt was made to construct CMOs depicting the success of intervention - and in any case
this would be fundamentally flawed. Without repeating previous data there are clinical and demographic similarities (and no more than that) between the two populations. Hence, without replication, there are some contextual comparisons but any endeavour to compare mechanisms is immediately invalidated by the lack of comparative information. And as for outcomes:

- Might not the Working Out figures be explained by the fact that follow-up data is only available at 6 months and 12 months post-course? Where is the evidence that these subjects <u>maintained</u> their positions?
- Might not the maintenance of the Working Out figures over six months reflect some subjects losing their jobs only for others to find jobs between first and second counts?

A remarkable figure is then the percentage resettlement rate at 12 months (51%) is just 1% less than the study sample returning to work at some point between injury and the mean 7.67 years final follow-up position (and it excludes from the count 6 subjects reported to have been referred elsewhere or not completing the programme).

Without further data (not available) that the Working Out programme leads to *secure* long-term employment, there is no evidence this occurs (and the claim by Working Out that they successfully resettle clients more than 2 years post-injury could be questioned. It may simply be a matter that many people with TBI require periodic 'recycling' through vocational programmes).

What appears to be the case is that the Working Out subjects did, on the whole, maintain employment during the period they were tracked. As indicated earlier in this study one can not take such a period of employment as a basis for assuming continuing paid employment albeit, it may be regarded as a reasonable prognosticator (on the basis that experience, but not recorded evidence, suggests that if subjects with TBI are going to lose their positions they are likely to do so quicker than this period. The issue of tracking subjects and validating data is discussed in the Conclusion). In terms of realistic evaluation the questions that need answering are 'How did these subjects return to work?', 'What is it about the Working Out programme that led to such a <u>collective</u> RTW rate within such a short period of leaving the programme (irrespective of whether or not this was maintained)?

The framework for analysing these questions is presented below. The significant issue is in respect of how the contexts are addressed by the mechanisms. Hence, the analytical

#### **Overview of CMOs. Case Studies**

Context	+	Mechanism =	<u> Outcome</u>
Something about	+	Something about =	Positive outcomes
the demographic		the intervention/	
clinical and vocational		support	
factors			
Table 8.4:	Over	view of CMOs: Working Out	
Contexts		Mechanisms	Outcomes <sup>17</sup>
Problems with		Assessment	(12 months follow-up)
memory (57%)		Head injury background intervie	w 12 f.t. empl.
attention/concentration (48%	)	Head injury problem schedule	4 f.t. empl.
anger/irritability (20%)		Head Injury Semantic Different	ial 3 supported
dysexecutive syndrome		Scale	1 vocational tr.
(not reported)		Hospital Anxiety &	3 therapeutic work
organisation & planning (17%	6)	Depression Scale	8 volunteer work
depression (21%)			4 rehabilitation
speed of info. processing 51	%)	Cognitive group	2 no regular activity
			2 referred on
Problems also reported with		Psychological Therapy	2 did not complete
adaptive behaviour		Rehabilitation Counselling	2 moved away
physical condition		Personal Issues Group	

motor functions

<sup>&</sup>lt;sup>17</sup> The full list of outcomes is provided even though it is maintained that the objective of VR should be paid activity. This is by way of a concession and recognition that Working Out subjects undertaking some regular structured activity probably received more community support than the study sample described as being at home and in receipt of incapacity benefits.

Work issues task orientation social skills motivation conformance presentation vocational qualifications Vocational Assessment Work preparation (12 weeks+) community rehab. activities individual project work vocational counselling voluntary work trial (12 weeks+) work placement (6 months+) Placement support group Education/training

Because of the way the Working Out data is presented as programme detail, rather than relating to specific individuals, it is not possible to construct CMOs in the same fashion as the individual case studies. However, the issue in this examination is one of establishing why it is that Working Out has been able to report maintained resettlement rates.

In contrast to nearly all of the study sample the Working Out subjects received a detailed vocational rehabilitation programme, the framework to be examined. Whilst it can conceivably be maintained that spurious factors not under consideration contributed to the outcomes, there are two obvious differences between the Working Out groups that require prior consideration:

- (i) Litigation. Whilst it is understood that some of the Working Out subjects did have litigation cases pending, this is not the case with all of them. Why 28 members of the study sample should make a return to work post-injury but 18 fail to maintain employment post-settlement of their litigation cases would appear to suggest that litigation did not play a substantial part in their deliberations unless so many subjects contrived to fail, and there is no evidence to support such a proposition.
- (ii) Motivation. It may be considered that the Working Out group were more motivated than the study sample because they all volunteered to attend a rehabilitation programme (a common criticism of rehabilitation outcomes). Whilst any such criticism could have some validity the issue being addressed in this instance is the way the subjects presenting problems were addressed within the programme.

It is considered that the accumulation of evidence in this case facilitates the establishment of middle range theory, namely:

# Vocational rehabilitation that identifies TBI subjects specific barriers to employment and deploys intervention strategies that directly address such matters will produce positive outcomes (however these may be defined).

An examination of the neuropsychological test results indicates that those unable to return to work did not score significantly higher than those able to return to work. Where there is a difference is in respect of those returning to work being rated by staff as having significantly less problems on the Functional Assessment Inventory (Table 4.1) and significantly more vocational potential on the Work Personality Profile (Table 4.2). Overall, compared to the normative group, on the Functional Assessment Inventory the Working Out subjects were reported to have significantly greater problems in Adaptive Behaviour, Motor Function, Cognition, Physical Condition and Vocational Qualifications. On the Work Personality Profile the group scored significantly lower than the normative group on all factors that is Task Orientation, Social Skills, Work Motivation, Work Conformance and Personal Presentation. In addition, on the COTNAB, a specialist assessment battery designed specifically for brain injury rehabilitation, comprising twelve sub-tests, three in each of four functional areas:

- U Visual Perception: (overlapping figures, sequences)
- Constructional Ability (2D construction, 3D construction, block-printing)
- Sensory Motor Ability (Stereognosis, dexterity, co-ordination)
- Ability to follow instructions (written, visual and spoken instructions)

a high proportion of participants displayed difficulties of all sub-tests. The proportion scoring more than one standard deviation below the median overall performance (combining ability and time) ranged from 31% on Visual Instructions to 88% on Dexterity (bi-lateral trial) with more than half recording low average scores on seven of twelve tasks: Overlapping Figures: Block Printing; Stereognostic Dexterity; Co-ordination; Written Instructions and Spoken Instructions. Low scores reflected contrasting pattern of ability across sections: on Visual Perception low scores mainly reflect slow speed; in Constructional Ability low scores reflect a mixture of low ability and time grades; on sensory-morbid tests low scores on Dexterity Co-ordination result from slow speed; following instructions on Written and Visual Instructions slow speed put low scores on Spoken Instructions, Impaired Memory and Slow Speed.

The issue in respect of evaluation is how these presenting problems were addressed within the VR programme. Within the realistic perspective, the VR programme could be seen to be the context, with a means for addressing such problems and the subject responses as the mechanisms. Revisiting the context, mechanisms and outcomes one has the following:

Contexts	Mechanisms	Outcomes <sup>18</sup>
Denial	Work preparation group	Realistic self-assessment
Lack of insight	(33 participants)	of work potential
	- group discussion	Fostering positive
	- group exercises	attitudes and behaviour
	- role play	
	(presentation of injury, etc.)	

Without employment details in respect of the subjects taking part in the Work Preparation Group, and evidence that a positive attitude and a realistic self assessment contributed to a positive outcome, it is considered that if reporting anything more than the information provided by Working Out one is potentially inferring outcomes. One can only identify the individual barriers to employment in respect of specific case studies. The refinement of CMOs does require a detailed consideration of Contexts - and in this respect circumstances in which variables become barriers is brought out. (In an ideal world starting with a detailed assessment programme from which it ought to be possible to identify which barriers apply to which subjects.)

In the circumstance, it is considered that it is only through the process of cumulation that one is likely to gather sufficient evidence to assess whether or not it is the mechanism, the nature of the intervention, that contributes to the outcome, although, in the absence of data on which subjects undertook which programme and their specific outcomes, the Outcome column in the next CMO (Table 8.5) has been left blank - albeit 51% subjects were in some form of paid activity at the 12 months follow up and 43% otherwise undertaking some structured activity<sup>19</sup>.

<sup>&</sup>lt;sup>18</sup> As reported.

<sup>&</sup>lt;sup>19</sup> Whilst Working Out reports that the structured activity include therapeutic work it does not report it separately from voluntary activity.

Table 8.5:

# Contexts and Mechanisms: Working Out

Contexts	Mechanisms	Outcomes
<b>Rehabilitation</b> Develop awareness of difficulties and coping strategies (31 participants)	Commonly rehabilitation activities - running an allotment - building a children's playground - renovation work - project work Individual project work eg. in-house exercises and domestic work for a person wishing to return to work as a kitchen assistant	
Cognitive deficits - memory - attention - reasoning/planning/ problem solving (13 participants) Dealing with feelings, frustration, worries over head injury and its effects Address psychological difficulties eg. anxiety, depression, anger Explore, understand & cope emotionally with new selves and situations (22 participants)	Cognitive rehabilitation group Implementation of coping strategies - group education - individual rehabilitation - summary sessions Personal issues group	
Promotion of insights and realistic expectations Issue restricting progress Resettlement planning (31 participants)	Rehabilitation counselling, further information/explanation	
Anxiety/post-traumatic stress disorder (5 participants) Anger (7 participants) Depression (6 participants) Insight/adjustment (10 participants) Compulsive behaviour (2 participant Social behaviour difficulties (3 partic Pain (1 participant)	Psychological therapy s) ipants)	
Develop understanding of vocational aptitudes, limitation arising from TBI Matching	Vocational guidance/counselling	

Re-assurance (34 participants)

Voluntary Work Trials (30 participants)

- independent assessment of work potential

- identification and adapting to outstanding difficulties
- re-establishment of work routine & behaviours
- supervised and graded re-building of self-confidence
- independent reference for those employed for a job

Minimising risk of failure on returning to work Build up stamina Increase chance of appropriate job selection Monitoring by project staff - on-site visits - telephone consultation

Placement support group

of managers, supervisors,

health & safety, etc.

providing advice & responsibility

- individual support
- attendance at the placement support group

Provide personal support Help subjects understand & cope with complexities of work after TBI Facilitation of adjustments required to maximise/maintain work trials and placements

Identification of long-term placement

DEA Project staff Self Other

In an ideal situation, that is given individual data, this process of cumulation could be further refined by reference to individual case studies and empirical uniformities established and hypotheses examined. As matters stand one can only contrast the Outcomes with the study sample to dispel any notion that the Outcome data is not the spurious product of some unforeseen factors and suggest that the frequency (regularity) of positive outcomes confirms that it is focussed intervention that produces the results.

Whilst it will be evident from the study sample that there is evidence to support the view that there may be random patterns of a return to work following TBI, and a lack of expert TBI VR services, and that it is possible to identify individual barriers to employment, the notion that they can be successfully addressed founders on:

- a lack of individual data from Working Out
- a lack of long-term follow-up data

So what can be concluded?

# 8.3 Drawing Together the Findings: What Produces Changes to the Status of a Subject with TBI?

The contexts from which the consequences of TBI may flow are indicated below:



The evidence suggests that the extent to which such factors affect the subsequent history of the injured person will vary considerably, indeed, some factors will not show up as statistically significant although they may have the most important bearing on any one individual. This is demonstrated in the study by reference to the group association statistical findings in contrast to the role of the employment position of V and the education history of KW.

Social programmes are designed to bring about changes to regularities. Without change the position in which someone finds themselves following TBI will not alter. In this case what occurs after TBI is a period of incapacity (Fig 8)

#### Contexts, Mechanisms and Regularity



Without anything (mechanisms) operating to change circumstances the regularity that may be anticipated in many cases of TBI is long-term unemployment/incapacity. This is not always the case because, as the study sample illustrates, some people with TBI will make a spontaneous return to work (or one at least that does not rely upon social programmes; too little is known about the return to work process and the role played by employers and family to satisfactorily describe the exercise as always being 'spontaneous').

As indicated, the role of social programmes is to bring about change. The initial regularity is perceived to be problematic. What are social programmes? In this case we have:

• The benefits system. Is it the role of the incapacity benefits system to bring about change to the lives (employment status) of claimants? It clearly has not been, hence, the creation of Jobcentre Plus and the introduction of condition management programmes. These are explicitly designed to change the employment status of customers but, during the period of this study, were not operational. Even now there are no specific proposals for the TBI population.

So, if someone has been 'caught' in the benefits system what is likely to have happened to them? What happened to the case studies V and G once attempts to return to work failed?

Clearly there are considerable limitations on forming any sort of definitive opinion from the experience of two people but the issue is further considered when developing a framework for mapping the post-injury employment paths of the TBI population in the next chapter.

Fig. 8

- **Clinical rehabilitation.** A point was made in Chapter 4 that historically in the UK clinical rehabilitation has addressed the functional skills of patients with a view to community re-entry/participation, rarely has it expressly addressed a return to work and, as this study has demonstrated, such are the specific needs of the TBI population, particularly in respect of the generalisation, transfer and maintenance of skills, that one should not expect any statistically significant relationship between clinical rehabilitation and a return to work, although, in some cases, it may be perceived as a necessary precursor. (In addition, there are also the points that the provision of clinical rehabilitation in the UK appears to remain inconsistent and it may be the case that, on the whole, only more severely injured people, with greater potential employment difficulties, will be offered clinical rehabilitation).
- Jobcentres (now Jobcentre Plus). For long before the merger with Social Security
  officers Jobcentres designed to return to work people with disabilities (Chapter 4). In
  respect of the case studies the following services have been particularly relevant:
  - ⇒ DEA service
  - ⇒ Assessment service
  - ⇒ Work preparation

Whilst one may have anticipated Supported Employment regularly featuring this has not been the case.

In short, unless insurers pay for private sector vocational rehabilitation or subjects 'spontaneously' return to work people sustaining TBI are likely to be very dependent upon Jobcentre Plus services for assistance in returning to work. What happened to the case studies?

KW: a DEA declined to offer any support.

G: a work preparation agency inadequately managed the RTW process

V: an assessment was not implemented (although there are reasons to question its expertise) and there was no follow-up after an initial return to work.

Again, it may be reasonably maintained that three cases prove little, albeit the discussion in Chapter 7.3 further develops subject experience of Jobcentre services. The point is that, if not

making a successful return to work, and Jobcentre services 'do not work', subjects are back into the benefits system.

The only means at this study's disposal to demonstrate that appropriate VR facilitates change is reference to the *modus operandi* of Working Out.

In Figure 8 the regularity that is produced is the continuing receipt of incapacity benefits. The role of the mechanism 1, VR intervention, in Figure 9 is to produce change.

#### Fig. 9 How Working Out Produces Changes in Regularity

Contexts

Mechanism 1 ↓ Changes in Regularity→

This figure raises a number of questions:

Mechanisms: What is it about a measure that produces a desired outcome?

In this case it is considered that the following issues emerge as pertinent:

- An accurate and detailed assessment of the client's circumstances, including the identification of barriers to employment.
- > In-house rehabilitation designed to reduce/ameliorate identified barriers
- > Matching with potentially suitable employment
- > Extended and supported work trials gradually building upon previous success
- Careful placement considerations

Whilst this thesis seeks to argue that this process could be further enhanced through the development of *in situ* compensatory strategies and long-term support, and these matters are built into the model VR programme in Part 3, the salient issue to note at this juncture is the contrast to the work preparation programme as illustrated by the experience of G:

- 'An accurate and detailed assessment of the client's circumstances, including the identification of barriers to employment.' Although it was not been possible to establish just how much information was passed from the clinical rehabilitation team to the DEA and to the work preparation agency this was not a joined-up service.
- 'In-house rehabilitation designed to improve work readiness' by concentrating on increasing/improving job skills. The agency lacked the expertise to take into account the sequelae of the injury.
- **Contexts:** what conditions are needed for a measure to trigger mechanisms to produce particular outcomes?

In this respect it is considered that this thesis in identifying a (potentially) significant retention problem (the Working Out figures are not reported over a long enough period) draws attention to the fact that programmes designed to produce change are not hermetically sealed, witness the way G's 'overload' on her work preparation course was increased by her late night babysitting for her sister and, although the case studies do not fetch it out (V did not go on a work preparation programme), the work retention figures draw considerable attention to the possible role played by employers (and, in the first place, they are obviously crucial to placing prospects). Hence outcomes are also influenced by factors operating outside the mechanism(s) (Fig.10).

#### Fig. 10 Programmes, Change and Contexts



It is considered that a rigorous evaluation would require the application of CMOs to individuals in the Working Out programme to demonstrate how any changes in regularity (outcomes) are produced by the specific measures within the programmes. Unfortunately all that is available is programme and not individual and (long-term) data.

**8.4 Summary and Main Points:** Relying on survey data, basic statistical analysis, and applying the realist approach to case studies, and a VR programme, has produced some interesting information that needs to inform any programmes designed to improve employment rates amongst the TBI population, in particular:

- The need for joined-up services.
- The need for a greater degree of knowledge and expertise on the subject of TBI and employment amongst Jobcentre and generic work preparation staff.
- The (potential) role of employers in this process.

The first point raises an interesting issue in respect of VR services. It will be apparent that that in view of the number of potential factors influencing the decisions (choices) that TBI subjects, their families and other advisors, may make there is good case for an holistic approach to their resettlement (perhaps along the lines of the Working Out programme). However this is not feasible in view of costs and when agencies are 'simply' funded to provide an employment placement service. Rather than saying that in the absence of the ability to develop such services there is no reasonable prospect of delivering an efficacious model of TBI this thesis argues for joining up existing services so that if a particular subject requires support from a specific source of expertise there are mechanisms for doing this. VR agencies should be allowed to concentrate on what could be described as 'the sharp end', getting clients into suitable placements and providing the required vocational support to them, and employers, to ensure that they are able to build on this experience.

It is considered that the value of referring TBI customers to non-specialist agencies is open to question. It is apparent that even the additional funding (see Chapter 4) for work preparation courses is unlikely to meet the needs of the TBI population with regard to the 'testing out' of assessment findings in a 'real' work situation and the development of appropriate compensatory strategies (not that there is specific evidence from the UK in respect of the long-term efficacy of the latter two strategies) and the provision of long-term follow-up. Such needs do not square with the short treatment and job club approach of the current condition management programmes.

In particular it is considered that this research highlights the need to address a job retention problem. This is a matter considered in the next chapter.

Returning to the questions asked at the start of this chapter:

Why did the Jobcentre network not offer support to potentially employable subjects?

What went wrong when support was offered (why did it not materialise into permanent employment)?

What are the dynamics of the return to work process?

The answers to the first question would appear to be because historically long-term recipients of incapacity benefits wishing to use Jobcentre services have been required to positively seek assistance (which the creation of Jobcentre Plus has been designed to address), hence potentially employable subjects were not identified (and the discussion in Chapter 7 indicates a sizable number of the subjects returning to work at some stage 'simply' went back to their pre-injury employer/employment). However in respect of what is now Jobcentre Plus the situation may be more complicated than this and there remains a need to examine the process of engagement.

In respect of the second question there was either a lack of expert knowledge amongst on the subject of TBI and/ or an attempt to make the subjects 'fit' generic services.

The response to the third question is complicated and reflects the fact that variety of factors will act upon a person sustaining TBI and circumstances will vary from person to person.

However, as this chapter has illustrated, there are some uniformities and in order to fully answer this question it is considered appropriate to develop a framework for examining the RTW process (Chapter 10).

#### CHAPTER 9

#### **REVISITING BACK TO WORK**

#### **Contents**

9.0	Overview	266
9.1	Identification, Engagement, Recruitment , Compliance and Retention	267
9.2	Summary and Main Points	275

**10.0 Overview:** There are three reasons for including this chapter:

- a) Both the group and case study findings in the two previous chapters suggest that there is a problem in accessing (appropriate) TBI VR programmes.that needs to be investigated (and that this may involve more than the simple availability of programmes so, for example, even when there is something available it may not be taken up ).
- b) The thesis has identified a number of specific issues related to the TBI population, namely problems in the accurate identification of Jobcentre Plus customers with TBI, weaknesses in generic VR practice and a significant job retention problem. Before these issues can be addressed, or a model TBI VR programme developed, there is a prior need to be able to identify, recruit and retain subjects.
- d) Following the suspension of recruitment to the Back to Work (BtW) programme a short qualitative review addressed subject identification, engagement, recruitment, compliance and retention to VR programmes. In the absence of any mandatory rules on participation it would appear that customer preference has to be given considerable importance. One can hardly enforce clinical intervention. Strategy based on a view that large numbers of incapacity benefit recipients will voluntarily participate in work intervention programmes may be misplaced.

Hence the purpose of this chapter is to see what lessons can be learned from the BtW review with regard to meeting the aims and objectives of the thesis, specifically with regard to developing a potentially efficacious VR programme that identifies and addresses individual barriers to employment. The chapter considers such questions as;

How were the BtW customers identified?

What was the recruitment process?

Why did BtW fail to retain customers?

What lessons for running VR programmes can be learned from this experience?

Ethics prevented the contacting of customers who had not consented to the programme. However, it was possible to draw up the attrition tables from telephoning those customers who consented to participate in BtW but failed to appear or subsequently dropped out. Whilst an interview format was devised in practice there was often the need to act appropriately in response to the interviewee. As part of this review local Jobcentre Plus staff were also consulted.

**9.1 Identification, Engagement, Recruitment, Compliance and Retention:** It was difficult to draw any firm conclusions on non-participation from the attrition rates. Customer responses to questions may be influenced by what they perceive to be acceptable. For instance, it was surprising to find that a fear of losing entitlement to incapacity benefits did not feature, yet in informal discussions with customers this was often an issue. On the strength of the available evidence, it was considered that the reasons for the referral and retention rates were better explained by reasons other than the randomisation process. Briefly, these reasons were structural (factors associated with the organisation and priorities of Jobcentre Plus), attitudinal (factors associated with staff interpretation of the programme) and financial (availability of Jobcentre Plus resources to support the identification of customers). From the original Salford pre-pilot programme there had been:

- Changes to the structure of Jobcentre Disability Services.
- The incursion into the incapacity benefit (IB) registers (as opposed to recruiting voluntary IB customers and compliant patients).

#### 1. Identification

In the 1999/2000 pre-pilot programme the customers were known to the referral sources. When recruiting for a rehabilitation programme providing medical treatment Jobcentre Plus staff cannot undertake treatment selection. It is a matter for the treating clinicians to determine suitability. Because of the need to quickly increase the number of referrals during 2003/04, to

get the programme running, Jobcentre Plus staff were asked to identify potential customers, complete the application form, and pass to the contractor's administrator. This only contributed to a high ratio of referrals per programme take up.

A fundamental problem was identified during the identification process, the recording of disability data within the DWP was unreliable. For statistical purposes, the DWP relies upon the Pension Contribution Assessment System (PCAS) maintained by Social Security offices. There are over 400 categories of disability. Staff read GP and/or self-completed claim forms and enter the given information on illness/disability in the appropriate boxes. There is no specific category for people sustaining traumatic brain injuries. I found numerous cases when a common symptom of musculo-skeletal pain, depression, was given more emphasis on 'sick notes' than the causation, and entered into the PCAS system as a mental health problem. Given that head injury, and specifically in this study traumatic brain injury, can give rise to physical, cognitive, and behavioural symptoms, it is considered probable that many people with TBI are not identified in the DWP's data system as having sustained such an injury.

In addition, it is evident from official statistics (DWP 2002) that not all IB customers can be regarded as potentially employable and any random trawl of the IB registers will inevitably identify customers who:

- 1. Are keen to return to work without a rehabilitation programme.
- 2. Who may be, or become, employable but are likely to require a rehabilitation programme.
- 3. Who are not fit for work, nor are they likely to become fit.
- 4. Do not intend to return to work.

The problem is that there is no easy way of recognising into which group many customers may fall and, in any event, the categories may not be exclusive. Over time IB customers may move between them. Staff time can be wasted in identifying customers within the second group. If, for example, taking the BtW completion rate, 11% of the register fall within this group then 89% of staff time is wasted in trying to identify them from the registers.

In the circumstance, one can understand the dislike some regional Jobcentre Plus linemanagers had for trawling the registers.

As indicated, clinicians and a number of Disability Employment Advisors (DEAs) referred the

by any agency (Jobcentre or Social Security staff) for periods of up to 18 years.

- The data held by Social Security on the Pension Strategy Computer System (PSCS) is designed to ensure that entitlement to benefit is established and accurately paid on time. As indicated the recorded clinical information is not always accurate (and there is no category for TBI).
- iii) Trawling the IB registers to identify prospective customers was time consuming but in the absence of mandatory interviews for all new IB customers, now introduced part of the current reforms, may have been the only effective way of recruiting a sufficient numbers of customers to sustain the research but the amount of work this required of Jobcentre Plus staff was a major issue for regional line-managers. A major reason as to why all recruitment was stopped in 2004 was a recognition of the numbers required to meet the research targets. For example, assuming Edinburgh's retention rates remained stable then to meet a target of 80 customers then over 550 referrals would have been required.

The amount of staff time allocated by regions to recruitment varied enormously, depending on local priorities. It was considered that there was probably insufficient incentive for staff at a local level to refer to Back to Work (given that 'results' were likely to be many months in the future), and certainly insufficient incentive to 'work up' customers on the stock IB registers. Time spent on such tasks was time not spent on working towards immediate local performance targets.

#### Identification of customers by the medical profession

The response from the medical profession to making BtW referrals was particularly disappointing. There were no known referrals from Schlumberger SEMA, the organisation contracted to carry out Personal Capability Assessments, although the extent to which information was cascaded to individual doctors was not known. The most productive site for referrals from the medical profession was Bristol where the clinical psychologist and physiotherapist extensively marketed the BtW to professional colleagues. They also had the advantage of delivering NHS pain management programmes from two hospitals. When customers were referred by clinicians they were more likely to take up and complete the course than referrals from other sources (Table 9.2).

Source	No. of Customers	Total No. of	% of
Clinical Psychologist	3	5	60.0
Self Referred	11	25	44.0
Pain Management	7	30	23.3
Physiotherapy	4	21	19.0
Hospital Consultant	1	6	16.7
DEA	6	62	9.7
Job broker	5	55	9.1
Social Security/	14	238	5.9

#### Table 9.2: BtW Course Completion by Referral Source\*

\* Figures as of March 2004.

#### Self Identification and Referral

The national NHS ethical agreement prevented advertising for customers and there was an agreed recruitment procedure. In Bristol, a local newspaper ran a publicity feature. This resulted in 18 people referring themselves. The publicity exercise was not repeated because of a complaint from the local Ethics Committee that this was advertising for recruits.

#### Job Brokers

Job brokers were introduced in 2002 to encourage diversity and foster the expertise of specialist disability/placing organisations. They are funded for registering and placing customers. Whilst some individual Job Brokers made referrals there was no consistent response from this source. An objection raised by one organisation was that identifying potential customers was 'too time consuming'; time could be spent on 'more profitable activity'.

Identification is only the first part of the VR process. The problems may be summarised as the inability to use Social Security and Jobcentre IT systems to identify potential customers, the lack of a .response from the medical profession, a lack of 'voluntary' IB customers registering with DEAs and the position taken by Job brokers.

The experience of the study sample suggests that many potential VR clients simply 'disappear' into the stock of Jobcentre Plus IB customers.

2. Engagement : Once identified, subjects need to be engaged. In this respect the qualitative review identified the factors in Table 9.3. Although performance measures require policy considerations, and there is little VR staff can do about many other issues that clients may regard of foremost importance, the general position would appear to reflect a need to 'work up' clients. It is unrealistic to expect people who may have become reliant on incapacity benefits over many years to 'jeopardise' such security by stepping into the unknown.

#### Table 9.3: A Summary of Engagement Issues

1. Motivation

Historical legacy (customers being left in receipt of incapacity benefits possibly for many years without any contact) Occupational pensioners (that is people of working age regarding themselves as retired) Single parents ( with child care arrangements) Fear of losing benefits/benefits dependency Timing of programmes to meet individual circumstances Ease of claiming IB (in contrast to signing on every 2 weeks for the Jobseeker's Allowance) Possible influence of litigation

- 2. Lack of customer knowledge of Jobcentre Plus/image of Social Security.
- 3. Impact of performance targets on staff.
- 4 Lack of a counselling interview (instead subjects often being given a list of options open to them)
- 5 The need to 'signpost' options allied to the lack of a case management approach.
- 6 Timing/maintaining contact once subjects left the office.
- 7 Providing programmes that meet needs (nobody ever asked the customers 'what would you like to see to help you return to work?')

**3. Recruitment:** In respect of the actual recruitment process a number of practical issues occurred. Seemingly simple matters such as referral agents accurately completing referral pro forma was not always undertaken accurately. The lack of secure electronic referral systems in some instances delayed the recruitment process.

A debateable matter was the question of whether or not to have a central referral point (as opposed to referral agencies referring directly). In Salford, Bristol and Neath referrals were made directly to the contractor whereas in Edinburgh Jobcentre Plus preferred to appoint a

person to act as an intermediary. The latter measure meant that Jobcentre Plus was always aware of the recruitment position and as the intermediary was personally known to many of the referral agents was able to 'drum up' recruitment .

The essential issue, however, appears to be one of accurate mechanisms for making referrals and for the organisation delivering the service to expeditiously follow these up.

**4. Compliance:** Once subjects have said they will participate in a programme there is an obvious need to maintain their support. In this respect the review identified a number of shortcomings, again, not all of which can be addressed within a VR programme. They are listed in Table 9.4:

#### Table 9.4: A Summary of Compliance Issues

- 1. The need for continuing assurance (and the possible need for a case management approach in some cases).
- 2. Within the research programme ethics required the subjects to be given 24 hours to think over their consent. This possibly created a hiatus and another layer in the recruitment process. Whilst this process would not apply to an actual VR programme, the issue of subjects being given the opportunity to 'think over' their participation, with accessible guidance available to them, needs to be thought through.
- 3. A number of consenting subjects subsequently found that public travel arrangements, and finding the (refundable) costs, presented a seemingly insurmountable barrier to participation.
- 4. Because subjects have been at home for a long period it is easy to fall into the trap of thinking that they should be readily available for a VR programme. In reality potential customers of the BtW programme had often other commitments, particular child care.
- 5. The issue of some customers perceiving BTW has an exercise to simply get them off incapacity benefits has already been mentioned. This is a thorny issue because, at the end of the day, this is a consequence of a successful VR programme. It is important to stress the return to work focus of the programme and have available accurate welfare rights advice.
- 6. Follow-up arrangements need to be in place for when consenting subjects fail to appear.

**5.Retention:** In respect of retention it was considered that the acceptability and significance of running a programme from a hospital needs to be considered once a patient has been discharged.

Although in the UK we have not arrived at the bridge of mandatory participation in VR programmes there is probably a case for the trialling of contracts setting out mutual obligations. Matters such as signposting/gate keeping (informing patients, assuring VR is not as IB test) need to be addressed.

**9.2 Summary and Main Points:** It is considered that when designing a VR programme it is probably easy for the professional person to be drawn towards the intricacies of assessment, evaluation and placement strategies. As the BtW review demonstrates the reality, in response to answering the questions in the Overview, is that such matters are not necessarily ones that concern the potential clients/customers. Unless there are in place efficacious mechanics identifying, recruiting and retaining subjects then the best of programmes may fail.

The BtW review demonstrates that organisation is not simply a matter of getting right the administration, important as it is to give attention to the accurate completion of referral forms, public transport and the timing of programmes. Individuals prematurely leave rehabilitation programmes such as BtW for a multiplicity of reasons, and there is a need to consider all aspects of delivering such services.

In the case of BtW the higher percentage participation and completion rates of BtW customers referred by professional staff, as opposed to administrators, will have been noted. This may be because of the relationship with the customer, a higher degree of expertise with regards to matching the patient with the programme or a combination of the two.

Identifying customers of a TBI VR programme remains a problematic issue because of inadequate DWP data systems and the fact that staff, particularly Personal Advisors (PAs), may not have the expertise to recognise appropriate referrals and there may be a lack of incentives to other potential referral agents.

The lessons appear to be in respect of :

- Developing direct referrals from clinical sources.
- 'Working up' a number of customers who may have been in receipt of incapacity benefits for a number of years and responding appropriately to their concerns.
- Establishing a *relationship* of trust and confidence.
- Recognising and responding to the training needs of referral agents.

#### **CHAPTER 10**

# ADDRESSING JOB RETENTION ISSUES AND A FRAMEWORK FOR MAPPING EMPLOYMENT PATHS FOLLOWING TBI

#### <u>Contents</u>

10.0 Overview	276
10.1 The Nature of the Retention Problem	278
10.2 Summary and Main Points	295

**10.0 Overview:** The scale of the job retention problem amongst the study sample was not anticipated (and it follows that the need for this chapter was not anticipated and some new literature is cited). An objective of this thesis is to identify the variables influencing the employment of subjects sustaining TBI so they may be considered in any programme designed to improve post-injury employment resettlement rates. In this respect it is apparent that the part played by employers is critical and requires examination to further an understanding of the prospects of people sustaining TBI and 'other' (than clinical or demographic) variables influencing outcomes.

This process necessitates an understanding of how and why people with TBI become excluded from the labour market and access to employers. In this respect a framework for mapping the employment paths of people sustaining TBI is developed based on information in Chapter 4 on available services in the UK, group and case study findings in Chapters 7 and 8, the BtW review in Chapter 9 and issues identified in this chapter. In this respect this chapter ultimately 'pulls together' the findings. The clinical consequences of TBI have been discussed in Chapters 2, clinical and demographic variables influencing outcomes and the role of rehabilitation in Chapter 3 but, as the findings have indicated, a major part of the equation (affecting resettlement), the role of employers, has received little attention. It is considered that this is a consequence of little or no consideration in the reviewed literature on TBI and employment. This is a serious omission.

In respect of meeting the aims of this thesis with regard to developing a potentially efficacious VR programme the case for job coaching and *in situ* support has been made on clinical grounds. In order to be successful any such intervention must fit in with the policies and

practices of employers.

Particular concerns Chapter 10 seeks to address are why:

i) a large number of people with TBI in the UK 'disappear' into the mass of long-term incapacity benefit claimants. (For research purposes this means that there are fundamental problems in identifying and tracking them.) There is (limited) evidence from this study that some of this number may be potentially employable (or, at least, they may not have sustained injury as severe as some people with TBI who return to work) and one is left wondering why they remain excluded from the labour market.

ii) so many members of this study sample failed to retain employment (unless colluding to fail for litigation purposes, albeit this was not evident). Whilst the literature suggested that a problem was to be anticipated, the scale of it was not expected. Moreover, the literature primarily focuses upon cognitive and work adjustment explanations, leading to a position being taken that such matters need to be addressed by the development of appropriate *in situ* compensatory strategies and long-term follow-up (an opinion that remains, albeit there is no UK based evidence to support the efficacy of such strategies). However an absence of available *in situ* support does not satisfactorily account for why so many members of the study sample appeared to 'drop out' of the labour market (as opposed to making continuing efforts to return to work).

The nature of the retention problem is discussed alongside other findings in Chapter 10.1.

Chapter 10.2 draws together the findings, including ones from the preceding chapters, by developing a framework for understanding the employment paths and decision making processes following TBI.

Hence, Chapter 10.2 seeks to answer such questions as:

If there are structural barriers (to returning to work) where and how do they operate?

Why do a number of TBI subjects appear to choose to stay on incapacity benefits?

What pathways does the return to work process follow?

What sort of policies and practices do employers have that can facilitate the resettlement process?

**10.1 The Nature of the Retention Problem:** This thesis has identified an unexpectedly high job retention problem amongst the study sample. This is reflected in three ways:

- i) the inability of the subjects with pre-injury employment histories to return to work;
- ii) the inability of many of the subjects injured prior to entering the labour market to subsequently go on to obtain and retain work;
- iii) the inability of a large number of subjects to build on post-injury work experience.

A problem in relying upon so much North America literature is that it does not make reference to factors affecting the UK labour market. It is apparent that within the UK there are potentially significant structural factors in operation, and cognitive based compensatory strategies would not address all the problems of identification, engagement, recruitment and even retention identified in this study. Amongst the study sample explanations for not maintaining a position include a lack of communication between an occupational physician and the employer and a lack of expert guidance for employers

It is evident that there are a number of potential reasons for a failure to make a successful return to work including:

- Being medically unable to work at all
- Not having recovered sufficiently at the time of a RTW
- Inadequate work preparation, for example the building up of stamina
- Returning to the 'wrong job', that is being unable to cope with the work demands
- Manifesting inappropriate social behaviour
- Inadequate support at work
- Lack of financial incentive

In the UK a traditional and typical approach to a return to work following TBI would appear to be:

• Return to previous employer/employment (if there is one)

- When offered support
  - psychological assessment
  - pre-placement support to build social skills and job readiness (may involve basic skills)
  - job search

.

This study criticises such processes with the TBI population. Behaviours and skills need to be adequate for specific jobs.

Little consideration is given to the *dynamics* of the decision making process, including the role of stakeholders, such as employers and other employees. For example in respect of young people families and staff within the education sector are likely to play a part. It cannot be assumed that all stakeholders are pulling in the same direction. There may be perfectly understandable reasons for someone saying 'I've had enough of this' (any work experience), especially a partner having to suffer from some of the more emotive aspects of TBI brought on by tiredness. It further appears that the employer's perspective requires investigation.

As retention has unexpectedly developed as a major issue reference is made to research that has addressed this matter (James, Cunningham and Dibben, 2003). James and colleagues were commissioned by the Health and Safety Executive to identify issues that employers and employees need to address to facilitate continuing employment through vocational rehabilitation. James and colleagues put forward a conceptual framework referred to as the "cycle of vulnerability" faced by ill, injured and disabled workers (Figure 11).



James, Cunningham and Dibben (2003)

The central thesis to the "cycle of vulnerability" is that appropriate rehabilitation action can be utilised to address the problems identified in Figure 11. (Interestingly, the authors acknowledged one of the difficulties in undertaking research in this sector contributing to tentative findings, the lack of UK-based research on the efficacy of VR improving retention rates).

James and colleagues went on to develop a framework document postulating seven management processes and practices contributing to development and operation of effective workplace rehabilitation programmes:

- provision of rehabilitation support, for example treatment, adjustment, functional evaluations, etc.
- the co-ordination of the rehabilitation process (joined-up services).
- access to worker representation to encourage openness and trust.
- the establishment of a policy framework, that is who is responsible for what.
- systematic action.
- mechanisms that allow any framework weaknesses to be addressed.
- 'the early and timely identification of vulnerable workers through health checks, maintenance and regular contact with absent workers, return to work interview, etc.'

When one looks at the general position of the study sample there is insufficient information to locate members within James' cycle of vulnerability. However, there is evidence to support six of the points above (representation does not emerge as an issue). There is little evidence in respect of attempts to work post-injury being subject to a systematic process with a clear picture of who takes responsibility for what. On the contrary, there is evidence of a lack of joined-up services, an absence of support and advice to employers and employees and any policy framework addressing such matters.

In the absence of any systematic means for identifying the TBI population and addressing their employment needs what is the return to work process?

It is considered that an approach to understanding the position of anyone sustaining TBI (and thereby developing appropriate VR programmes) is to try and place oneself in their position (and that of significant people around them).

In this respect there is a further reliance on realistic evaluation and Contexts (from Table 8.1) require addressing through an examination of the subjects ' response to such matters and the choices/options open to them:

#### **Contexts**

- Age at injury
- Domestic circumstances

As indicated one can anticipate a range of family responses such as denial, over-protection, support to 'move on' and so on. Mechanisms can only be triggered by the subjects' response to contexts. Any search for 'normalisation' with younger people will involve a return to education and/or seeking employment. Older workers, and their families, may consider that a return to work is not worth the effort. What are the options facing older workers when a return to work does not succeed for any reason?

Rather than the 'starting point' being the post-injury situation it is considered that the prevailing situation prior to injury must be taken into account:

#### <u>Contexts</u>

Young person:	education
	training
	start of working life
Of working age:	established/not established in the labour market
	nature of skills/qualifications

A point not previously considered, and which the retention problem has highlighted, is the nature of the relationship with an existing employer and the employer's mechanisms for dealing with absent sick/disabled workers.

The potential support of an employer was previously considered as a mechanism for facilitating a (positive) outcome. Revisiting this subject, part of the cumulation process, suggest that it is not a mechanism but part of the context in which the prospects of any TBI victim needs to be considered.

What choice does a young person have (or, probably more realistically members of their family)? The reality for most young people is considered to be:

- return to school (with support);
- return/attend college (with support);
- seek support of specialist careers officer or DEA;
- remain at home.

If returning to the education system decisions have to be made in respect of the curriculum to be followed.

The option of an extended supported work placement does not exist (albeit a number of college courses are likely to include work experience placements).

If returning to education a decision has to be made as to what to do when a course is completed (or when further funding is not available). At this juncture options are likely to be:

- stay at home and try to find some diversionary activity (voluntary or permitted work). Essentially this means staying in receipt of incapacity benefits.
- try and find a job (from a perspective of some disadvantage);
- try and find a job by consulting specialist support services ,the obvious one being a DEA (although there is now effective 'mainstreaming' that is general staff, particularly Personal Advisors, seeing people with health problems).

The options facing a DEA , or other Personal Advisor, are:

- · do nothing (witness the example of KW), advised to stay on incapacity benefits;
- refer for an assessment, but, as pointed out, the short assessment format has limitations when applied to subjects with TBI and does not allow for the development of in-situ compensatory strategies;
- refer to a work preparation agency, but, as pointed out, there are few such

specialist organisations and the existing funding arrangements are inadequate;

- refer to a supported employment agency (improbable without an assessment and a placement with a work preparation provider).
- refer to an employer. (There is often a mythology that DEAs keep a list of 'sympathetic' employers. In reality they invariably work on the basis of advising customers and getting them to present themselves in a positive fashion). Again, this step is improbable with a prior assessment and some work preparation.
- refer for training . Again this is improbable without a supporting assessment and successful work preparation course.

Even assuming a young person and his/her family get through this process (and it will be noted that in the case of KW even a support worker, appointed by a case manager, had to go through this process, before, eventually, 'settling' for therapeutic work) they then have to face the daunting prospect (for anyone without work experience, never mind possible significant continuing symptoms) of identifying suitable employment and adapting to the work environment and new colleagues. Older workers have additional considerations:

## <u>Contexts</u>

Age at injury (older worker)

- security of incapacity benefits (with relatively ease of receipt compared to the Jobseeker's Allowance);
- not having to face the stresses and strains that employment may bring;
- social acceptability ('I can't do my old job', 'Fred's got too many problems');
- possible perceived loss of compensation;
- lack of financial incentive (difference between benefits income and net wages 'not worth it') particularly in a position of reduced status and/or receiving an

occupational pension;

- loss of status/income if returning to the same employer in a different job;
- lack of knowledge/awareness as to how to access support services or the benefits of them.

In such circumstances it may be perceived that the long-term receipt of incapacity benefits is a rational choice, particularly if an initial return to work runs into difficulties. But what evidence is there to support such a proposition?

The receipt of incapacity benefits is not an 'absolute' measure of employment status - a dichotomous indication of the ability to work/not work (DWP, 2002). In the pre-pilot BtW research programme a large number of participants were recipients of incapacity benefits but volunteered to participate (this is substantially attributed to their relationship with the clinicians and the 'follow-along' nature of the service from clinical rehabilitation).

A problem with TBI is that recovery is a prolonged process. Whilst there is often talk of a two years' plateau others reject this (Kay and Lezak, 1990). This means that the TBI population, and certainly anyone sustaining more than a minor/moderate injury, are almost all likely to find themselves in the stock (as opposed to the flow) of incapacity benefit recipients. This has two significant implications.

- i) If employed, the employer's financial obligation to the person is likely to have expired (unless there is a private insurance scheme).
- ii) Historically the person has been unlikely to receive as much as an interview by DWP/Jobcentre Plus staff (DWP, 2002). Whilst there are periodic medical examinations carried out by contracted medical personnel even those tend to concentrate on more recent claimants (because of the inability to annually examine 2.7m people) and, in any event, the number of referrals from this source to BtW will have been noted (nil).

Hence, unless a General Practitioner was to refuse to provide an incapacity note, then the likelihood of any knowledgeable person having an informed discussion with a TBI subject as

their potential employment capability is remote.

In the circumstance, despite the epidemiological evidence, it is not surprising to find Jobcentre Plus staff reporting that they did not see many brain-injured people (personal experience of developing the BASIC programme in Salford) albeit this may also reflect the lack of any connection made by staff between symptoms and causation.

But whilst such rationalisations may explain why so many of the TBI population may not even seek employment, how does an approach explain the position of so many subjects returning to work and failing?

In this respect it is considered that the management processes and practices identified by James and colleagues (2003) are particularly helpful, for example:

# <u>Contexts</u>

• 'the early and timely identification of vulnerable workers through health checks, maintenance and regular contact with absent workers, return to work interview, etc.'

In respect of the study sample there was only one example of an employer-led managed return to work, and this was ultimately mishandled. Whilst an occupational physician made constructive suggestions the employee was expected to resume normal duties within two weeks of easier work.

The adjectives 'early' and 'timely' cause particular problems in respect of TBI employees. Anyone sustaining anything but a mild or moderate injury is likely to be off work longer than any period involving statutory payments. In addition it can be difficult for even experts to assess when is the right time for a TBI subject to return to work (the matter is addressed in the model theoretical VR programme in Part 3). Many people sustaining TBI may return to work too soon in a search for 'normality'.

There is a lack of research evidence on the relationship between employer and employee during sickness absence, but pertinent issues in respect of an employee returning to work may be:

• a keenness to see an employee back at work;

- a lack of willingness to challenge or question any perceived problems;
- a lack of understanding as to the consequences of any continuing symptoms;
- an inability to recognise such symptoms;
- a willingness to present as a 'good employer' to unions, and other employees, and observe legal requirements;
- a lack of (appropriate) medical advice as to the employee's fitness to work and, once the employee has returned to work or a new employee with TBI commenced work, a lack of vocational advice as to how to address an unsatisfactory work performance;
- a lack of advice as to what to do about any behavioural issues (there are examples from the study sample);
- a lack of perceived suitable employment (the case study V illustrates);
- concern regarding health and safety issues (again supported by the study sample);
- concern regarding the impact on other employees of one employee 'getting away' with a reduced performance, unreliability, etc.;
- a lack of awareness as to where to seek support or concern over costs.

Clearly circumstances are likely to vary from employer to employer, with such factors as size, the nature of the work and available medical services being influential. Nevertheless it is possible to begin to construct a model that begins to suggest that a return to work following TBI is an inconsistent process, if not entirely random, and that to *choose* to stay in receipt of incapacity benefits is a rational choice (notwithstanding many TBI victims being incapable of any paid activity). Putting oneself in the position of those subjects who have attempted work only for it to fail, what are their choices:

- to say, 'Well, I've tried but it did not work';
- to say, 'I'm not doing anything like that again, it was too much';
- to keep trying to return to work with a risk of repeated failure;
- to accept a changed self and lifestyle;
- to learn to manage on incapacity benefits (although, it is recognised that many of the study sample would be compensated for a future loss of earnings);
- to keep going to the Jobcentre (where they may or may not be offered appropriate support)?

It is apparent that one can not move on to what it is about mechanisms that may produce the outcome without revisiting the contexts in which decisions are made and, in view of the retention problem, recognise that employers and significant other people, such as DEAs, are stakeholders in this process (see Figure 6 - Basic Framework for Researching TBI Vocational Outcomes). The process whereby decisions are made on the future of people sustaining TBI is a complex one:



## Fig. 12: Contexts of Decision Making Process (\*Categories are not mutually exclusive)
Before mechanisms can be triggered a decision has to be made (by the person and/or those around him/her, such as members of the family or case manager) on what to do next. In turn this decision is likely to depend upon the perceived options available to them and the response at the next stage. These are indicated in Figure 13:





\* A TBI subject able to return to the open labour market is unlikely to have a case manager but there will be exceptions. Before mechanisms can be triggered, that ultimately result in the eventual outcome, decisions need to be taken based on the options (choices) available to people. In this respect there are potentially key players, Pawson and Tilley's 'stakeholders' (the extent to which they are applicable depending upon individual circumstances):

- the family and other significant people.
- GP (one has only to look at the BtW attrition rates to recognise the significance attached to being 'signed off') and whatever pathway is followed it is likely that the GP will be involved, if only to do this. In terms of clinical advice it might be seen that the Employment Medical Advisors undertaking assessments for incapacity benefits would have a role to play, and whilst this may be the case when finding a claimant fit for work there is no evidence from the study sample or BtW programme of this being an influential intervention.
- DEA (or, increasingly, other Jobcentre Plus and/or agency staff).
- employer (including employer's employees).
- school or college staff.

On revisiting the mechanisms in Table 9.1 it is apparent that the role stakeholders is likely to be crucial to the mechanisms, not just the intervention processes but the influence of stakeholders in response to the perceived status of the subject. (Fig 14):



#### Fig. 14: Role of Stakeholders in the Decision Making Process

The question mark (?) is in respect of what it is about the mechanisms that produces an outcome.

The literature, and the study sample findings, suggest one can not rely upon:

- a spontaneous return to work for a large number of people sustaining anything but mild/moderate injuries;
- clinical rehabilitation, because:
  - □ a large number of people sustaining TBI in the UK do not receive it;
  - □ the focus is upon community re-entry (and not job entry);
  - those receiving clinical rehabilitation may be the most severely injured
     TBI subjects and unlikely to return to work in any event;
  - skills (re)learned in clinical rehabilitation may not generalise and transfer to the labour market.

Occupational trials have been found to be a productive way forward but this begs the question as to why such a high proportion of the study sample failed to retain jobs? The answers appear to be because:

- they were not provided with managed trials.
- there was a virtual absence of any support or guidance for employers.

This suggest that a managed process can facilitate good job placement figures (as in the Working Out programme). In turn, what is it about the 'appropriately managed process' that results in positive outcomes? The answer to this question is investigated through the concept of two mechanisms.

## Mechanisms

- VR programmes
- Support of employers (see James et al Fig 11)

It will be apparent that VR models vary but an expert programme is likely to contain elements, if not all, of the following activities:

- clinical factors affecting employment
- occupational factors (skills, ability, aptitude, etc.)
- ii) counselling, addressing such matters as:
  - self-awareness/denial
  - appropriate social skills
- iii) occupational trial(s), following job analysis (matching strengths to the demand of the job):
  - building self-confidence and esteem
  - increasing stamina
  - practical assessment of skills and behaviour
- iv) assistance with placement:
  - in situ support/application of compensatory strategies
  - advice to employer and other workers
  - monitoring/follow-up

The problem with describing work preparation courses as vocational rehabilitation is the lack of any sequential link between iii) and iv). On completion of a course subjects are referred back to a DEA and the extent to which there is any action taken varies considerably (Banks and Riddel, 2002).

One then ends up with a complex framework to explain eventual outcomes following TBI (Figure 15):



## Fig. 15: Framework Mapping Employment Outcomes Following TBI

- In-situ support, that is applied compensatory strategies and support for employers and employees are not included in this list because of the limited evidence for such practice in the UK.
- \*\* A number of outcomes can be divided, for example open employment, part/full-time, return to previous employer/new employer, same job/change of job and so on.

A number of features of this model are considered striking:

- The lack of any connection between Jobcentre Plus VR services and employers. There are no formal mechanisms to ensure that when an employee has kept an injured worker 'on the books' the employer will receive expert advice on resettling the employee, never mind mechanisms for ensuring that support is provided should difficulties occur.
- There is little evidence from the study sample of employers being offered, and implementing, medical advice. A TBI subject with an existing employer may by-pass expert services for this reason yet it cannot be assumed that successful resettlement will follow.
- A TBI subject returning to work and failing effectively begins the loop again, having to claim incapacity benefits.

In the circumstances it is considered easy to understand why TBI subjects who have returned to work once, twice or three times (as many of the study sample did) subsequently 'drop out' of the labour market, entering the stock of incapacity benefit claimants.

It is suggested that the research provides considerable support for this framework making 'real connections' to cite Pawson and Tilley. How does it explain:

#### i) A failure to return to work or take up any paid activity?

By taking into account personal and clinical circumstances and the role of the GP in certificating an inability to work.

It allows for an IB customer being found 'fit for work', in which case the GP is notified (but not Jobcentre staff - this only follows a claim for benefits).

#### ii) A failed attempt to return to an existing employer?

By indicating that this process is likely to by-pass expert vocational services (unless an employer has their own means of obtaining advice) and advice to the employer and employees.

## iii) A failed attempt to return to work with a new employer?

By indicating the lack of any formal connections with expert VR services, including continuing support to the employer and employee.

## iv) 'Giving up'?

By indicating that the person has to begin the whole job search process again, with a record of failure and once in receipt of incapacity benefits he/she is likely to become isolated from RTW support services.

It will be noted that this framework make no claims that expert VR will necessarily result in job retention.

**10.2 Summary and Main Points:** The running of VR/condition management programmes requires not only appropriate professional intervention but mechanisms for ensuring the identification, engagement, recruitment, compliance and retention of the participants. The BtW programme identified a number of limitations (although many of these, such as prioritising the service and mandatory interviews) have been addressed within the first batch of condition management programmes.

The research has identified a significant job retention problem amongst the study sample. This relates to:

- an inability to resume previous employment
- an inability to take up and retain alternative employment (paid activity)
- an inability to 'build on' occupational trials
- 'dropping out' of the labour market

Most of the RTW literature is of North American origin and whilst 'job separations' are reported (Sale, West and Sherron, 1991) they are attributed to cognitive/adjustment reasons.

Retention can not be seen simply in terms of the problems of the individual or a failure to deliver adjustment services. Whilst the model theoretical VR programme developed in Part 3

takes on board the development of in situ compensatory strategies VR cannot operate in a vacuum. In particular, it is dependent upon:

- Jobcentre Plus, for identifying, engaging and recruiting VR clients (compliance and retention are issues that VR agencies have also to face).
- Employers. In this respect the 'cycle of vulnerability' identified by James et al (2003) and the issues affecting the policies and practices of employers are considered useful for understanding their operational practices.
- The role played by other key stakeholders.

Equally critical is the need for joined-up services. In the absence of any clearly delineated pathways for ensuring that Jobcentre Plus IB customers with TBI have their employment capability addressed any number of stakeholders may play a crucial role. It may require a case management approach to 'pull together' all of the threads of resettlement identified in the model theoretical TBI VR programme advocated in Part 3 for some subjects although the model foresees job coaches providing the crucial (but currently missing) link between VR services and employers. As matters stand it is considered that whilst very many people sustaining TBI have profound employment problems Figure 13 indicates that for many such people the long-term receipt of incapacity benefits may also be an inevitable outcome. Any condition management programmes that only recruit from the stock of IB claimants and fail to address long-term retention issues are unlikely to succeed in reducing the number of long-term TBI claimants.<sup>20</sup>

 $<sup>^{20}</sup>$  During 2006 the DWP announced the intention to expand condition management programmes to the stock of IB claimants .

### Part 3

## CONCLUSION

Chapter 11	Main Findings and a Return to the Hypotheses	297
Chapter 12	Meeting the Aims of the Study	314
Chapter 13	Research Issues	340

#### CHAPTER 11

#### MAIN FINDINGS AND A RETURN TO THE HYPOTHESES

#### **Contents**

11.0	Overview	298
11.1	Discussion of the Main Findings	298
11.2	Revisiting the Hypotheses (Chapter 5)	304
11.3	Structural Issues Affecting Outcomes	310
11.4	Summary and Main Points	312

**11.0 Overview:** Chapter 11.1 provides a brief review of the main findings. This is followed at Chapter 11.2 by revisiting the hypotheses presented in Chapter 5, when discussing realist methodology, to see to what extent there is evidence to support such propositions. (Their role in meeting the Aims and Objectives of the thesis are set out in Chapter 1).

Chapter 11.3 then focuses on one of the major findings of this thesis, the extent to which structural issues affect outcomes. This may be perceived as taking into consideration the wider societal context within which VR/condition management programmes must operate.

**11.1 Discussion of the Main Findings:** In the UK there is a remarkable lack of information on the employment experience of people sustaining traumatic brain injury. This is probably a consequence of a number of inter-related factors. This research has identified that there are no accurate means of identifying this group of people from the incapacity benefit registers. It follows that nobody knows just how many people sustaining TBI are able to spontaneously participate in the labour market, how many continue to struggle to maintain employment and how many never work at all. This absence of information is in marked contrast to the plethora of studies reporting the clinical sequelae of TBI. Unlike the general population with TBI patients are identifiable until they are discharged.

Whilst a reading of the literature may lead to a view that participation in the labour market can be influenced by many factors besides symptoms, such as the availability of appropriate support from family, employers and vocational rehabilitation agencies, other than age this thesis has not been able to provide corroborative evidence. There are potentially a number of explanations for this situation. One is that the study sample may not be representative of the TBI population because they all had personal injury litigation cases (which begs a question in respect of what circumstances result in litigation being pursued) and, on the whole, were more severely injured than the general TBI population. An additional, and more plausible, reason is that any study can only report on the population under examination and the lack of statistical significance between all of the selected variables and a return to work has been reported in one study or another. Although this lack of a statistical relationship prevented the development of an 'employability index' it is considered that the thesis has still developed a greater understanding of the issues involved in the return to work process for the TBI population in the UK than has previously been available. In particular a significant job retention problem has been identified. Such an issue needs to be faced if problems of social exclusion are to be addressed.

To facilitate an understanding of what happens to patients once discharged a framework for mapping the post-injury employment experience of people with TBI has been developed (Fig. 15).

Amongst the study sample two subjects with clinically very severe TBI returned to work whereas two others, with mild/moderate injury, failed to do so. These examples illustrate the danger of simple rationalisations. Even though there are studies that demonstrate a link between the severity of injury and RTW there will always be individual exceptions to such statistical findings. The framework points to a possibility that remaining in receipt of incapacity benefits may be a rationale choice for some people.

A strong case is made for 'joined-up' services, linking clinical and vocational rehabilitation to continuing support for TBI subjects **and employers** once someone starts work.

The thesis identifies the reasons why generic vocational rehabilitation programmes may not meet the needs of TBI subjects and (Chapter 12.3) develops a model theoretical VR programme that:

a) addresses issues relating to the identification, recruitment and retention of subjects,

b) moves the focus of intervention away from pre-placement activity to working *in situ*, and c) would be potentially deliverable within the context of current condition management programmes. There are currently no proposals for the brain-injured population although the epidemiological evidence in Chapter 2 suggest that they are likely to be well represented amongst IB customers of Jobcentre Plus..

This thesis has demonstrated that without intervention and even with (inappropriate) intervention, return to work rates following TBI may remain poor. It is also considered

significant that many people sustaining TBI may return to work too soon and without appropriate advice. There is likely to be considerable scope for improving the quality of vocational rehabilitation for people with TBI in the UK. The government's commitment towards the rehabilitation of incapacity benefit customers may yet provide the necessary impetus to do this but the funding arrangements for the length of current programmes suggest that any development will not follow the model of Working Out. Other cost-effective means need to be devised for identifying and delivering a service that meets the needs of the TBI population.

This matter requires addressing because the literature, and this research, suggest some consensus in respect of the demographic and clinical characteristics of the TBI population. On the whole they are young, either in education or in the early years of their working lives. Major cognitive factors affecting their employability include memory problems, speed of information processing, anxiety/depression, anger and irritability, although a reliance on different means of collecting data makes anything more than noting such matters less meaningful.

The population is also predominantly male and, otherwise, most likely to be employed within the manual sector of the labour market, either in a skilled, semi-skilled or unskilled capacity. Few acquire qualifications post-injury. However, even the acquisition of qualifications does not presuppose employability. There would also appear to be evidence that few find their way into supported employment, although it would appear ostensibly suitable.

The reasons for failing to successfully return to work amongst the study sample (when known) appear no different to those demonstrated in the literature and relate to such matters as neuropsychological deficits and inappropriate interpersonal skills, a lack of job 'matching' and inadequate support. In addition to cognitive factors affecting job retention the lack of any systematic strategy for supporting employees and employers once a return to work is made also requires addressing.

Many of the subjects in this study continued to live in the parental home well beyond an age at which one might otherwise have expected them to leave. This may be because the overall injury severity of the group was more severe than one finds amongst the general TBI population making it more difficult to live independently. Available domestic support does not necessarily result in better employment outcomes. The significant issues to consider are the reasons why someone continues to live in the parental home and the specific harnessing of support to foster a return to work.

If the experience of the study sample is considered representative of the UK TBI population then many amongst them remain at home receiving long-term incapacity benefits, even though some may be potentially employable given the right support. On the other hand, it has been shown that the available VR did not necessarily meet the needs of the subjects although, whilst the case studies offer some insight into the experience of the subjects, it has not been possible to develop any empirical uniformities from such a limited sample.

The last paragraph presupposes that appropriate intervention facilitates a return to work, whereas the National Traumatic Brain Injury Study found no evidence that clinical rehabilitation resulted in a return to work and this study has also found no relationship between clinical and/or vocational relationship and a return to work. In the absence of more detailed research such matters may only reflect:

- only more severely injured people being offered clinical rehabilitation
- the lack of expertise in a number of vocational interventions

Whilst it is possible to describe the likely general characteristics of the TBI population the DWP data systems are inadequate for monitoring the number of such people in long-term receipt of incapacity benefits/unemployed. Whilst this factor may contribute towards the inadequate provision of expert services in the UK, with many parts of England and Wales having no access to expert services, so are such factors as the needs for additional funding and the availability of expert vocational rehabilitation personnel.

In respect of rehabilitation over the last twenty years, recovery following TBI has evolved from intensive neurosurgery management to practical approaches designed for community and vocational re-entry, particularly in the United States. It is difficult to quantify objective outcomes following brain injury and rehabilitation although employment is invariably considered a major issue. In both the UK and USA, programmes have evolved without a systematic evaluation of how the needs of the TBI population are met by many vocational re-entry programmes. This study has demonstrated that reporting 'snap-shot' return to work figures can be misleading. Whereas 54% of the study sample returned to work at some point post-injury, on follow-up (average 7.67 years post-injury) only 18.5% had remained in continuous employment.

Evidence suggests that in-patient clinical rehabilitation alone and/or relying on a spontaneous return to work, is an insufficient basis for TBI patients returning to employment in any significant numbers. Jacobs (1988), in the USA, and Brooks et al (1987a), in the UK,

respectively found that only 27% and 29% of their samples returned to competitive employment. In the latter sample, many of the subjects were not referred for clinical rehabilitation, a position that appears to remain common in the UK (Thornhill, 2000).

There are potentially a number of ways of providing vocational rehabilitation services to meet the needs of the TBI population. There is no one 'ideal' model, hence the importance of an early assessment of the client/patient's needs, although there is generally consensus in respect of the value of (lengthy) occupational trials.

The value of occupational trials is also recognised by Jobcentre Plus. Regrettably, its funding of expert TBI vocational rehabilitation services, as part of the work preparation programme, remains limited. For a long time it has tried to fit the TBI population within the provision of generic services for the disabled population - whereas the need for TBI population are unique. No other injury results in such widespread cognitive, physical and behavioural disturbances. Whilst jobs may vary considerably in nature they all require some combination of such skills. At the present time the stance of the DWP is inconsistent. Despite the House of Commons Select Committee on Health (2001) recommendation to the NHS/Employment Service to replicate the Working Out model, there has been no replication, yet, at the same time, Jobcentre Plus must recognise the limitations on work preparation provision by providing extra funding for the length of courses and contracting with Rehab UK, the Papworth Trust and Banstead Place. The failure to develop monitoring standards that ensures that the needs of the TBI population are met by work preparation agencies is particularly noted. (On the other hand, it is recognised that such agencies serve the general disabled population and they are unlikely to have the resources to develop the additional support required by TBI clients, particularly providing in-situ support).

In addition to insufficient funding for work preparation agencies, there are limitations on the employment of job coaches in the UK because of the lack of any formal accredited training ensuring that they are equipped with the necessary skills and knowledge to carry out the potential range of activities associated with such work. There may also be a lack of employer/employee awareness as to the role of job coaches that could lead to them being considered intrusive.

As matters stand return to work interventions for people experiencing TBI are approached in different ways in the UK, from making the client fit the model of available practice, for example generic work preparation courses, to geographically limited but detailed TBI rehabilitation

strategies, for example Rehab UK.

A major problem with regard to the resettlement of the study sample was the lack of any systematic intervention and continuing support. Even when there was vocational support it was not always appropriate. Any intervention is only likely to succeed if the needs of the person are met in the most appropriate ways. Given the multiplicity of presenting problems following TBI then devising cost-effective programmes that meet the needs of all participants throughout the UK presents a considerable challenge. In summary it is considered that:

the full extent of the problem of TBI and unemployment is not "officially" recognised because of inadequate recording mechanisms;

whilst the unique vocational needs of this group must be recognised by senior personnel within the Disability and Rehabilitation Services of Jobcentre Plus, given the additional funding to the work preparation agencies, to date there has been no national strategy to tackle the problem (possibly because of the implications for both costs and required expertise);

whilst models of expert practice are recognised (such as Working Out and Rehab UK) there is a lack of political will to make such models more widely available (possibly because of the required funding);

if the government is to meet its intention of making available VR (condition management) programmes to all those receiving incapacity benefits, then efficacious means need to be found of doing this without the same broad staffing levels and costs of the current expert programmes for people with TBI.

Whilst it is still 'early days' for Jobcentre Plus it is apparent that there are major issues with regard to identifying the TBI population both in and out of employment and providing them with the type of support likely to enhance their employment prospects. In particular, it is considered this population may continue to be neglected because the emphasis of current condition management programmes is upon pre-placement treatment and job search activity. Not only do Jobcentre Plus data systems require amending but staff awareness of TBI issues needs to be significantly raised

However, even such measures are not enough. There is a need for joined-up services, and not just from clinical services to Jobcentre Plus but one that also includes employers, and there is a need for continuing long-term monitoring and support.

It may be perceived that the findings of this study based on the literature, the experience of the study sample and a qualitative review of the recruitment problems experienced by Back to Work, can only be expressed tentatively and that they are insufficient to entirely support the model VR programme, hence its efficacy requires testing. Whilst a start has been made with a neurological after-care charity in Salford, it is likely to be some years before any results are available.

**11.2 Revisiting the Hypotheses** (set out in Chapter 5.2 in respect of applying realistic evaluation):

- The severity of injury can be related to successful labour market
   participation/return to work, even if the relationship is not always a strong and
   consistent one (the more severe the original injury then the chances are that
   the consequences will be more severe than a lesser injury).
- Other clinical and demographic factors, such as neuropsychological sequelae, domestic circumstances and pre-injury employment history, may also have a bearing on outcomes.

Whilst there is no statistical significance in this study between the severity of injury and return to work it is apparent that the more severe the injury, the more severe the consequences are likely to be. In this case, statistical findings are confounded by a small number of subjects sustaining injury of minor severity experiencing secondary complications. Hence, whilst there are examples of subjects sustaining very severe injury making a spontaneous return to work there are also examples of subjects sustaining minor injury not doing so.

Again, whilst it is statistically difficult to establish the influence of specific neurological and demographic variables upon outcomes, in individual cases (as opposed to group analysis) the present analysis suggest that there may be a range of significant factors to be taken into account.

The underlying theory behind this study is that people sustaining TBI may experience a random pattern of returning to work, but that appropriate vocational rehabilitation can facilitate higher (than spontaneous) return to work rates.

The findings to this study do not entirely confirm a random pattern. Amongst the study sample there was a positive relationship between younger age and a return to work. However prediction is an imprecise art.

If a return to work is not an entirely random matter then it follows that there are variables influencing this process. This subject has been approached in the questionnaire component to this study by reference to significant independent and dependent variables identified in the literature. Two matters such an approach does not address, and ones that are crucial to the realist approach, are the *choices* that people make, and the options open to them, and the influence of *stakeholders*, matters that are brought out by the case studies and the Back to Work recruitment experience. All of the TBI RTW research literature is either based in countries where participation in VR programmes is either part of statutory provisory (and in countries like Canada and Australia carries penalties for non-participation) or else, as in the UK, it has been provided as a sequential continuation of clinical rehabilitation. Issues relating to subject identification and recruitment have simply not occurred.

 The provision of clinical and vocational rehabilitation is "patchy" and there are likely to be difficulties establishing a relationship between rehabilitation and vocational outcomes with a small study sample.

The position with regard to the study sample being provided with rehabilitation was worse than anticipated. Whilst a reading of Thornhill et al's (2000) Glasgow study alerts one to the limitations on the availability of clinical rehabilitation, and personal experience led to the view that many of the subjects would not be offered vocational rehabilitation, all of the subjects had (sizeable) claims for damages pending, including loss of earnings, and it was still surprising to find so many were offered little or no support. Even when support was forthcoming it was invariably so many years post-injury as to potentially reduce its influence on a successful return to work. In addition, it will be apparent from the example of the case study G that even when VR was offered it was not always appropriate or, in the case of V, not followed-up.

The experience of the study sample (Table 11.1) is likely to lead to the conclusion that there

are few systematic means of addressing the individual employment needs of this population in the UK (not surprising given the difficulty in identifying them). It follows that the provision of appropriate services will be inadequate.

Whilst based on a small study sample it is considered that the only positive note to have come out of this experience is a recommendation for policy practice, that Jobcentre Plus does not place people who have sustained TBI on generic vocational programmes without a specific vocational evaluation, ensuring that work preparation agencies have the necessary expertise and resources to provide appropriate support including follow-up. However, this transgresses from the hypothesis which is considered supported. Would the matter be any different with a larger study sample? This is considered doubtful considering the findings of the NTBIS (1998) in respect of the relationship between clinical rehabilitation and a return to work and the fact that the study sample for this study was drawn from various parts of England and Wales.

- Any search for a model predicting employment in the UK amongst people sustaining TBI may be confounded by:
  - (i) the difficulties in isolating clinical variables and measuring their specific input (because of the practical difficulties in collecting such information and, even when it is available, the close collinearity);
  - (ii) determining the influence of demographic factors (such as whether or not a partner is supportive) and;
  - (iii) the inconsistent provision of appropriate support services.

Again, it is considered that this hypothesis is supported and, as a consequence, undertaking research in this area in the UK is likely to continue to be difficult without some of the issues raised in Chapter 13 being addressed. In respect of the study sample, clinicians did not always accurately use the recognised definitions of head injury severity, never mind rely on the same instruments and express their findings in any consistent fashion.



## Table 11.1: Summary of Post-Injury History of the Study Sample

\*2 cases the severity of injury could not be established

External factors, such as the influence of the family, can not be assumed to be a consistent factor. Without a control group for assessing the influence of such factors as the nature of family support there is no way of establishing the potential significance of such a factor yet, in the case of at least one member of the study sample, it was the most crucial aspect influencing his failure to return to work.

Whilst it may be maintained that given a sufficient study size, use of logistic regression would enable one to determine the significance of such matters provided one could agree upon accurate standardised reporting, the extent to which such an approach can offer a satisfactory explanation for individual cases is open to question.

Whilst quantitative approaches may be helpful in establishing group relationships they lack ontological depth and a methodology such as realistic evaluation is likely to be more helpful in vocational rehabilitation research in explaining the experience of individuals.

Apart from the impracticality of running a RCT the obvious weakness is in explaining the experience of individuals. The 'real issue' however is not whether or not any planned programme of intervention works or not but what can be done to facilitate the resettlement of specific individuals. Does research focusing on group processes facilitate this process? In reality, what applies to the group may not apply to the individual, but what does apply to one individual might not necessarily apply to others. However, realistic evaluation allows one to develop issues in respect of the individual and within the context of CMO configurations, these studies can be cumulatively utilised. However, the process is not straightforward.

Subjects do not have the same "starting points". Because subjects A and B may have the same degree of injury severity as measured by PTA, a possible context (c), it does not follow that mechanism (m), any intervention, will always produce the same outcome (o). The second issue is in respect of the representativeness of the case studies to the population under study. A point repeatedly made, if at times implicitly, is that the brain injured population only has homogeneous *features*. The third difficulty follows the first two. It is in respect of reaching an empirical generalisation, that is to move from a statement "this programmes leads to this outcome" to a universal statement that "these programmes or interventions or circumstances" always lead to these outcomes.

Whilst it would have been useful to apply the realistic methodology to many more subjects, the need for brevity has prevented this. As matters stand, it is considered there is a good case for continuing the implementation of RE. Its application in this thesis clearly shows why the RTW process broke down but further development is required in respect of what works. It might be more helpful in respect of establishing what not to do rather than what to do. This means that there are limits to the extent that the next hypothesis can be supported.

Moving on from realistic evaluation it is possible to plan individual vocational rehabilitation intervention by looking at the barriers to employment for people sustaining TBI and developing a vocational rehabilitation approach, including matching identified neuropsychological and other clinical deficits with compensatory strategies to facilitate resettlement.

As indicated, more application is required. Nevertheless, both the literature and frequency of symptoms suggest sufficient commonality to devise VR programmes that address major barriers and, moreover in this instance, could be delivered within the framework of incapacity benefit reforms.

Where does this leave the theory that the inconsistent provision of appropriate vocational services in the UK is likely to be reflected in irregular patterns of RTW rates but it ought to be possible to identify and address many of the barriers to employment by considering appropriate placements and developing compensatory strategies?

It is considered that this study has the same failing identified by Dickinson (2000) in clinical RCTs following head injury, too small a study sample to emphatically support or refute such proposition.

However, it is maintained that substantial progress has been made towards:

- Recognising the lack of any consistent and systematic means of enabling the TBI population to participate in the labour market.
  - Identifying the reasons why research in this area is so difficult (and what could/should be done about it is addressed in Chapter 13) namely:
  - the use of a methodology (or methodologies) that identifies not only group relationships but variables influencing outcomes that can be analysed in respect of any one individual.
  - the practical difficulties in identifying (homogenous) TBI populations, tracking them and collecting valid data from different sources.

Identifying the (general) barriers to employment. How such information can be used to develop VR programmes for individuals is addressed in the next chapter.

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Identifying the practical difficulties (particularly the way VR programmes are funded) with regard to developing 'appropriate' placement considerations (again a matter further developed in the next chapter). The use of compensatory strategies was addressed in Chapter 4.6.

In making such progress it is considered that this research exercise has added to the sum of knowledge on TBI VR practice in the UK, in particular the need to address job retention rates.

Hence, no dogmatic claims are made in respect of theory development (more work is required analysing the nature of the programme being developed in Salford, hence promoting the type of feedback between theory and practice advocated by Pawson and Tilley) and, diverging from their opinion, more comparator data is required in respect of TBI subjects returning to work by other means (including spontaneously) before practitioners can make consistently good assessments of the likelihood of any one individual successfully returning to work with and without expert VR support.

**11.3 Structural Issues Affecting Outcomes:** A number of related issues emerged from Chapter 10. At the outset of this thesis it was postulated that Jobcentre Plus VR services do not adequately address the employment prospects of TBI customers and an approach to testing this opinion has relied upon:

- Describing the generic nature of assessment and work preparation, in contrast to the strategies adopted by expert VR programmes, with particular reference to Working Out.
- ii) Matching presenting problems (cognitive/neuropsychological) to rehabilitation strategies.
- iii) Identifying the relationship between the most commonly found variables, reported in the literature as influencing outcomes, and employment outcomes amongst the study sample - with a view to examining how these were addressed by intervention. In the event, and with the exception of age, there was a lack of statistical association.

A number of other matters have emerged considered highly relevant to addressing the barriers to employment of TBI subjects :

- a. Recovery from TBI is a prolonged process. Unless continuing to be paid by employers, or insurers, people experiencing such an injury are likely to enter the stock of incapacity benefit claimants.
- b. Unless called for a Personal Capability Assessment (PCA) Jobcentre Plus customers in the stock of IB claimants may have no other contact with the service. Even if found 'fit for work' there are no mechanisms for ensuring a referral to a DEA, or other specialist disability/employment advisor, nor for vocational rehabilitation.
- c. There may be little incentive for Jobcentre Plus staff to engage the stock of IB customers.
- d. The degree of expertise with regard to the nature of TBI may considerably vary amongst Jobcentre staff.
- e. The provision of vocational rehabilitation (whether expert or not) is a random matter, and may depend upon such factors as:
  - the influence of significant stakeholders.
  - the availability of local provision
  - the support offered by Jobcentre Plus staff
- f. There are no mechanisms for ensuring:
  - expert arrangements for the transition between education and the labour market. (Whilst there is some expert College provision such resources are not widely available).
  - contact is maintained between employees and employees sustaining TBI.
  - employers are provided with expert guidance on the employment of employees with TBI.

It is impossible to say how many members of the study sample were potentially employable, for so many to undertake some post-injury work-related activity (only to fail) suggests that they, and other stakeholders, held a view on the subject.

In addition, there is a need for a greater understanding of patterns of current labour market participation. People do not have jobs or careers for life and there is a great deal of labour market mobility. People move between jobs according to economic and personal circumstances. The issue is in respect of the extent people who sustain TBI are able to do this

and what can be done to facilitate this process. The 'snap-shot' reporting of employment figures is of dubious analytical value. It is the *flow* into and out of employment that should be significant to a researcher studying the post-injury employment experience of anyone sustaining TBI. Moreover, this needs to be understood in terms of individual experiences if appropriate intervention is to be designed to facilitate greater labour market participation.

**11.4 Summary and Main Points:** This thesis has demonstrated that whilst the clinical characteristics of the UK TBI population may be similar to that reported elsewhere in the world, particularly the USA, there are factors unique to the UK labour market that may subsequently affect participation in the labour market. These factors are:

- The nature of the incapacity benefits system.
- Inadequate data in respect of the numbers of people with TBI experiencing employment problems.
- The lack of any statutory provision for assessing and meeting their employment needs.
- A lack of joined-up services.

Whilst the return to work process cannot be described as entirely random, because there are some regular features such as the influence of incapacity benefits, the role of GPs, the Jobcentre network and employers, *such factors do not operate with any noted degree of consistency.* 

At the outset to this research it was envisaged that the focus of developing a VR service for the TBI population would be on moving the emphasis of intervention strategies away or on from pre-placement activity to one of providing in situ support.

However it has become clear that this would not be enough to address the shortcomings in 'the system' (and, in the meantime, it is highly improbable that any scale for predicting the likely return to work of any one individual can be successfully developed).

Whilst the current condition management programmes are addressing some of the problems, by, for instance , having an initial mandatory interview and there are plans to make inroads into the stock of IB claimants, if staff lack the expertise to recognise the specific problems of the TBI population and programmes retain an emphasis on clinical rehabilitation and job search activity then there is little likelihood of improving the long-term resettlement rates.

Undoubtedly more research is required into the dynamics of the RTW process but, in turn, this requires a number of research parameters to be in place (considered in Chapter 13). Realistic evaluation appears to offer one way forward but requires more application.

#### Chapter 12

#### MEETING THE AIMS OF THE STUDY

#### **Contents**

12.0	Overview	314
12.1	Lessons Learned, Methodological Issues and Limitations	314
12.2	Variables Influencing Employment Outcomes, Barriers to Work	
	and the Recognition of Suitable Employment	317
12.3	Developing a Theoretical Model TBI Vocational	
	Rehabilitation Programme	322
12.4	Summary and Main Points	339

**12.0 Overview:** Chapter 12.1 initially considers some of the lessons to be learned from this thesis in respect of the value of research-based evidence and the findings. Limitations are acknowledged. The Chapter continues by addressing the aims of the study at Chapter 12.2, investigating the variables influencing vocational outcomes, barriers to employment and the type of work engaged in following TBI. This is by way of a forerunner to Chapter 12.3 considering means of addressing many of the structural problems identified in Chapter 11 by developing a model theoretical TBI VR programme, including a detailed consideration of placement options. Prior to presenting the model this section makes reference to two common issues i) age and adjustment and ii) the severity of injury and timing a return to work that need to be taken into account when considering intervention.

**12.1 Lessons learned, methodological issues and limitations to the thesis:** The research process has been a lengthy and difficult process including a number of journeys down blind alleys.

The value of research based practice: Part 1 introduced the subject of traumatic brain injury and employment. It started with the incidence, causes and consequences of the injury itself. It moved on to examine the value of understanding employment outcomes and made a chronological review of return to work studies, firstly reporting outcomes and identifying significant influential variables, secondly, considering the development of vocational rehabilitation programmes both in the USA and UK. It is noted that with the exception of a small number of TBI VR services, in England and Wales the emphasis of intervention is on preplacement activity. Even the specialist services employing job coaches do not do so in the same intensive fashion as found in the USA. Most of the return to work literature is of American origin. There are fundamental cultural and organisational differences between the delivery of services for the TBI population between the USA and UK and, as it has been noted, frequent limitations on subject data. Hence, there are questions to be asked in respect of how much can be learned and applied from the extrapolation of seemingly salient data. On a prima facie basis the practice-based research evidence from the USA supports a view that specialist approaches are more likely to identify and address the sequelae of a TBI than generic interventions. This is particular the case in respect of the problems of generalisation, the transfer of skills from a clinical to a vocational setting and the maintenance of appropriate work-based interpersonal skills. However there remains a need to be careful as to the extent one can take findings from research undertaken in other countries and apply them to the TBI population in the UK. For example, whilst it may be considered that the nature of clinical sequelae ought to be the same, as Schwab et al (1993) demonstrated, when the subjects were war veterans more likely to receive discreet penetrating injuries, as opposed to the more diffuse damage from a head hitting a car windscreen, the nature of the subsequent clinical sequelae may reflect a need for significantly different intervention processes both prior to and in the workplace.

In the circumstance there was a need to examine the approaches to intervention in the UK. There was also the need to examine further what it is about the specialist services that is more likely to meet the needs of the TBI population than generic programmes. The labour intensive approach of the Working Out programme will have been noted. There remained the question of how to deliver a potentially efficacious TBI VR service within the context of current condition management developments.

**Methodological issues:** Most RTW studies have relied upon quantitative survey data, with few studies focussing on the dynamics of intervention, for instance matching identified cognitive deficits to appropriate rehabilitation/compensatory strategies.

In an ideal world it is considered that a randomised controlled trial and the deployment of logistic regression would establish what works with whom and why. Part of the original thinking was to develop an 'employability index' identifying i) subjects likely to spontaneously return to work, ii) subjects only likely to return to work given appropriate support, iii) subjects unlikely to return to work in any event. Whilst it was recognised that there would be insufficient data for regression techniques it was hoped that univariate analysis would demonstrate enough significance to develop a post-injury 'employability index' (see Annex 7) relying on the major

potential variables identified in the literature, albeit this would need to be prospectively evaluated. In the event this was not possible because of the lack of statistical significance. Whilst it is a conjectural matter whether or not the situation would have been different with a larger study sample such a matter draws attention to the methodological difficulties in undertaking research in this subject area. An RCT requires a large sample size, particularly in this case as the literature suggest there is potentially a large number of variables influencing outcomes. The support of Jobcentre Plus and at least one NHS Trust would be necessary. It will be noted from Chapter 5 that Jobcentre Plus declined to participate in the tracking of its patients and ethical approval was sought. However a change in management personnel resulted in a change of heart, on the grounds that there were insufficient resources to support the data collection. The one disability organisation that participated was only able to collect data on three subjects and, for research reasons, they had to be discounted.

In any event, experience of managing the Back to Work programme for Jobcentre Plus suggested that major structural issues need to be addressed before an RCT could be successfully managed (or VR programmes run that identified and attracted TBI customers on the incapacity benefit registers). It was also recognised that what applies to the group does not necessarily apply to the individuals. Some other means needed to be found to account for the individual experiences of members of the study sample and assessing and addressing individual barriers to employment, and one not relying upon a very large study sample.

Case study offers a way to do this and to make the process more rigorous it was decided to apply realism. Again, in this subject area, this was setting sail on uncharted seas with no exemplars. Whereas this approach has the apparent virtue of simplicity, in practice it can be difficult to apply, particularly in an easily readable account (given the way cumulation operates by going backwards and forwards between outcomes, contexts and mechanisms).

Establishing the 'ideal' research programme 'explaining' the post injury employment experience of subjects sustaining TBI in the UK, including examining what intervention works with whom and why, is a task beyond the resources of any one individual and, in any event it would require a number of research conditions to be met before commencing any such exercise (these are addressed in Chapter 13). In addition such an approach would not necessarily account for and explain the position of specific individuals. A particular disappointment in this thesis that highlights the limitations of relying on a survey, without any control over the subjects, is the number offered vocational rehabilitation services. At the very least it was thought that the subjects would be more likely to be offered rehabilitation than the general TBI population because they had all had personal injuries claims for damages and they would all come into contact with Social Security/Jobcentre services because they were of working age.

Chapter 13 further develops the explanation as to why undertaking research in this subject area is difficult, and provides information on identifying and tracking subjects, research variables and 'problem issues' that should be invaluable to future researchers. In particular the thesis makes the point that research aimed at developing definitive predictive models of RTW following injury is likely to remain an academic Holy Grail without a number of research conditions being met, and, in any event, resources could be more profitably spent on identifying and addressing individual barriers to employment.

# 12.2 Variables Influencing Employment Outcomes, Barriers to Work and the Recognition of Suitable Employment:

i) Variables: In respect of the first aim of this study it is considered that the variables identified and considered in Chapter 3 have been reported in the literature as influencing vocational outcomes following TBI. The nature of the relationship to outcomes has also been explored. This information would not benefit from repetition.

**ii) Barriers:** Variables potentially influencing outcomes following TBI may not all be considered as barriers. For example, being young is not a barrier. It is the relationship between the variables influencing employment outcomes and the labour market that are considered to potentially create barriers. In this respect, it is considered that Table 12.1 takes the variables and presents the barriers that may result as a consequence of any adverse deficits.

#### Table 12.1: Barriers to Employment Following TBI

Variable	Barrier	
1. Age	Older workers may experience more difficulties than younger ones in returning to work <sup>21</sup> . Lack of previous work experience for age	
2. Education	Relatively low level of education/qualification An inability to use existing qualifications Difficulty in acquiring new qualifications	
3. Employment History	May not have a pattern of regular employment/ unattractive history of previous employment May not have acquired work related skills Lengthy period off work as a consequence of injury Few retained, transferable or generalised skills May not have employer to return to	
4. Family/Domestic Support	May not be harnessed positiv May not have any support	vely
5. Economic and psychological incentives	May have no incentive because of benefits position May be adversely influenced by personal injuries litigation including a claim for the loss of earnings (no obvious evidence found in this study) May have been left in receipt of incapacity benefit for years	
6. Neurological	Epilepsy - statutory barred from certain activities eg. driving and need to work in a 'safe' environment <sup>22</sup> May have problems with: - vision - hearing - pain - smell	
		- co-ordination

<sup>&</sup>lt;sup>21</sup> Whilst UK return to work study indicates that age is a significant variable (Brooks et al, 1987), a situation supported in this research, it is considered that the issue requires further investigation. Whilst it may be the case that adults do not recover as well as younger ones, in order to establish whether or not it is the brain injury that is the fundamental problem, then comparisons would be needed with older workers without disability losing their jobs and unemployed older workers with other disabilities.

<sup>&</sup>lt;sup>22</sup> Epilepsy is a good example of the need for a trained VR counsellor to understand the occupational implications of a disability and ask the right questions. For example, someone with only nocturnal epilepsy may not face such restrictions.

7. Physical	May be incapable of undertaking certain tasks because of: - lifting ability - walking distance				
	May tire				
8. Psychological	May have problems with:	<ul> <li>memory</li> <li>attention/concentration</li> <li>visual/spatial difficulties</li> <li>speed of information processing</li> <li>organisation and planning</li> <li>denial</li> </ul>			
9. Behavioural	May lack appropriate interpersonal skills, eg. not recognise social cues, disinhibition May be aggressive				
10. Communication	May have difficulty in expression either in writing and/or words or in comprehending and acting on written/spoken word				
Being out of work itself may create barriers to (re)entering the labour market.					
11. Lack of Employment	Uncertainty/lack of confidence over job readiness Unrealistic expectations				
12. Inability to Maintain Employment	Inappropriate interpersonal s Inability to learn new work rou 'Mismatch' between cognitive employment position	kills utines deficits and			

This list cannot be exhaustive because of the multiplicity of factors that may affect an individual but it is considered that it focuses upon the most commonly found barriers. It is apparent that the planning of any programme of vocational rehabilitation must specifically address the individual barriers to employment and include systematic planning for skill generalisation and maintenance.

**iii)** Suitable Jobs Following TBI: A difficult issue is determining what type of jobs are best suited to the brain injured person. It is all very well for clinicians to say "this person requires routine, structured work" or a job "not requiring much organisation and planning", as one often finds in litigation reports, but such descriptions do not come with an attached job label. In the absence of detailed job descriptions, as found in the American Dictionary of Occupational Titles, placing agencies need to undertake a job/task analysis before placing any brain injured person. If the experience of the study sample is a reliable guide such detailed consideration is

an exception. A possible issue for agencies is that funding is triggered by placement, not retention (and retention requires funding for continuing monitoring). There would appear to be a tendency for TBI subjects (and agencies) to take what work is available.

Another issue experienced (when implementing the recommendations) is the view of experienced industrial/commercial personnel undertaking placing activity that asking employers if they can undertake a job/task analysis is, or would be, perceived as intrusive and could lead to friction with other employees perceiving themselves subject to a time and motion study. Implementing research findings clearly must take into account such practical pitfalls. Nevertheless, without persistence, there can be no progress and the Salford programme is proceeding with a modified version of a job analysis (Callahan and Bradley Garner, 1997, Annex 8). There remains the guestion "What type of work?"

Because the study sample came substantially from a narrow sector of the labour market, and there was a tendency to try to return to the same sector or job, reference is also made to the literature.

There are few guidelines on matching TBI subjects to suitable employment and none that relate to the UK. Blair and Spellacy (1989), cited in the literature, aimed to identify suitable vocational options for people with TBI who could not return to their pre-injury occupation. A questionnaire was used to examine the attitudes of 122 employers regarding common TBI sequelae including decreased motor control and fatigue, personality changes, memory problems, distraction and lack of initiative.

Employers in agriculture and forestry gave the greatest number of "acceptable" responses, employers in service industries gave the fewest. Differences in mean number of "acceptable" responses between the four employer groups (agriculture/forestry, service, manufacture/construction, wholesale and retail trade) were not statistically significant.

Evidence from the study sample suggests that those with frontal lobe damage are likely to be more successfully placed in routine jobs where a requirement for complex decision making is minimised. (Possible compensatory strategies may include facilitating decision making with the use of colour-coding and the use of checklists, dealing with potential conflict situations with supervisors and co-workers possibly with psycho-social training courses and providing the subjects with priority lists and duties in order of importance.)

It would also seem important to avoid public contact jobs and supervisory positions where planning and memory are required. In respect of people with memory problems the maxim for job placement appears to be "the simpler the better". Parenté and colleagues (1994) suggested priority check lists filled out each evening. These categorised tasks into "hot" (requiring immediate attention) and "warm" (lower priority) activities. Subjects wore watches that beeped on the hour to maintain a time sense. Job coaches helped with use of time spent looking for things. When giving instructions, the job coaches emphasised the most important points last in the statement. Routine activities were over-learned, to ensure consistent performance. The optimal learning of job skills utilised the clients' memory strengths, for example visual or verbal. The job coaches also helped the clients generate their own organising schemes to ensure that they were meaningful. The job coaches saw that they were used. Clients received constant feedback from the job coaches and they were encouraged to immediately translate instructions into their own words.

When dealing with personality problems, it was reported that, "*The simplest and most effective management strategy we have tried has been to try to find the client a job where odd behaviour is tolerated.*"

Hence, despite the occasional study examining jobs in which TBI subjects have been placed, the essential response to the question "What type of work is best suited to a person with TBI?" depends upon the specific nature of the continuing clinical deficits, residual skills, and the demands of any specific job. In turn this does not involve seeking a job as an order checker or machine operator (the name may be the same but the tasks could vary considerably between jobs with the same title) but one of adopting an appropriate placement and support strategy including a pre-placement job analysis.

**12.3 Developing a Theoretical Model TBI Vocational Rehabilitation Programme:** *"For months everyone involved in the head injured victim's rehabilitation has been working towards getting him fit enough to go back to work, school or college. Unfortunately, return to work is sometimes 'botched', in spite of the very best of intentions."* (Gronwall, Wrightson and Waddell, 1990).

There is a need for mechanisms to decide what type of vocational intervention is most appropriate for each person sustaining TBI. It is apparent from the analysis in the preceding sections that there is a wide range of factors to consider. These include factors that can be positively influenced, such as some cognitive deficits, and factors that cannot be influenced, such as age and the pre-injury level of education and employment (albeit such variables are not statistically significant in this study). In view of the factors that cannot be influenced by rehabilitation, whether or not such intervention is likely to be cost-beneficial is likely to require consideration. There is also a need for a uniform database so that the efficacy of various approaches can be evaluated.

Those responsible for providing vocational rehabilitation services for people with TBI need to be able to determine the most appropriate intervention (followed by means of measuring the success of the intervention).

#### Can one programme for vocational outcome following TBI?

Notwithstanding the multiplicity of factors that may influence outcomes, it ought to be possible to devise better means than generally exist in the UK to facilitate a return to work for people with TBI. In the first instance, there is a need to identify the population and the individual barriers to employment. There is then a need to relate such information toward intervention, particularly promoting the generalisation and maintenance of compensatory strategies. There is a case for differential planning to address the particular TBI sequelae affecting employability established through assessment. This includes the advisability of all those sustaining mild and moderate injuries being screened by an experienced vocational rehabilitation counsellor.

**Age and Adjustment:** As the RTW studies and this study illustrate, those who sustain TBI are likely to have different experiences of returning to work. It is likely that the age of the subject and the severity of the injury will need to be taken into consideration when planning a return to work.

Pre-injury skills and knowledge are often the best preserved (the learning of new material is invariably adversely affected by cognitive deficits) and the approaches to the resettlement of subjects with labour market experience needs to be different to those without such experience. One approach assessing the extent to which retained skills and knowledge can be utilised and, the other, building on education and work experience that can be generalised and transferred to the labour market, albeit this is likely to require some in situ assistance.

Power and Hershenson (2003) investigated the effects of mid-career TBI on work adjustment.

They also examined the utility of Hershenson's model of work adjustment as a framework for organising relevant data in cases of mid-career disability (Hershenson, 1996).

Whilst it is apparent that many of the issues affecting the resettlement of those sustaining TBI as pupils/students are the same as adults, such as the need for a careful assessment of their capabilities and matching with job requirements, separate issues also arise, namely:

- Pupils/students do not have previous work experience upon which to draw. Hence, they are likely to require extended supported work placements.
- There needs to be a clear line of responsibility for co-ordinating relevant services. The individuals taking the lead responsibility with members of the study sample included specialist Careers Officer, Disability Employment Advisor, college staff with responsibility for disabled students, TBI case manager, support worker and parents. None started with a strategy based upon an initial detailed assessment of capability. The process of entering the labour market more often appeared as an ad hoc response, involving varying standards of support, ranging from a brain injury case manager arranging, supporting and monitoring a work trial to a DEA sending a disinhibited client on a residential course.
- There is a need to extensively involve the family and other stakeholders.

Rusch et al (1986) examined the issue of preparing students with TBI for employment. They noted that, "Educational efforts, to date, reflect the assumption that what is learned in the classroom, or during simulated work stations, are also performed outside of the school or in real work situations. Because this assumption is frequently faulty, it is important for teachers to establish and provide instructions in community-based training stations."

Rusch and colleagues recommend providing students with work experience from the age of 12. In the UK, compulsory work experience does not begin until the age of 15 and, even then, only for two weeks. The focus of Rusch and colleagues' argument is that there is a need for a community-referenced curriculum focussed upon the demand for local jobs. To facilitate the transition into community-based employment, Rusch and colleagues advocate using the (American) supported work model, in much the same way as for adults but with a greater emphasis on managing the transition from school to work. In this respect, a Transition Planning Team is recommended.

**Severity of Injury and Timing a Return to Work:** Chapter 2 considered the vocational problems of those sustaining a mild/moderate head injury. The resettlement requirements of those sustaining such injury are only addressed by way of reference to seven members of the study sample. This subject should not be neglected when considering the potential problems faced by this group, nor the contribution job coaches could make towards successful vocational resettlement.

A more immediate concern is in respect of the occupational status of those sustaining more severe injuries. This research reaches the same conclusion as made in the late 1980s in the United States (Ben-Yishay et al, 1987) and in the 1990s in the UK (NTBIS 1998) that clinical rehabilitation without a specific vocational strategy is unlikely to be sufficient for enabling many people sustaining TBI returning to the labour market. There is a need to provide and ensure that vocational rehabilitation services meet the needs of TBI survivors, rather than processing them through what happens to be available, such as placing them with inappropriate work preparation providers or training agencies simply because they are available. However, there are few specialist TBI VR agencies in the UK.

The need to counsel, including challenge, those wishing to return to work when it is evident to the vocational counsellor that they are not ready to do so, still begs the question as to "When is the appropriate time to offer an appropriate programme of support?". If waiting for an optimum recovery (if identifiable), then the prospect of a return to the same employer, even a different position, may be lost. On the other hand, there is Johnson's (1998) observation that if patients sustaining very severe head injury had not returned to work within two years post-injury then they rarely did so afterwards. The clear inference is a need for early intervention in order to assess employment prospects and barriers to employment. There would appear to be some minimum standards that need to be met before TBI subjects can be considered fit to return to work. They are considered to be:

- The attention and concentration span must be sufficient to allow work to be undertaken effectively and safely for a specified portion of the work day.
- Specific skills required for the job must be adequate (and this has implications for the
importance of a job analysis before any return to work).

Social skills must be adequate.

The next question is "What is adequate?" The answer is going to depend upon the specific nature of the job. In all jobs the specific psychological requirements will vary, for example, the attention and concentration required by an air traffic controller are very different to that of a porter.

It may be considered that the only practical answer to the person who insists on going back to work when not ready, is to allow them to do so. There are (better) alternatives, such as counselling, co-counselling and, if there is the opportunity for simulation, the use of video-taping to show discrepancies between claimed competencies and behaviour and actual performance. If a person with TBI does go back to work too soon and cannot cope because of tiredness, complaints of headaches or loss of temper, then they risk having their employment terminated.

The point is that assumptions cannot, and should not, be made over the expected return to work, even by well-qualified clinical staff. The process is likely to be influenced not only by the severity of injury but *the nature of work undertaken and the level of available support*.

Whilst it is possible to generalise that the more severe the injury the more problematic a RTW becomes, this is not always the case and the specific circumstances of those sustaining TBI need to be evaluated with a view to vocational rehabilitation planning.

This raises the question as to whether or not a TBI subject requires the same degree of recovery to commence the VR process as when considering a return to work.

There can be pressure on members of a rehabilitation team to get a head-injured person back to work as soon as possible, for example when expensive rehabilitation is being funded by an insurer. A return to work justifies both costs and the role of the rehabilitation team. Pressure can also be created by medical experts making observations in respect of their own discipline alone and failing to take a 'global' view of the situation. Informed opinion on employment prospects (even if not definitive) can only be made when there is a complete picture available that is likely to involve not only the head-injured person's progress through an appropriate vocational rehabilitation programme, but includes detailed information with regard to the work that they are likely to be doing.

It is apparent that a vocational evaluation needs to be undertaken before a return to work, but for this optimum recovery may not be necessary. The process itself may facilitate recovery and/or the development of compensatory strategies. If the study sample is taken to be representative it would appear that, in the UK, people who sustain such injury are at considerable risk of being left in receipt of incapacity benefits without anybody realistically assessing their employment capabilities. Alternatively, they may attend a vocational agency only when referred by someone such as an OT or when (eventually) 'signed off'.

By reference to an evaluation programme, Jobcentre Plus staff ought to be able to make an initial assessment as to the prospects of the subject being able to cope at work or, at least, identify likely barriers to employment and plan a rehabilitation programme that incorporates the generalisation and maintenance of appropriate work-related skills. Nevertheless, problems can arise if the subject and family ignore advice. If a head-injured person lacks insight this can be particularly problematic because it can seem to them that there are no potential problems, for example, failing to recognise that getting up and walking around because of an inability to concentrate is no more acceptable to employers than forgetting to undertaken certain tasks.

Consideration of the timing of a VR programme/return to work leads to a framework for intervention (objective 3).

# Recommendations for a UK TBI vocational rehabilitation programme based on the literature and the experience of the study sample

The vocational assessment and evaluation of people with TBI is substantially covered in Chapter 4. A recommended process is indicated in Figure 16.

## Figure 16: Recommended TBI Vocational Rehabilitation Process

- 1. Referral from a clinical service/Jobcentre Plus to a vocational rehabilitation agency<sup>23</sup>.
- 2. Agency gathering of background information:
  - Demographic information
  - Medical history

-

3.

- Neuropsychological report
- Initial interview (with family member/support available)<sup>24</sup>
  - Cognitive Function<sup>25</sup>
  - Memory for things to be done in the future
  - · Ability to plan and carry out activities
  - Ability to learn
  - Ability to self-evaluate
  - Initiative to start and finish tasks
  - Speed of thinking
  - Insight

#### Social Skills

- Emotional status
- Sensitivity
- Social and interpersonal skills
- Emotional tolerance to stress
- · Relationship to family members and close friends
- Club membership and community and organisational involvement

#### Job Related Questions

- · Education and employment history
- Endurance

<sup>&</sup>lt;sup>23</sup> Reference is made in Part 2 on the inadequacy of the databases used by Jobcentre Plus.

<sup>&</sup>lt;sup>24</sup> Adapted from Corthell (1993).

<sup>&</sup>lt;sup>25</sup> This is not a formal assessment but a showing of some understanding of the client's possible position as the gaining of insight into the client's awareness (having already obtained clinical reports).

- Physical skills necessary for work, play and self-care
- Work potential for job placement or return to a former job
- Pre-injury skills and abilities having possible transferable skills
- Present hobbies and spare time activities
- Job goals both immediate and long term
- Specific job requirements (salary, location, benefits, working conditions, hours, etc.)
- Willingness and ability to travel or relocate for work

## Supports

- Financial stability and income sources
- Family support mechanisms
- Support group involvement or therapeutic support sources

## Other Questions

- Greatest concerns
- Alcohol, prescription and illicit drug use
- Description of a typical day's time schedule and activities
- 4. Decision to be made on whether or not the subject is ready to start the vocational rehabilitation process
- 5. (following acceptance)

## Assessment

Testing: Vocational Interests Vocational Aptitude Vocational Skills

Learning Style Work Personality Profile

In complex cases the testing of vocational skills may require the support of an occupational psychologist .

At this juncture it may also be appropriate for organisations with access to their own neuropsychologist to obtain an evaluation. It is unlikely that a clinical psychologist in a clinical setting will have administered and interpreted tests with a view to providing occupational guidance. 6. Rehabilitation Plan/Contract (supported by subject and family) setting out.

objective(s) duration of intensive support responsibility of agency personnel responsibility of client/family how barriers to employment are to be addressed review periods

## 7. Work Trial(s)<sup>26</sup>

Observation and recording of factors identified in the clinical evidence and assessment, such as: working memory interpersonal skills/social adaptive behaviour organisation and planning skills critical work behaviours

Leading to programming for generalisation and maintenance of compensatory strategies

- 8. Job Search and Interview Skills training
- 9. Permanent placement<sup>27</sup>

Options considered

- open employment (part-time or full-time)
- supported employment (part-time or full-time)
- sheltered employment (part-time or full-time)
- therapeutic/permitted work (part-time)
- voluntary work

<sup>&</sup>lt;sup>26</sup> In most instances, this is best started on a part-time basis in a "safe" environment, such as using in-house facilities, if available.

<sup>&</sup>lt;sup>27</sup> It is conceivable that a number of placements have to be tried before the subject is able to settle into a suitable position.

Preceded by:

- liaison with employer/co-workers/Jobcentre Plus (if appropriate)
  job/task analysis
- the identification of 'natural' supports
- 10. Follow -Up
- a) monitoring arrangements
- b) retention strategies

In practical terms how is it envisaged a Jobcentre Plus/NHS initiative would work? In the current condition management programmes (cardio-thoracic, mental health and musculo-skeletal) the role of contracted vocational agencies is 'simply' to provide a job club. Participants attend the participating hospitals for treatment and advise on disability management at work.

This is insufficient for TBI subjects requiring extended work placements and in-situ support.

Diagrammatically it is envisaged the programme could run as follows:

## Fig. 17 Delivery of TBI VR within Jobcentre Plus/NHS Framework

Referral	
NHS Trust/Jobcentre Plus	
to	
Vocational Agency	

**1.** Means of identifying TBI patients not referred to rehabilitation and, currently, not identified by Jobcentre Plus staff. Implications for both data recording and staff training.

Intake Individual interview Family/supporter interview Assemble background information Determine suitability **2.** Early consent of client/family for passing clinical data to vocational agency and for vocational agency to obtain clinical reports, eg. neuropsychological when not available and for referral back for specialist clinical rehabilitation services, eg. speech therapy.

**3.** Unlike other Jobcentre Plus/NHS initiatives it is considered that a **Case Manager** may be required to co-ordinate the services that may be required. The implication is for training (accredited) VR practitioners in TBI issues.

 Not accepted - referral either back to clinical rehabilitation or for community support.

# Vocational Evaluation Planning (use of neuropsychological and other Job-seeking/maintenance skills Functional capabilities Vocational interests, ability, aptitude

**5.** Agency undertaking such tasks needs either a trained VR counsellor or occupational psychologist acting as a case manager to undertake all such tasks. Whilst Rehab UK employs neuropsychologists (on a sessional basis) and occupational psychologists and other therapists including in-house trainers, this adds to the cost. Working Out has its own therapists but, when required, refers to Jobcentre Plus work psychologists.

Community-Based Employment Identify options Job/tasks analysis Plan to address barriers to employment Develop compensatory strategies Consider permanent placing options

6. Skilled job coach required to undertake the necessary tasks

**7.** Maintain liaison with Jobcentre Plus for work preparation, supported employment, training and permanent placement

# Maintenance and Follow-Up Plan for monitoring/retraining/replacing/ maintaining employer contact Involvement of family

8. Continuing (but reduced) case management

Such a framework has the advantages of:

- Not being capital intensive (requiring extensive in-house training facilities).
- Utilising existing expertise so that there is no duplication of limited and expensive resources, for example using NHS clinical reports and ensuring any additional clinical rehabilitation is focussed on employment skills and utilising Jobcentre Plus expertise as appropriate.
- Overcoming problems of transfer and generalisation by concentrating on providing in-situ support.
- Ensuring that retention strategies are put into place.
- Having a client-centred focus through the job coach regularly checking circumstances with a client, such as how they feel about a particular placement. (In this respect the model could develop a feedback loop so that if level was not satisfactory for any reason the situation could be reconsidered).

At the present time such a programme could not be implemented because of a lack of sufficient trained personnel to deliver it. Apart from this substantial caveat, given the availability of appropriately trained VR counsellors and job coaches there are no evident reasons as to why

such a programme could not be developed<sup>28</sup>.

Continuing the discussion of the recommended process from Point 4 of the recommended rehabilitation process, the decision on whether or not the subject is ready to commence the RTW process, it needs to be remembered that a standard vocational assessment is unlikely to be suitable with a brain-damaged population although standard instruments are of value providing the limitations in respect of administration to the TBI population are recognised (discussed at Chapter 4.3). The characteristics of a standard vocational battery fail to assess, either directly or indirectly, major deficits to be found in many brain-damaged individuals. Difficulties with initiation, planning, sustained concentration, short-term memory, new learning and other neurobehavioural and positive aspects literally can be missed by such a battery. The vocal assessment of brain damaged subjects needs to rely on both a vocational evaluation, focussing on specific cognitive, educational and physical attributes and neuropsychogical evaluation, particularly amplifying variables relating to executive functions, learning and neurobehavioural syndromes. Nevertheless, as Schuster and Marantz (1994) noted, "as deficits becomes more subtle, and retained capacities of individuals more prominent, it becomes increasingly essential to understand the needs of the market place, transferability of skills, vocational aptitudes, and labor market analysis, if an accurate interface between neuropsychological examination and vocational placement is to ensue".

Following an analysis of previous work and educational history, vocational aptitude testing is required to assess vocational capability. Such findings need to be integrated with the client's medical and psycho-social condition. Given this information, it is considered that a match can be made between the person and the job market. In this respect Schuster and Marantz considered that the "job matches can be exact" on the basis that data is available that not only "describes occupations throughout the United States labor market but also delineate the job requirements explicitly in terms of vocational capacities". In this respect, one has to recognise the greater availability of information in the United States than the United Kingdom. The Department of Labor Dictionary of Occupational Titles (1991) classifies jobs according to worker's trait factors (Field and Field 1992) and facilitates a better match than can be obtained in the UK through the British Standard Occupational Classification System providing only a brief job description. In the USA the following job information is available: requirements in respect of

<sup>&</sup>lt;sup>28</sup> In the programme being developing in Salford the VR counsellor is a psychology graduate and the job coach has extensive experience of placing disabled people into work. An 8 weeks training programme has covered essential issues such as collating information, using external sources and developing compensatory strategies.

vocational training; educational levels; general intelligence; verbal and numerical skills; spatial and form perception; clerical aptitude; motor, manual, and finger dexterity; and colour discrimination. In greater detail, specific vocational preparation is divided into nine domains (from very short to extended); educational levels are divided into six levels (from elementary to college plus) and aptitudes of classified into five categories (from the lowest 10% to the middle, to the highest 10%). Strength demands are delineated and physical and working conditions are described. Temperamental factors and interests can also be analysed. In this way the client's profile can be compared to specific job requirements to determine what positions are within the client's vocational capability.

The absence of such detailed occupational information in the UK, and the limitations on appropriate vocational rehabilitation intervention, raises questions as to what purpose a great deal of gathered neuropsychological and vocational information is being put.

There is also a need to take into consideration the client's preferences as well as need for onsite diagnostic vocational evaluation. While the neuropsychological/vocational evaluation can be used to identify the parameters in which the individual may be expected to function, it is considered prudent to ensure the accuracy of such predictions in - vivo and following extended observation. "Fine tuning" is likely to be required once the client is placed in a job. In this respect, it is considered that a job coach is essential.

It will be noted that the suggested model process recommends the use of the Work Personality Profile and Learning Style Assessment at the assessment stage. It is beyond the scope of this thesis to develop such analyses but they are respectively detailed by Roessler and Bolton (1983 and 1985) and Wheatley and Rein (1990).

In the model rehabilitation process it is suggested that following the assessment stage, a formal rehabilitation plan/contract is drawn up between the vocational agency, the subject and his/her family. Whilst there is a case for a contract at an earlier stage, it is considered the assessment stage ought to enable the agency personnel to be more specific with regard to the aims of an agreement. In this respect, it is recognised that the contents of any plan/contract are likely to vary but should, at least cover point 6 of the model.

Once the assessment has been completed and contract drawn, the client should be mentally and physically prepared for a work trial to "test out" the findings of the assessment stage and to introduce compensatory strategies. As part of the job coaching support, both work trials and permanent placement options require careful management. It appears that subjects in the study sample simply took what work they could get, usually based on their pre-injury experience. Whilst there may not necessarily be anything wrong in doing this, the person with TBI symptoms may not retain all the necessary job and/or interpersonal skills even though they do not recognise this. Not all vocational rehabilitation agencies will have in-house facilities and as the issues affecting the arrangement of work trials and permanent placements are often the same, they are often addressed together. It also emphasised that clients should be encouraged to develop their own job search activity although this may entail some assistance as typically found in a Job Club. The first step in the trial process is to identify a suitable placement. A fundamental aspect of good placing practice and working with employers is considered to be a pre-placement job analysis. Annex 8 details an approach considered suitable for TBI subjects (and other disabled workers). In this evaluation the job coach should consider vocational, social and related skills required for job success. In addition, physical and social environments, and the expectations and attitudes of co-workers and supervisors must be taken into account (Hanley-Maxwell and Bordieri, 1989).

#### **Placement Options**

Given the observations that in the UK there is a tendency to take whatever job placements are available, and the random pattern of support amongst the study sample, it is not surprising to find that the subject of assessing placement options has been given little consideration. Although nine members of the study sample returned to the same employer, there was no instance of communication and advice from a vocational agency. Client support needs to focus on the nature and needs of the employer and the particular problems of the employee. As the majority of individuals sustaining TBI do not have visible signs of disability, it is likely that their employment capability will not be understood. Employers' experience of injured or ill workers returning to work is likely to be one of them 'getting better'. Few employers of a brain injured person are likely to be aware of the need for continued monitoring.

If placement and retention rates are to be improved then, with the consent of the client, it is considered that there is a need to offer the employer advice on:

- a) the disability;
- b) intervention techniques used at the job site (how to implement these techniques);
- c) medical implications that may accompany the worker's performance;
- d) social problems and possible methods to minimise stressful situations; and
- e) instructions regarding contact of support workers should problems arise.

When brain injury is described to employers (or potential employers) emphasis needs to be placed on describing methods of teaching and learning that produce

Corthell (1993) discusses the advantages and disadvantages of various placing options which are described as:

- 1. Return to previous employer same position
- 2. Return to previous employer different position
- 3. Same job different employer
- 4. New job new employer

**Subjects With Prior Work Experience:** In some cases, physical injuries will prevent a TBI subject returning to a former occupation. Placement will require an assessment of their residual skills and the exploration of options allowing for the transference of such skills. For example, a former mechanic may have all of the cognitive abilities to work in his field but not the agility or strength required to physically perform the work. On the other hand, a parts counter person may require knowledge similar to that of a mechanic but not the same physical ability.

In some situations, the primary issue affecting a return to work is one of accessing cognitive information. Since the mechanic may no longer physically apply his skills, an alternative means of utilising his knowledge may be through the use of a computer.

As a positive part of an assessment, residual skills should be noted and vocational development planned around these abilities. If the individual does not wish to return to a position related to former skills, other options need to be pursued. Personal qualities (ability to work well with others, mathematical abilities, cognitive levels, previous academic records, capabilities and so on) can be assessed and appropriate jobs pursued.

**Subjects Without Prior Work Experience:** A person acquiring an injury at an early age, or who was a full-time student at the time of injury, may have limited or no previous work experience to bring to the placement process. In such a circumstance, it is probably best to develop job options relying on intermediate goals to determine the suitability of a position.

In addition to open employment some TBI subjects will require consideration for supported employment or permitted work.

In all placement options it is advisable to have the support of the family. The family may assist with transportation, completion of application forms and in encouraging the acceptance of suitable positions although, on occasions, the family may have a negative effect. In such cases, appropriate interventions may be required.

#### Follow-Up and Retention:

In the model vocational rehabilitation programme (Fig. 17) the final consideration is follow-up. In the UK the funding position means that too often a placement is the final goal for vocational agencies. As the study sample illustrates, such an outcome is often short-lived. Only the Supported Employment Programme makes a payment to agencies when a client is moved from a supported position into open employment and remains in employment six months later.

The act of employment consists of two processes: gaining and maintaining a position. Whilst this study emphasises the value of extended work trials to enhance the prospects of job retention, this is not always possible to arrange. Nevertheless, this research has highlighted the difference between being able to get a job and maintaining such a position. Data on the *continuity* of post-injury employment suggests that pre-placement work activity, and planning for a permanent placement needs to be undertaken. Whilst abilities and skills acquired before TBI are often preserved, maintaining employment is likely to depend upon the maintenance of appropriate interpersonal skills and, over time, the acquisition and maintenance of new job skills, as with the case study V (Chapter 8).

The process of maintaining a job may also include any support to promote behaviours specifically set as the norms for the particular job. Both aspects of a return to work, job getting and maintaining, need to be addressed by vocational support and, it is this respect, it is suggested that extended work trials may offer the opportunity to investigate two issues requiring prior consideration.

- That the person with TBI is placed 'in the right job'. West (1995) discussed the importance of considering client preferences when undertaking job placements. Certain aspects correlated with successful vocational outcomes including the capacity to socially integrate and the availability of employee benefits.
- 2. Programming for generalisation and maintenance. Unless there is the opportunity to provide in-situ support (and job coaches may be intrusive) this process needs to begin once a potential workplace has been established. Clinical rehabilitation efforts to reduce deficits in memory, information processing and abstract reasoning cannot be assumed to be generalised and stay maintained in an occupational setting. Literature also suggests appropriate social skills are critical for job retention. In the approach of Haffey and Johnston (1989), the first step in programming for generalisation was the selection of functional target behaviours considered critical for sustaining employment and with a high probability of being reinforced when they occurred in the workplace. The rationale for the selection of target behaviour should be made clear to the client. This practice is especially important when working with clients who have motivation and denial problems (Maples and Webster, 1980). Efforts need to be made to move the responsibility for behavioural changes to the client by, for example, letting the client have a say in determining the goal, for example, choosing from alternative appropriate placements and identifying the behavioural changes that must occur.

Once target behaviour is selected, shaping procedures (reinforcing successive approximations to the desired behaviour) can be used to promote skill acquisition. Monitoring such behaviour can be enhanced by over-learning, involving errorless repetitions. The more a skill is rehearsed, the more likely that it will be recalled or used at a later time. Generalisation and maintenance are further enhanced when skills are rehearsed and reinforced on the job (Stokes and Baer, 1977). Intervention strategies at work are likely to produce better occupational outcomes than ones away from the work site.

Training should involve presentations and multiple exemplars of target responses in a variety of situations (Stokes and Baer, 1977). This is said to enable the client to learn a range of responses that are appropriate across different demand situations, for example directions for corrective feedback given by peers and supervisors in the context of a variety of different job tasks.

**13.4 Summary and Main Points:** The theoretical model VR programme is based on perceived 'best practice' from the USA and UK as well as being based on the general experience of the study sample and lessons learned from the Back to Work programme. It includes a mechanism for the early identification and referral of subjects, family involvement, an assessment format related to the specific deficits and barriers to employment associated with TBI, guided occupational trials and specific placement strategies as well as the development of in-situ compensatory situations and planning for long-term follow-up.

The model theoretical TBI VR programme not only requires joined-up services but a change in emphasis from pre-placement activity to working in-situ and this requires skilled personnel. Such a programme could not work without the role of job coaches being developed in the UK and a greater understanding of the role of compensatory approaches.

Even where there are established job coaches in the UK their work, in the main focuses on preplacement marketing and placement activity. Whilst this may be due to the nature of the preinjury work held by their clients, the nature of the disabilities and/or the perceived intrusiveness of working on employer's premises, as well as funding issues, it is maintained that if resettlement and retention notes are to be improved for TBI subjects then there is a need to recognise and respond to the difficulties faced by this group at work.

Acknowledged weaknesses are:

- i) the lack of evidence relating specific aspects of intervention to outcomes.
- ii) the fact that retention has been approached from the perspectives of preparing the subject for a placement, based substantially on a pre-placement job analysis; educating the subject, employer and co-workers; developing compensatory strategies and follow-up, whereas the experience of the study samples and the work of James et al (2003), suggests there are also systemic issues to take into account (relating to prevailing culture and practices within an employing organisation).

## Chapter 13

## **RESEARCH ISSUES**

## **Contents**

13.0	Overview	340
13.1	Research Methodology and Variables	342
13.2	Summary and Concluding Points	347

**13.0 Overview:** The research for this thesis experienced a number of difficulties in respect of analysing the post-injury employment experience of TBI subjects with regard to developing appropriate vocational rehabilitation strategies.

These problems relate to such issues as methodological limitations (such as the practical difficulties in running a randomised controlled trial); research difficulties (such as a lack of a 'uniform language'); and practical difficulties in respect of identifying, engaging and retaining subjects.

As a consequence of methodological limitations a combined methodological strategy (survey, case study) and methodological triangulation (data analysis, realistic evaluation and reporting a qualitative review) have been used in this study. The advantages are perceived to be:

- the collection of data from different sources adds weight to the findings when these produce consistent results;
- shortcomings from one methodological approach can be addressed from another perspective (for example group data can not represent individual experiences) and, thereby, contribute to a greater understanding of the subject.

The main weakness is that a reason for adopting such an approach (insufficient subjects for regression techniques) to answer the essential question underlying all such research 'What works for whom and why?' has still not been answered (albeit such an approach might not necessarily answer this question anyway).

In an ideal situation (that is given sufficient resources), an approach based on large comparable groups experiencing different degrees of support and no support would be favoured (and there is no agreement with Pawson and Tilley's blanket rejection of control methodology). In the absence of individual data from comparators there is no way of knowing with certainty that it is the nature of intervention that has contributed to the outcome. Whilst it could be argued that the realist approach could be used to accumulate a large amount of evidence from individual case studies, one is left with the question as to the extent such individuals would be representative of the population under study.

The question remains as to whether the various approaches and findings can be synthesised to provide a greater insight into the post-injury employment experience of TBI subjects. Whilst realistic evaluation is not considered to lend itself to a particularly readable account it does have the virtue of explanation as a core activity and , in this respect, it is considered that greater understanding of the issues and options open to people sustaining TBI has been achieved.

Assessing vocational outcomes following TBI, with a view to informing vocational rehabilitation practice, is an ambitious target. It will be noted that Jobcentre Plus, working in collaboration with external contractors, was unable to meet its research objectives in the BtW research programme informing current incapacity benefit reforms (Chapter 5) because of an inability to recruit sufficient subjects to run the preferred randomised controlled trial.

In the first place research programmes need to be able to recruit sufficient subjects, particularly ones acting as pilots for a national roll-out. There will not be a pilot brain injury programme (the National Disability Development Programme having been disbanded), so what can be learned from the Back to Work programme? For any future research (and this is certainly required in respect of linking interventions to outcomes) what can be done to address the problems that are likely to occur when a large number of compliant subjects are required for an RCT (if preferred) and, moreover, what can be done to ensure that VR programmes have, and retain, a sufficient flow of referrals?

In addition to considering alternative and/or additional methodological strategies (to an RCT) this chapter considers the collection of research variables (that is what they should be and, in some cases, how they can be collected).

13.1 Research Methodology and Variables: Whilst it is recognised that RCTs may provide robust research evidence, the demand for NDDP to use such methodology in the UK came not from the vocational rehabilitation sector but from the Treasury (and medical advisors within the DWP). The same sort of assumptions that may underlie disabled/sick people seeking treatment are not necessarily the ones operating within the unemployed sick/disabled population that might be capable of returning to work. Whilst research into why people in this group do not volunteer in any vast number for VR programmes is currently being undertaken, experience and qualitative research suggests that issues may arise in respect of such issues as benefits, overriding importance being given to the opinion of GP's certifying sickness from work, doubt in respect of potential benefits to be had from a VR programme, difficulties in counselling people resigned to long-term benefits receipt and a lack of expertise amongst Jobcentre Plus staff in respect of identifying and recruiting customers to VR programmes. The situation (in respect of a suitable chosen methodology) is clearly problematic for any researchers unable to exercise control over the subjects and having to rely upon an observational/survey approach or, indeed, a third party, for example Jobcentre Plus staff to collect raw data

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In addition, whilst it is considered that an RCT does produce robust results there are also practical issues to consider. Firstly, in the VR sector, denying support to 50% of the recruited subjects appears ethically questionable. It must be a matter of commonsense that some support will produce better resettlement results for some subjects than no support (even if this is not statistically demonstrated). On the other hand, it is possible to maintain that support that would not have otherwise been provided for 50% of the subjects is better than nothing. Secondly, there are misgivings as to the purpose of the exercise. It is difficult, if not impossible, to apply general findings to individuals and there is a case that expenditure on research in this sector is better spent on identifying and addressing individual barriers to employment. Thirdly, the numbers required to make the exercise worthwhile (through applying logistic regression) makes the actual running of an RCT very difficult.

It needs to be accepted that valid research in the VR sector may rely upon any one of a number of methodologies including the following list, the preferred one depending upon the nature of the research to be undertaken, the preferred means of analysis and practical consideration involved in the collection of data. In turn the evaluation strategy will be determined by the methodology and aims of the study.

342

- Case studies
- Group studies (using subjects in their own control)
- Studies contrasting different types of rehabilitation
- Studies contrast intervention with a matched control
- Randomised controlled trials

Practical considerations relate to such issues as:

- □ the identification of the study sample (and comparators)
- obtaining consent
- □ numbers required for statistical analysis/research evaluation
- □ number of researchers

It is further considered that whilst multiple/logistic regression offers "the best way" of identifying group variables influencing employment outcomes following TBI this is likely to require a substantial number of subjects (and controls). This number of subjects is only likely to be obtained through "official" support. Whilst some researchers may consider there is little new to be gained from an exercise that may not achieve its objective in any event (for such reasons as variables correlating too closely and the failure to explain *individual* circumstances) such an approach is necessary if an 'employability index' is to be established that goes beyond the limitations of univariate analyses.

Much has been made throughout the thesis on the issue of multi-collinearity. It is recognised that there are analytical ways of addressing this. However such analysis may be insufficient by itself and a multi-method approach may still produce a more comprehensible understanding.

The literature review for this study aided the development of a flexible strategy by identifying the likely "success" of statistical approaches in identifying and confirming variables said to influence TBI vocational outcomes and the lack of explanation for *individual* histories. In addition it was recognised that such is the number of variables (possibly) affecting outcomes that generalising and applying to other TBI populations has limitations. There is much to be said for an approach that explains the history of specific TBI subjects and, in this study it was decided to employ realism to do this although this also has had limitations. The nature of the data influences the avenue of investigation. A basic difficulty when relying on collecting available data, as opposed to running a prescribed research programme, is that clinicians,

rehabilitation practitioners and employing organisations, do not record client/patient information in a standardised fashion.

It is apparent that a uniform database and common assessment tools are needed to enable researchers and rehabilitation practitioners to communicate in a common language and facilitate the investigation and demonstration of the value of their work. Those funding programmes need to know whether a programme is cost-effective and produces outcomes commensurate with other programmes treating similar subjects. It would be beneficial for providers to know how their effectiveness compares with that of other programmes. A uniform database should also facilitate the collection of a sufficiently large amount of data for analyses that limit the possibility of chance findings.

Generally, it is considered that the research in this sector needs to follow a framework that is based upon standard agreed variables, ideally:

- Employment-related variables. With each study subject, it is considered appropriate to record the pre and post injury/rehabilitation educational qualifications/level, employment status, including definitions of regular/irregular employment and relying upon an agreed category of the Standard Occupational Classification (in the absence of anything else) and pay.
- Indicators of severity of injury. Given the support of the Department of Health it ought to be possible to obtain individual Glasgow Coma Scales (even though it is recognised that there are still limitations depending upon when this was recorded, for example on admission or during hospitalisation). The study by Dikmen et al (1994) used GCS and the Abbreviated Injury Scale (AIS) and a modified Injury Severity Score (ISS) establishing the severity of other system injuries excluding the head. It is considered that the Disability Rating Scale (DRS) has considerable potential value for recording functional deficits but the use of a standardised instrument is the overriding issue.

There is much work to be done with regard to the early identification of TBI victims likely to experience difficulty in returning to work. Potentially functional scales may have some utility with regard to assessing future employment status (Cifu et al, 1997; Ponsford et al, 1995). Combining information from functional scales with other data could potentially result in more accurate predictions but, as matters stand, there remains a need to improve their predictive

capability if between one quarter to one third of TBI victims are not to be incorrectly assessed. A problem for vocational rehabilitation agencies in the UK is that they do not have sufficient information to be able to apply functional scales. It is only when clinical and vocational rehabilitation are combined that such data is likely to become available in the first place.

#### Neuropsychological Variables

In respect of neuropsychological guidance it is considered that administration of the Full Scale WAIS-R is essential. It would also be helpful to have a Halstead-Reitan Impairment Index but since the full Halstead-Reitan battery (or even parts of it) are not administered consistently, the battery including Trials A and B, the Symbol-Digit Modalities test and Name Writing could be quickly administered to gain a baseline measure of cognitive efficiency, flexibility and motor speed against which outcomes could be compared. There are few choices for measuring emotional status and what is "best" requires neuropsychological consideration.

#### Chronicity

It is also apparent the chronicity (time since injury) needs to be taken into account when considering virtually all outcome data (Johnston, 1999).

#### Vocational Rehabilitation Process Variables

It will be recognised that vocational rehabilitation services are likely to have a combination of such activity as counselling, job search skills training, assistance with placement and these matters need recording. Clients receiving additional support such as cognitive remediation, should also have the services recorded and categorised for the purpose of relating such activity to outcome.

#### • Job Procurement

Whilst the initial success of intervention can be assessed by identifying whether or not a client secures employment, such matters as the agreed status and level of pay needs to be recorded. The number of hours that services had to expend to secure a placement also needs to be recorded.

The lack of an operational definition of successful employment outcome is a major issue with studies. An important issue is that the employment outcome needs to be separated

between a return to a previous company position and a return to a new job, a much more difficult task to achieve.

#### Job Support and Retention

Given the fact that obtaining work may ultimately not be as difficult as retaining a job, there is a need to consider what happens on the job site. Protocols need to be established and standardised across intervention programmes to verify the specific activity of job coaches and other rehabilitation counsellors. There is a need to validate the nature and context of interventions associated with successful placements with varying degrees of TBI. Only when there is specificity in such protocols can there be any replication.

Retention needs to be recorded over an agreed period of years. With economic downturns, changes in health and occupational aspirations, subjects with TBI may move in and out of the work force throughout their lives.

During this research it was discovered that the DWP has advanced its ability to track people in and out of work through their National Insurance numbers. Assurance has been given that subject to participants' consent, and Departmental support, there are no obvious reasons as to why this system can not be used in future research.

There are so many variables influencing outcomes following TBI that generalising and applying such information to any one individual is an exercise fraught with difficulty. Whilst this is not the same as saying that factors regularly featuring as significant should be ignored when planning any intervention (on the contrary they should be taken into account) it does mean that using variables in isolation, or even in clusters, to predict an outcome can be a spurious exercise. Unfortunately, the lack of significance of the data collected on the study sample in this research does not lend itself to the establishment of an index enabling any vocational rehabilitation counsellor to make an early prediction as to the potential outcome and the type of support likely to be required to effect an early return to work. Nevertheless, it is considered that if one had sufficient data (such as the original data from a number of homogenous studies) this should be possible although any recommendation to adopt a model for providing guidance on outcomes, based upon identifying influential variables, can never provide a definitive prescription in any one case. There will always be those who fail to benefit (for reasons outside the control of the intervention service and that could not be predicted). In addition, ethical considerations suggest that 'marginal cases' should be given the benefit of any doubt.

#### Further Research:

Although pre-injury factors, severity of injury and cognitive deficits on neuropsychological testing have been correlated with prognosis, there has been limited research on the impact on neurobehavioural disorders, medical complications and fluctuation of deficits on a return to work leading to job separations (Dikmen et al, 1994, Wehman et al, 1993a). Little research has been done correlating the impact of behavioural states, for example, depression, on employment outcomes. However, studies have demonstrated such disorders are present in large percentages of individuals after TBI (Levin et al1979); 25.9% of the study sample suffered from depression, 35.2% from anger/irritability and such factors may influence the ability to return to work after TBI.

In an ideal world it is considered that further research into assessing outcomes following TBI would require "official" support and involvement, such as Jobcentre Plus and NHS Trusts coming together and providing appropriate support and the selection of an agreed methodology. It is considered that there is much to be said for being able to analyse and demonstrate the accumulated histories of individuals following TBI and whether or not intervention 'works' and, if not, why not.

**13.2 Summary and Concluding Points:** It is considered that the experience of undertaking this study supports the view that the main focus of research needs to be based as an examination of intervention variables and how these relate to individual subjects. When undertaking research there are practical and ethical objections to RCTs but any observational or survey approach is likely to experience difficulty synthesising the major research variables. There is a need for a uniform data base and agreement in respect of the chosen variables to be studied. Issues surrounding subject participation in VR (research) programmes were considered in Chapter 9 and need to be addressed *before* commencing any research or VR programme.

The experience of the study sample suggests that one can not rely upon a spontaneous return to work or generic services to produce good return to work figures. In any event job retention is a major issue.

It needs to be recognised that there are many factors outside the individual affecting resettlement. Matters identified in this study include how people with TBI are identified and

engaged, and the level of understanding and support offered by and to employers.

Of particular significance is the role of Jobcentre Pus. Whilst it is apparent that in the roll-out of condition management programmes some of the issues identified in this research are being addressed, such as the introduction of mandatory interviews for the stock of IB customers, there are still issues in respect of how the TBI population are identified, how their *voluntary cooperation* is to be ensured and how condition management programmes are run that not only address the employment problems of the subjects but *the consequences of long-term benefits dependency*, such as a reliance on public transport, 'role-swapping' and what may be termed a 'detached resignation' from the labour market, a view that 'I am not going to get a job', 'I've tried but It didn't work'. 'One-off' mandatory interviews and passing the customers for treatment and job search advice may be all that many IB customers require, but it is improbable that such an approach will make any significant inroads into the number of TBI claimants.

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# **ANNEXES**

1.	Commonly Used Neuropsychological Tests	375
2.	Valpar Work Samples	381
3.	Study Sample Questionnaire	383
4.	Statistical Package for the Social Sciences (SPSS) Categorisations	401
5.	Work Personality Profile: Roessler and Bolton (1985)	406
6.	The British Standard Occupational Classification System	411
7.	Constructing an Index of Employability Following TBI	414
8.	The Job Analysis Process: Callahan and Garner (1997)	417

#### Annex 1

#### Commonly Used Neuropsychological Tests

# The Halstead-Reitan Neuropsychological Testing Battery (HRNTB)

One of the most widely researched neuropsychological test batteries was developed for use with adults by Halstead (1947) and later revised and extended for use with adults and children by Reitan (1969) and Reitan and Davison (1974). The original battery included 27 tests of which 10 were used to derive an "impairment index". Reitan later dropped 3 of the original 10 tests and supplemented the remaining 7 with additional measures. The revised battery for adults included the **Category Test** (a measure of concept formation); **Tactual Performance Test** (a measure of various sensorimotor functions); **Tactile Form Perception Test** (a measure of spatial organisation and kinesthesis); **Seashore Rhythm Test** (a measure of sustained attention and non-verbal auditory visual discrimination); and the **Finger Oscillation Test** (a measure of finger tapping speed). The resulting **Halstead-Reitan Battery** (HRNTB) generated an index of possible brain damage, the "Impairment Index", as well as other specific data useful in differential diagnosis of location, chronicity, and the nature of the suspected lesion.

The HRNTB, has generally been supplemented with various measures of intelligence, achievement, sensory perception, sensorimotor functions and/or emotional-personality inventories. The most commonly used test of intelligence are the **Wechsler Adult Intelligence Scales** (WAIS) (Wechsler, 1955) and more recently, the revised WAIS (WAIS-R) (Wechsler 1981). The **Wide Range Achievement Test** (Jastak & Jastak, 1965) and the **Minnesota Multiphasic Personality Inventory** (MMPI) (Hathaway & McKinlay, 1967) have been frequently incorporated into the battery as measures of achievement and emotional-personality factors, respectively. The assessment of perceptual and sensorimotor functions has often been augmented by the **Trial Making Test** for Adults (also considered to have a cognitive component) (Reitan, 1958), grip strength using a hand dynamometer, tactile finger recognition, finger-tip number writing and tactile coin recognition. Certain speech, language and visual-constructional abilities have ordinarily been evaluated using the **Alphasia Screening Test** (Wheeler & Reitan, 1962).

# Wechsler Adult Intelligence Scale - Revised WAIS-R (Wechsler, 1981) Influence on Verbal and Performance Sub-Tests

#### Influences on verbal sub-tests

#### Information:

educational attainment

culture/social sophistication and/or class

language

interest in current affairs

information absorption

environmental

long term memory

#### **Digit Span**

**Digits Forward** 

immediate recall (non-semantic material)

concentration

attention

familiarity with numbers

order effects/sequencing

#### **Digits Backwards**

immediate recall, retention, manipulation (non-semantic)

concentration

attention

familiarity with numbers

order effects/sequencing

#### Vocabulary

educational attainment

language

ability to express oneself

range of semantic fields

culture/social sophistication

familiarity with language concepts environment long term memory

#### Arithmetic

educational attainment/concept of numbers/operations language concentration attention short term retention recall mental manipulation of numbers problem solving sequencing/order effects

#### Comprehension

language culture/social sophistication general knowledge/educational attainment verbal reasoning/logic understanding/meaning of words and expression with words evaluation of past experience/application to every day/social situations ability to generalise from the particular long term memory

#### Similarities

language meaning of words cultural/social sophistication general knowledge/educational attainment number of semantic categories/concepts used ability to classify, recognise classes of concepts capacity for associative thinking long term memory

\* (Number of available categories/number of categories able to generate has been correlated

with creativity).

An additional function of all of these sub-tests is speed of response, being more important on some sub-tests than others.

#### Influences on Performance Sub-Tests

#### **Picture Completion**

visual recognition/perception/discrimination observation skills concentration essential/non-essential elements (ie. recognition of important elements/selectivity of perception)

#### **Picture Arrangement**

social/cultural understanding sequencing/order effects logic reasoning visual perception/recognition comprehension of whole from parts organising abilities planning

#### **Block Design**

visuo/spatial abilities perception/recognition of patterns visual analysis planning/strategies/organising motor activity

#### **Object Assembly**

visual analysis/co-ordination visual perception/recognition constructual abilities/assembly skills motor dexterity/speed persistence

## **Digit Symbol**

visual recognition (of symbols/digits or characters) motor speed/dexterity persistence ability to learn unfamiliar task

**The Behavioural Assessment of Dysexecutive Syndrome** (BADS) self-complete questionnaire is often used to identify the degree of awareness a TBI subject may have.

Clinical tests must be administered by chartered psychologists training in neurological testing. Occupational tests may be administered by people trained to Level A standard in the British Psychological Society Certificate of Competence in Occupational Testing. There are numerous tests of skills, abilities and aptitudes on the market - areas commonly used, and publishers, are:

Basic Skills: Literacy and Numeracy, ASE/NFER Nelson.

Differential Aptitude Battery, Psychological Corporation.

Modern Occupational Skills Test Series, ASE/NFER Nelson.

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#### Annex 2

#### VALPAR WORK SAMPLES

#### Valpar produces over 20 work samples.

Small Tools (mechanical) assesses the ability to make precise finger and hand movements and to work with small tools in tight or awkward places.

Size Discrimination assesses the ability to perform work tasks involving size discrimination, manual dexterity and finger dexterity.

Numerical Sorting assesses the ability to perform work tasks involving sorting, categorising and filing by number arrangement and using numbers and numerical series.

Upper Extremity Range of Motion assesses upper extremity range of motion and work tolerance in the upper body.

Clerical Comprehension and Aptitude assesses a variety of clerical work skills.

Independent Problem Solving assesses the ability to pay attention to detail and to compare and discern differences among variously coloured geometric designs.

Multi-Level Sorting assesses the ability to make rapid sorting decision involving several levels of visual discrimination of colour, numbers, letters and combinations of these.

Simulated Assembly assesses the ability to perform repetitive assembly work requiring manipulation and bilateral use of the upper extremities.

Whole Body Range of Motion assesses whole body range of motion, agility and stamina through gross body movement of the trunk, arms, hands and legs.

Tri-Level Measurement assesses work skills related to inspection and measurement tasks, ranging from simple to precise.

Eye-Hand-Foot Co-ordination assesses the ability to move the eyes, hands and feet in coordination. Soldering and Inspection (electronic) assesses the ability to use small tools and to make precise hand and finger movements in close co-ordination with the eyes.

Integrated Peer Performance is designed to stimulate interaction among workers.

Electrical Circuitry and Print Reading assesses work skills related to understanding and working with electrical circuits.

Drafting assesses drafting and blueprint reading skills.

Pre-Vocational Readiness Battery is designed to cover a wide range of populations from cognitively disabled to special needs students with specific learning disabilities.

CUBE (Conceptual Understanding Through Blind Evaluation) is a multi-purpose battery of exercises designed to assess various skills and abilities that are used to compensate for loss of vision by the visually impaired and blind.

Dynamic Physical Capacities assesses various physical capacities while stimulating work of a shipping and receiving clerk.

Physical Capacities and Mobility Screening evaluation assesses quickly a number of workrelated physical capacities.

Mechanical Assembly/Alignment and Hammering assesses work skills that require proper selection, placement and use of a variety of hand tools.

Mechanical Reasoning and Machine Tending assesses work skills involving machine tending, positioning and guiding items into a machine or under a needle; and assembling and disassembly using hand tools.

Fine Finger Dexterity assesses the ability to perform work tasks that require a high level of finger dexterity.

Independent Perceptual Screening (Spatial Aptitude) assesses the ability to envision geometric forms and to comprehend two dimensional representations of three-dimensional objects.

#### Annex 3

## QUESTIONNAIRE

Code No.

The answers to the enclosed survey are strictly confidential and they will be used only for the described purposes.

If you would like a summary of the research findings when available, please tick here......

#### CONTENTS

- Section A Personal Data
- Section B Personal Data to be completed only by those injured prior to entering the labour market.
- Section C Clinical Data For information, the clinical data records the severity of injury and subsequent disability.

Discussion has taken place with job coaches and clinicians with regard to completion on behalf of those participating in the survey.

PLEASE NOTE MOST OF THE QUESTIONS ONLY REQUIRE A TICK (YOU MAY LEAVE A BOX BLANK OR PUT IN A CROSS X IF IT DOES NOT APPLY TO YOU). SOME OF THE QUESTIONS REQUIRE A NUMBER AND SOME WRITTEN REPLIES.

# PART 1

SECTION A PERSONAL DATA Code No:			
	TO BE COMPLETED B OR ON BEHALF OF SURVEY PARTICIPAN	SY T	FOR RESEARCH ANALYSIS
1. Identification	Code No:		
2. Gender	Male:		
	Female:		
3. Age	Age:		
	Date of Injury:		
	Age at time of injury:		
	Date of Birth:		
4. Current Family Circumstances	Married or living with partner		
	Married or living with partner & dependent children		
	Single, living alone with dependent children		
	Single, living with parent(s)		
	Other For example, staying with friends, in sheltered accommodation or hotel/hospital.		

.

	TO BE COMPLETED BY OR ON BEHALF OF SURVEY PARTICIP	ANT	FOR RESEARCH ANALYSIS
5. Education History	a) At what age did you leave full-time education?	2	
	Minimum school leaving age 15/16		
	18		
	21 or older		
	If you had returned to education as a mat student or undertaken day release training indicate:	ure g, please	
	b) What is the <b>highest</b> level of education qualification(s) you hold?	al	
	None		
	CSEs/GCSEs (D-G)		
	O levels/GCSEs (A-C)/		
	Standard Grades		
	A levels		
	HND/degree		
	Post-graduate degree		

	TO BE COMPLETED BY OR ON BE OF SURVEY PARTICIPANT	CHALF	FOR RESEARCH ANALYSIS
6. Pre-Injury Work History	a) Prior to injury, were you in regular ful employment?	l-time	
	Yes		
	No		
	b) Do you have a history of part-time casual employment?	or	
	Yes		
	No		
7. Occupational Position at time of injury	<ul> <li>Student (incl. pupil)</li> <li>Registered unemployed</li> <li>In receipt of Incapacity Benefit</li> <li>Part-time employment</li> </ul>		
8. Contractural terms in immediate pre-	PAYE (employee)		
mjury position	Self-employed		
	Other (state)		

.

	TO BE COMPLETED BY OR ON BEHALF OF SURVEY PARTICIPANT	FOR RESEARCH ANALYSIS
9. Current occupational status	<ul> <li>Full-time employment</li> <li>housewife</li> <li>On the sick</li> <li>Registered unemployed</li> <li>Full-time employment</li> <li>Part-time employment</li> <li>Supported (sheltered employment)</li> <li>Attending day centre or undertaking other therapeutic or voluntary activity</li> </ul>	

ONLY FOR THOSE MAKING A RETURN TO WORK			
10. Have you returned to the same employer?			
<ul> <li>11.(a) Have you returned to the same job?</li> <li>(b) If not the same job can you describe the nature of current work (in a way which can be contrasted with pre-injury position) eg. skilled, unskilled, etc.</li> </ul>			
12. Are you working full-time or part-time?	Full-time		
<ul><li>13.(a) Have you sustained a loss of earnings capacity compared to the pre-injury position?</li><li>(b) If so, by approximately how much?</li></ul>	No. of hours per week Yes No		



17. Continued.	If yes, please specify:	
18. How quickly following injury did you return to work?	Less than 6 months	
	$\square_{6 \text{ months to 1 year}}$	
	$\square_{1 \text{ to } 2 \text{ years}}$	
	$\square$ 2 to 3 years	
	If after 3 years, please	
	specify (years)	
19.(a) Prior to returning to work, did you receive any cognitive rehabilitation, eg. assistance with memory retraining, behaviour modification with a head injury rehabilitation team at a hospital?	□ <sub>Yes</sub> □ <sub>No</sub>	
(b) If the answer to the above question is "yes", can you provide some information in respect of the support received.		
20.(a) Prior to returning to work, did you receive any vocational rehabilitation, for example, receive support from the Employment Service or attend a course?	□ <sub>Yes</sub> □ <sub>No</sub>	

(b) If the answer to the above question is "yes", can you please specify the support received (please add any comments).	

Thank you for your assistance.

Please put the survey into the enclosed envelope and return. If there is anything else you would like to tell me, feel free to do so:

If there is any aspect of your answers of which I am uncertain or if I require further information, may I contact you again by telephone?

□ <sub>Yes</sub>	Telephone No.
$\square$ <sub>No</sub>	

SECTION B ONLY FOR THOSE INJURED AT AN AGE PRIOR TO ENTERING THE LABOUR MARKET	FOR RESEARCH ANALYSIS
21. If you were in education at the time of injury, at what level, for example, junior school, senior school, further education, college, etc.	
22. If you ware on a course loading to qualifications	
what were you studying?	
23.Have you obtained qualification since your injury, if so what?	

ONI V FOD THOSE INITIDED AT AN ACE	FOR RESEARCH
PRIOR TO ENTERING THE LABOUR MARKET	ANALYSIS
b) If you have the same level of qualification and you were studying pre-injury, do you consider there was any difference in your grade(s)?	
□ <sub>Yes</sub>	
$\square$ No	
If "yes" please specify	
24. a) Were you able to make a successful return to the same course?	
$\square$ Yes	
b) If the answer to the above question is "no" (for example, taking a "year out", dropping subjects, changing courses, or going to Special School), please specifiy what happened to you.	
25.a) Following injury, have you at any time received any cognitive rehabilitation, eg. assistance with memory retraining, behaviour modification with a head injury rehabilitation team at a hospital?	
□ <sub>No</sub>	
b) If the answer to the above question is "yes", can you provide some informationin respect of the support received	

•

ONLY FOR THOSE INJURED AT AN AGE PRIOR TO ENTERING THE LABOUR MARKET	FOR RESEARCH ANALYSIS
26. Following injury, have you at any time received any vocational rehabilitation, for example undertaken an occupational assessment?	
$\square_{\text{Yes}}$ $\square_{\text{No}}$	
If "yes" please specify the support received	
27. Have you had a job since leaving education?	
T Yes	
□ <sub>No</sub>	
If "yes" what sort of work?	
28. If the answer to the above question is "yes", how many jobs have you had?	
More than 3	
Please specify	
29. For how long have you on average been in each job?	
less than 6 months	
6 months to 1 year	
less than 2 years	
2 years and more	

•

	1 1
ONLY FOR THOSE INJURED AT AN AGE PRIOR TO ENTERING THE LABOUR MARKET	FOR RESEARCH ANALYSIS
30. a) If currently in work, are you employed:	
□ Full-time	
D Part-time	
□ Not employed	
b) How many hours each week did you work?	
31.a) Have you been given any special consideration(s) by your employer(s)?	
T Yes	
□ <sub>No</sub>	
b) If the answer to the above question is "yes", what support has been provided, please specify	
32. Are you aware of any factors which continue to adversely affect your employment?	
T Yes	
□ <sub>No</sub>	
b) If the answer to the above question is "yes", please specify the nature of the problem(s).	

**.** \*
SECTION C	CLINICAL DATA	CODE NO.

Aged:

**D.O.B:** 

Age at time of injury:

No. of years post injury:

Severity of injury:

PTA	

5.1

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# CLINICAL

# **Problems Resulting from the Accident**

Problem	Yes	<b>Observation of Reporter</b>
PHYSICAL		
Balance		
Lifting		
Walking		
Spinal cord injury		
SENSORY AND MOTOR		
Visual		
Hearing		
Pain Perception		
Smell		
Seizures		
Taste		
Co-ordination		
PSYCHOLOGICAL		
Memory		
Writing		
Attention		
Organisation and Planning	-	
Communication		
- Receptive		
- Expressive		
Visual-Spatial		
<b>EXECUTIVE FUNCTIONS</b>		
Unable to initiate motor acts Planning/executing goal		
directed behaviours		
Sequencing difficulties		
Loss of self monitoring ability		

Problem	Yes	Observation of Reporter
Inability to analyse social situations and self adjust		
EMOTIONAL Alcohol or chemical		
dependency		
Depression		
Anxiety		
Frustration		
Anger		
Paranoid or Suspicious		
Auditory hallucinations		
Behaviourally out of control		
OTHER		

#### Annex 4

# SPSS CATEGORISATIONS

Personal I	Data:	
Gender	Μ	
	F	
Age (A) at	follow up	Actual age recorded
Age at Inju	ry (AI)	Actual age recorded
Chronicity		Nos. of years difference between A and Al
Married/livi	ng with partner	
Ditto and d	ependent child(ren)	
Single, livir	ig alone	
Ditto with c	ependent children	
Single, livir	ig with parents	
Other		
Education	History	
	ristory.	
Age left ful	-ume education	Actual age recorded
Highest lev	el of qualification	
. ng./eet.ret		
None		
NVQ 1 or 2	; CSEs/GCSEs	
A levels or	equivalent	
HND/Degr	ee	
Vocational	qualifications	
Profession	al qualifications	
Employme	ent History:	
History of r	egular employment	
History of	part-time or casual emp	loyment

# Status:

Manual White Collar

Status at time of injury: Student/pupil Registered unemployed In receipt of incapacity benefits Part-time employment Housewife

Current (follow-up status): Incapacity benefits Registered unemployed Full-time employment Part-time employment

Supported employment

Day centre/therapeutic activity

## **Return to Work:**

No return to any employer at any time

Return to same employer	Yes
	No
Return to same job	Yes
	No

Full-time Part-time

Nos. of jobs since return to work: One Two Three or more Average duration of job: Less than 6 months 6 months to less than a year 1 to 2 years 1 to 5 years

#### **Received rehabilitation:**

Cognitive rehabilitation	Yes
	No
Vocational rehabilitation	Yes
	No
Injured prior to entering the labour market:	
Junior or Secondary School	
or 6 <sup>th</sup> Form/college	
Received cognitive rehabilitation	Yes
	No
Received vocational rehabilitation	Yes
	No
Had a job since leaving education	Yes
	No
If 'yes', number of jobs	1
	2
	3
	4+
Average duration of job:	- 6 months
	6 months to 1 year
	1-2 years
	2 years plus

#### **Current Status:**

Employed full-time

part-time

Not employed

**Clinical Data** 

# Post-Traumatic Amnesia:

Minor

Severe

Very Severe

# Disability Physical:

Balance Lifting Walking Spinal cord injury

# Sensory and Motor:

Visual

Hearing

Pain perception

Anosmia

Seizures

Taste

Co-ordination

# Psychological:

Memory Writing Attention/concentration Organisation and planning Visual-Spatial

# **Dysexecutive Syndrome**

#### Executive skills:

Unable to initiate motor acts Planning Sequencing Loss of self-motivation Inability to analyse social situations

# **Emotional:**

Alcohol or drug dependency Depression Anxiety/stress Frustration Anger/irritability Paranoia/suspicion Auditory hallucinations Severe behaviour problems

#### Other:

#### Annex 5

#### THE WORK PERSONALITY PROFILE: AN EXPERIMENTAL RATING INSTRUMENT FOR ASSESSING JOB MAINTENANCE SKILLS

Roessler, R and Bolton, B (1985) Vocational Evaluation and Work Adjustment Bulletin/Spring 1985

Roessler and Bolton (1985) considered the importance of interpersonal, task performance and team skills for the tenure of employment, particularly for rehabilitation clients, citing a number of studies (Selz, Jones and Ashley, 1980; Greenspan and Shoultz, 1981; Kolstoe, 1961; Lewinsohn and Graf, 1973). The concluded that rehabilitation clients must either possess job maintenance skills upon entering services or develop them as a result of work adjustment intervention. To determine whether a person possesses job maintenance skills they developed an assessment instrument designed to measure vocational functioning, isolating those skills central to meeting the demands of the work role or maintaining th ejob (Roessler and Bolton, 1983) known as the Work Personality Profile (WPP). Use of the WPP identifies deficiencies that if not remediated may prevent a disabled person (not just someone with a head injury) from achieving or maintaining employment.

Fundamental work capabilities (referred to collectively as the Work Personality of the Client) consist of 58 specific work behaviours organised into 11 categories of work performance.

## WORK PERSONALITY PROFILE

Please describe the client's observed work performance using the five options listed below to complete the 58 behavioural items.

- *4 A definite strength, an employability asset*
- 3 Adequate performance, not a particular strength
- 2 Performance inconsistent, potentially an employability problem
- 1 A problem area, will definitely limit the person's chances of employment
- X No opportunity to observe the behaviour
- 1) Sufficiently alert and aware

- 2) Learns new assignments quickly
- 3) Works steadily during entire work period
- 4) Accepts changes in work assignments
- 5) Needs virtually no direct supervision
- 6) Requests help in an appropriate fashion
- 7) Approaches supervisory personnel with confidence
- 8) Is appropriately friendly with supervisor
- 9) Shows pride in group effort
- 10) Shows interest in what others are doing
- 11) Expresses likes and dislikes appropriately
- 12) Initiates work-related activities on time
- 13) Accepts work assignments and instructions from supervisor without arguing
- 14) Improves performance when shown how
- 15) Works at routine jobs without resistance
- 16) Expresses willingness to try new assignments
- 17) Carries out assigned tasks without prompting
- 18) Asks for further instructions if task is not clear
- 19) Accepts correction without becoming upset
- 20) Discusses personal problems with supervisor only if work-related
- 21) Accepts assignment to group tasks
- 22) Seeks out co-workers to be friends
- 23) Responds when others initiate conversation
- 24) Conforms to rule and regulations
- 25) Maintains satisfactory personal hygiene habits
- 26) Changes work methods when instructed to do so
- 27) Pays attention to details while working
- 28) Maintains productivity despite change in routine
- 29) Recognises own mistakes
- 30) Asks for help when having difficulty with tasks
- 31) Comfortable with supervisor
- 32) Gets along with staff
- 33) Works comfortably in group tasks
- 34) Appears comfortable in social interactions
- 35) Initiates conversations with others
- 36) Displays good judgment in use of obscenities and vulgarities

- 37) Arrives appropriately dressed for work
- 38) Maintains improved work procedures after correction
- 39) Maintains work pace even if distractions occur
- 40) Performs satisfactorily in tasks that require variety and change
- 41) Initiates action to correct own mistakes
- 42) Performance remains stable in supervisor's presence
- 43) Supportive of others in group tasks
- 44) Joins social groups when they are available
- 45) Listens while other person speaks, avoids interrupting
- 46) Expresses pleasure in accomplishment
- 47) Listens to instructions or corrections attentively
- 48) Moves from job to job easily
- 49) Needs less than average amount of supervision
- 50) Offers assistance to co-worker when appropriate
- 51) Is sought out frequently by co-workers
- 52) Expresses positive feelings, eg. praise, liking for others
- 53) Displays good judgment in playing practical jokes or "horsing around"
- 54) Transfers previously learned skills to new task
- 55) Handles problems with only occasional help
- 56) Assumes assigned role in group tasks
- 57) Expresses negative feelings appropriately, eg. anger, fear, sadness
- 58) Controls temper

The WPP requires that each of the 58 behavioural items are rated using a standard 4-point scale. The ratings represent judgments regarding employability strengths and deficits on 11 dimensions of work performance. The results of the evaluator's ratings are summarised on a profile form that graphically portrays the client's work personality strengths and deficits. It is suggested that such data can serve as the basis for:

- a the development and assignment of clients to 'remedial programming', and
- b the measurement of improvement in targeted work behaviours by completing the WPP at regular intervals.

The summary below represents a format for recording WPP results on 11 dimensions of work performance.

WPP	SU	MM	ARY
**1 1	00	181181	

Name		Sex	Age	Race .			
Educa	tion		Disability				•••
				4	3	2	1
I	Acceptance of Work	Role					
11	Ability to Profit from In	nstruction or C	orrection				
111	Work Persistence						
IV	Work Tolerance						
V	Amount of Supervisio	on Required					
VI	Extent Trainee Seeks Assistance from Supervisor						
VII	Degree of Comfort or Anxiety with Supervisor						
VIII	Appropriateness of P Supervisor	ersonal Relatio	ons with				
IX	Teamwork						•••
Х	Ability to Socialise wit	th Co-Workers					
XI	Social Communicatio	n Skills				• • • • • • • • • • • • • • •	•••
Critica	l employability deficits,	ie. behaviours	rated '1' or '2'				
'1' Pro	blem areas	'2' Pot	ential problems	6			
							•••••
						• • • • • • • • • • • • • • •	•••••

The key for scoring the WPP items on the 11 scales is presented below:

#### **References:**

Greenspan, S and Shoultz, B (1981)

Why mentally retarded adults lose their jobs: Social competence as a factor in work adjustment. Applied Research in Mental Retardation, 2, 23-38.

Kolstoe, O (1961)

An examination of some characteristics discriminating between employed and not employed mentally retarded adults. American Journal of Mental Deficiency, 66, 472-482.

Lewinsohn, P and Graf, M (1973)

A follow-up study of persons referred for vocational rehabilitation who have suffered from brain injury. Journal of Counselling Psychology, 1, 57-62.

Roessler, R and Bolton, B (1983)

Assessment and enhancement of functional vocational capabilities: A five-year research strategy. Richard J Baker Memorial Monograph Series. Vocational Evaluation and Work Adjustment Association, 1.

Selz, N; Jones, J; Ashley, W (1980) Functional capacities for adapting to the world of work. National Center for Research in Vocational Education, Ohio State University, Columbus, OH.

#### Annex 6

#### THE BRITISH STANDARD OCCUPATIONAL CLASSIFICATION SYSTEM

In the UK, occupations are classified by the Office of Population Censuses and Surveys (1980). Classifications are independent and relate to separate aspects of the employment or former employment of a person.

- Occupation. The occupation of a person is the kind of work which he or she performs with regard to the conditions and this alone determines the particular group and occupational classification to which the person is assigned.
- 2. **Industry.** The industry in which the person is employed is determined (whatever may be the occupation) by reference to the business or economic activity in which the work is undertaken.
- Employment status. This is primarily a distinction between the employed and the selfemployed.
- Economic position. This distinguishes those economically active from the inactive.
   Among the active population, separate groups are provided for those in employment.
   The groups are defined as follows:

#### A. Economically active

#### (1) Persons in employment

Persons with a paid job or self-employed or working in a family business. Temporary, part-time or casual employment is included. Persons absent from their employment due to holidays, strikes, lockouts, short time working or temporary stoppage are regarded as in employment. Persons off work sick are regarded as 'in employment' if their job is waiting for them on their return.

#### (2) Persons out of employment

Persons without a paid job:

- (a) Waiting to take up a job already accepted
- (b) Seeking work
- (c) Prevented by temporary sickness from seeking work

#### B. Economically inactive

#### (1) Permanently sick or disabled

Persons, whether or not previously in employment not now seeking employment because of permanent sickness or disability. Persons also included are those who have spent more than six months in a chronic sick or psychiatric hospital and are returned as out of employment.

#### (2) Housewives

Persons engaged entirely in unpaid domestic duties.

#### (3) Retired

Formerly occupied persons who have ceased working are no longer seeking further employment. Females engaged on unpaid domestic duties even though previously employed are treated as 'other economically inactive'.

#### (4) Students in educational establishments

Persons aged 16 and over who are or will be attending full-time, during the next term at an educational establishment not provided by an employer:

- (a) those with a paid job
- (b) those without a paid job

#### (5) Others economically inactive

All persons who have never been in employment and are not now seeking employment, and those who have spent more than six months in a prison and are returned as out of employment. Persons also included are those of independent means or engaged entirely on unpaid domestic duties even though they may have had paid work at some time.

#### Social and Socio-economic Classifications:

In addition to the above categories the OPCS also refers to social classifications. The social classifications are as follows:

- I Professional, etc. occupations
- II Intermediate occupations
- III Skilled occupations
  - (N) non-manual

(M) manual

- IV Partly skilled occupations
- V Unskilled occupations

# Annex 7 CONSTRUCTING AN INDEX OF EMPLOYABILITY FOLLOWING TBI

An employability index answering the following questions would have a number of advantages including the early identification of those only likely to return to work given appropriate vocational rehabilitation.

- 1 Is it possible, using information that is routinely available, to distinguish at an early stage of recovery from TBI, subjects likely to return to work and those not likely to do so?
- If so, can such information be used to identify those who are unlikely to return to work without additional advice or assistance and who, therefore, might benefit from early referral for vocational rehabilitation.

An underlying expectation to this study is that there would be significant relationships between a number of clinical and non-clinical independent variables, indicated in the literature as possible determinants of vocational outcome following TBI, and one binary dependent variable - return/non-return to work in the follow-up period.

In an ideal world, that is given adequate data, in terms of quantity and homogeneity, logistic regression should enable researchers to establish and 'weight' the significant variables. Logistic regression is multiple regression but with a categorical dichotomised outcome variable (in this case employed/unemployed). The predictor variables can be continuous or categorical ... hence its particular suitability. Because of data limitations it was anticipated that this study would have to rely upon  $x^2$  analysis to test for each variable a null hypothesis of no difference between (i) those subjects who returned to work during the period of follow up and (ii) those subjects who returned to work and remained in work at the final follow-up (it is recognised that additional variables could be added, such as regional unemployment statistics, but as the study sample came from different parts of England and Wales the numbers would be so low as to preclude any meaningful analysis). It was considered that the variables for which the null hypothesis was rejected could be used to construct an Index as indicated below:

Employability Assessr	nent 1 year P	ost-Injury	
Variable	x2	dif	р
Age			
Gender			
Education			
Employment History			
Employment Status			
Severity of Injury			
Clinical Symptoms			

Variables that distinguished between those who return to work and those who did so later, or not at all, could form the basis of a Vocational Rehabilitation Index, along the lines of the table below, depending on the identified variables.

#### A Vocational Rehabilitation Index

ltem

Returned to Work (%)

Index Score

#### **Age group** 16-30

16-30 31-40 41-50 50+

# Post-Injury Occupational Status

Professional/Intermediate Skilled manual Semi-skilled manual Other non-manual Unskilled manual Reg Employment History Irregular Employment History

#### Labour Market Conditions Low unemployment Medium unemployment High unemployment

Severity of Injury Very severe Severe Moderate/minor Logistic regression would also enable the researcher to provide a more exact ranking of scores in relationship to outcome and VR requirements. Indeed, from adequate data, the list of clinical variables could probably be considered extended.

# VRI Scores, vocational rehabilitation requirements & vocational objectives

VR Index score range*	% in emple Initial contact	oyment At follow-up	Vocational rehabilitation requirements	Vocational objective
Lower			Very few, possibly some need for information or advice	Placement in open employment Early placement in open
Lower middle			Information, advice, vocational guidance, counselling, job modification	employment after counselling, assessment, rehabilitation or training
Upper middle			Counselling, occupational assessment, employment rehabilitation, training or retraining, special rehabilitation	
Upper			Specialised clinical, behavioural & social rehabilitation programmes	Placement in part-time, subsidised, sheltered or therapeutic employment

\* Ranges to go in depending upon outcome of analysis.

This table addresses the issue of capability and, in turn, this is not dependent on the labour market. The fact that someone with TBI fails to get a job does not mean to say that vocational rehabilitation intervention has failed if, for example, the injured person has improved from a position of unemployability to one of potential employability in, say, the Supported Employment Programme, but is unable to obtain a placement because one is not immediately available.

In this research, a number of factors have prevented the development of any such scale, and the completion of the pro-forma that was prepared (Annex 3) including sub-sample sizes and the lack of association between the selected variables and a return to work. Even if it was possible to construct such scales there would still be a need for refinement and prospective evaluation.

#### Annex 8

#### THE JOB ANALYSIS PROCESS

#### Callahan & Garner (1997)

#### STEPS

- Conducting a Vocational Profile or other individualised planning process to determine the client's needs and desires.
- 2. Targeting job responsibilities in relation to the client's conditions, preference and contributions (from a profile meeting).
- Assessing the culture of the workplace. At this stage, the employment specialise needs to examine the potential for natural supports.
- 4. Through site visits record all components and requirements of the job using the Job Analysis Form. This provides an overview of the potential required job task and routines and can serve as a source for later refinement, observation and investigation.
- 5. Considering all the information about the job in relation to the potential employee and, if the 'fit' appears right, then move on to Step 6. If not, there is a need to target another job.
- 6. Visit the job site to begin a detailed Job Analysis for the task/routines identified in Step
  4. There is a need to advise the employer that notes will be taken on this aspect for the job analysis process.
- 7. Observe the way in which current employers perform the various routines. During this process it is likely to be helpful to have discussion with workers to gain their perspective on the required work routine. Typical questions to be asked include:
  - 1. What are the most important components of the task or routine?
  - 2. Which aspects of the job are most troublesome?
  - 3. Where is accuracy an absolute requirement?
  - 4. Are there any subtleties of the task or routine that an outside observer might not notice?
- 8. Based on the analysis, there is a need to determine who will be the initial trainer and a decision is to be made on the contents of a detailed job analysis and inventories for various tasks/routines of the job. Some tasks may be considered especially important by the employer; other may correspond to an identified limited skill with a perspective employee. Job coaches may have direct input into the most critical routines and may work less directly with co-workers and supervisors in less critical, more infrequently

performed routines.

- Performing the routines that are the most critical for success until they have been learned. There is a need to notice the procedures, cues, amount of supervision provided and complexity of the routine.
- 10. There is, then, a need to write task analyses and inventories for the tasks/routines which are considered to require the most support and assistance. Initially, the list should reflect the natural methods used by the company and, secondly, the particular needs of the employee.
- 11. Getting approval from the employer of the methods chosen for the tasks/routines to be trained and any modifications or adaptations that the job coach considered are necessary.
- 12. Identifying procedures, including natural cues and consequences, in the work routines of the employee.
- 13. Based on Step 10, the knowledge of the needs and skills of the employee, there is a need to consider potential training strategies, motivating strategies, possible adaptations and opportunities for job restructuring and participation with other workers. There is also a need to develop data sheets to reflect the number of steps considered critical to the employer in performing a required task. Data sheets should be based on the steps identified in the analyses and routines developed in Step 9.
- 14. There is a need to meet and get to know other co-workers and supervisors in the settings.
- 15. There is a need to ask about and observe company policies, acceptable dress codes, orientation procedure and components of the company's culture.
- 16. There is a need to set a start date and communicate with the employee and his/her family.

The actual performance of the job analysis by the job coach requires a visit to the job site of at least half a day, but ideally one or two days.

# JOB ANALYSIS FORM

Participant:	Provider:
Company:	Comp. phone:
Address:	Contact:
Date job begins:	Site:
Job title:	Immediate supervisor:
Provider:	Provider phone:
Core routines: (identified by employee)	Episodic routines: (identified by employer)
Job-related routines: (identified during Job Analysis)	Important cultural aspects: (and possible accommodations based on info. In Profile)

Job summary:

# Job facilitator:

### 1. The way in which job tasks typically are performed

#### a. Method

The facilitator should observe the manner in which each job is performed by typical employees in the setting. This is accomplished by assuming an unobtrusive observation position and carefully watching the employee(s) perform their duties. The facilitator should strive to make a 'mental video-tape' to be used later as a standard of correct performance and as a way to assist the supported employee to perform in a natural manner.

Job observed	Employee observed	Date & Time
1		
2.		
3.		
4.		
5.		

#### a. Content

The employment facilitator should ask whether the employer has step-by-step procedures for the job tasks observed above. If so, then these procedures should service as the initial content task analysis for each task. If not, then the facilitator should write content steps that would be appropriate for an average employee in the workplace. These content steps should be presented to an appropriate decision maker in the company for approval and refinement. Attach step-by-step procedures to this form.

C.

#### Specific requirements identified by employer

(Check only critical items; fully describe the extent of the demand and outline possible

adaptations/accommodations believed to be problematic for targeted employees).

Physical demands:

Sensory/communication demands:

Lifting		Vision
Standing		Hearing
Continuous movement	-	Speaking
Rapid movement	-	Judgement
Walking	4	Academic demands
Climbing		Reading
Stooping	4	Writing
Crawling		Maths

General strength/endurance requirements:

Pace of work:

Potentially dangerous components of job:

Critically important components of job:

Established learning curve or probationary period for job:

d. Worksite considerations

Special clothing, uniforms, safety equipment required:

Tools to be used:

Equipment to be operated:

Materials to be handled:

Special terms used at worksite:

Description of environmental conditions of worksite:

# 2. The means used by the employer to train and support new employees

# a. Description of the company's orientation procedures

Ask to review any written documents that describe typical orientation procedures. Discuss with a supervisor or decision maker the flow of typical procedures. Ask employees about their experiences. If possible, and if it is believed to be necessary, ask to be taken through an orientation.

# b. Description of the company's procedures for initially training and supporting new employees

Follow the suggestions in 2a above. In addition, ask for training from the employee on at least one of the tasks to be performed by the supported employee. Use this training as an opportunity to assess the capacity and flexibility of the employer in reference to the needs of the supported employee.

# c. Description of specific strategies used by the employer:

- 1. Who typically provides new employees with training?
- 2. Availability of company trainer assigned to employee:
- 3. Availability of co-workers/supervisors as trainers:
- 4. Description of strategies used by the employer:
- 5. Important rules stressed by employer and co-workers:
- 6.Unwritten rules unique to the setting:
- 7. Potential for use of adaptations, modifications in worksite:
- 8. Willingness of co-workers/supervisors to provide support and assistance:

# d. The 'culture' of the workplace:

- 1. Employer's concern for quality:
- 2. Employer's concern/need for productivity:
- 3. Flexibility/rigidity observed.

#### 4. Personnel: Managers, Supervisors, Co-workers:

- a. Supervisors of employee
- 1. Title:
- 2. Title:
- b. Co-workers of employee
- 1. Title:
- 2. Title:
- 3. Title:
- 4. Title:
- c. Employee social groups and non-work activities:
- d. Leaders and potential allies among co-workers and supervisors:

## 5. Job description

Schedule:

..... days of work per week: Days: Hrs Hrs Hrs Hrs

# Sequential chronology of typical work day (include all job tasks):

Type of job task (core, episodic, job-related):

Name of job task:

How often performed:

Content steps/skills

Strategy for facilitation (including instructional and natural cues and adaptations):

#### Annex 11

## THE VOCATIONAL ASSESSMENT PROTOCOL(VAP) - Thomas\_and Menz (1996)

Thomas and Menz emphasise that the Protocol is not an instrument designed as a yardstick for assessing whether or not a person is capable of and maintaining competitive employment. It is a functional skills profile of vocational-related factors intended for use with TBI subjects. The purpose of the VAP is to:

- a) systematically identify work skills, assets and strengths upon which to focus vocational efforts.
- a) provide a structure and protocol for examination of the most frequent cognitive, physical and psychosocial factors likely to affect employment and community integration for people with TBI.
- a) define vocational rehabilitation strategies based upon minimising vocational barriers for development of compensatory techniques and the use of creative problem-solving strategies.
- a) define vocational barriers, language and similar format used by consumers and vocational rehabilitation providers.

The VAP is structured into profiles and scales as well as data processing instruments that group information by its source, such as medical, neuropsychological, family information, etc. A summary of the instruments used in the VAP:

# **Background Information Interviews (Profiles)**

Personal Demographic Questionnaire Personal Demographic Interview

# **Clinical Rating Profiles**

Physical profile Social-emotional profile

#### Neuropsychological profile

#### **Vocational Adaptive Profiles**

Job search skills profile Interviewing skills profile Critical work behaviors profile Social adaptive behaviors profile

#### **Structural Summary Section (Optimal)**

This element of the protocol is used in synthesising information. In this process, the evaluator is encouraged to:

detail strengths and problems found in the profiles.

summarise referral questions and address them.

identify preferred learning styles and suggested teaching strategies.

suggest behaviour intervention strategies, supervision and support needs.

detail additional services suggested.

The VAP evolved during ten years of research and clinical experience involving several research studies involving consumer-provider consensus meetings sponsored by the Research and Training Center, at the University of Wisconsin-Stout that made reference to a 'National Think Tank'. The focus was upon developing instrumentation and processes to assist vocational evaluators in providing comprehensive and functional assessment of work-related skills and behaviours. The most prominent of these research efforts included the development and validation of the Vocational Adaptivity Scale (1983), completion of the Wisconsin Traumatic Brain Injury Survey (1986), and completion of the activities associated with Project Hire (1987-1991).

#### The Vocational Adaptivity Scale

Thomas (1983) identified common psycho-social factors affecting the ability to obtain and maintain work and compile this information into the Vocational Adaptivity Scale (VAS). This was developed with the intention of providing a comprehensive rating scale that "combined the vocational adaptive behaviors and work-related skills suggested by the literature as important to the employability of the cognitively disabled (worker)". Thomas (1983) identified many common psychosocial factors affecting the ability to obtain and maintain work and compile this information into the VAS. This was developed with the intention of providing comprehensive rating scales that "combine the vocationally adaptive behaviors and work-related skills suggested by the literature that is important to the employability of the (cognitively disabled) worker". Behaviours identified in the literature were used to develop rating scale items that could be used to assess each behaviour. The resulting in instrumenting included 59 items rated on a 5-point Likert scale, plus 14 items documenting background information. The validity of the instrument was evaluated against two criteria. The first was the prediction of the ability to obtain a job. The second was vocational adaptivity, defined by Thomas as the ability to maintain a job for a minimum of 60 days after placement. Hoyt's internal consistency reliability estimate indicated that the rating scale had a high degree of internal consistency (R= .954). Inter-related reliability was found to be moderate, r = .70. Content validity was determined by expert judges and was "found to exhibit adequate factual and predictive validity" (Thomas, 1983).

#### **Project Adapt**

A further development of the VAS followed project Adapt, a transition curriculum programme assisting students with mild to moderate cognitive and intellectual handicaps move from school to work (Thomas, Coker and Menz, 1988). Twenty-nine additional items that assess behaviours cited in other placement studies as predictive of employment success were included in the 1988 published version (Thomas, Coker and Menz, 1988).

The scale for conducting ratings was also changed. The item pool was expanded to include 88 items divided into 4 separate rating forms or profiles on a composite profile to summarise the 4 rating instruments. The following list of scales appear in the final version of the VAS:

The Job Search Strategy Assessment Profile. Telephone Inquiry Skills Assessment Profile. Personal Interview Skills Assessment Profile. Work Supervisor's Assessment Profile. Composite Profile.

#### The Head Injury Re-Entry Project (Project HIRe)

Project HIRe was a three years demonstration research project to develop a model for providing community-based employment services to subjects with TBI living in rural communities (Thomas and Menz, 1993).

In the first year of the project, efforts were made to secure as much information as possible about suggested employment practices for subjects with TBI. Information was gathered from subjects with TBI, the family members and significant others in both the public and private sectors. A literature review also supplemented the work of the National Think Tank.

In the second phase of Project HIRe data collected under another project of the Research and Training Center, the University of Wisconsin-Stout was analysed to identify consumer needs and barriers to employment for TBI subjects. The Wisconsin Brain Injury Survey, conducted in 1986 served as a source of the data. This survey was originally intended to measure the incidence of personal, economic and social losses experienced by TBI subjects in the State of Wisconsin. Over 700 respondents were involved.

The analysis of the survey data focussed on identifying and prioritising problem needs associated with brain injury, as reported by respondents. Descriptive and inferential statistical analyses were used to analyse the data and provide information on the incidence of identifying rehabilitation problems. The findings from the survey provided the basis for parts of the contents of the VAP. Specific items from the survey were subsequently integrated into the initial version of the Personal Demographic Interview.

The final phase of Project HIRe developed and implemented a community-based employment model for individuals with brain injury using input from the Think Tank and other sources.

The Project HIRe model was developed and implemented on two field sites. Two communitybased vocational rehabilitation agencies were contracted to participate in the project. Agency staff were provided with training and offered technical assistance and all instrumentation to record information and progress of those served. Details of the development and implementation model are found in the final report (Thomas and Menz, 1993). During the completion of Project HIRe, the VAP in its first experimental format was field tested. Data from this study was later compiled within the protocol data to perform initial analyses for validation purposes.

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