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LIVING LONG-TERM WITH ACQUIRED BRAIN INJURY IN IRELAND: TOWARDS A COUNTER DISCOURSE

PHIL MCGOWAN

JULY 2008

This thesis is submitted in partial fulfilment of a PhD degree from the National University of Ireland, University College Cork, School of Occupational Therapy.

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DECLARATION PAGE

I declare that while registered for the Degree of Doctor of Philosophy [PhD] I have not been a registered candidate or enrolled student of any other award at another academic or professional institution.

This thesis is a record of work carried out by myself and has not been submitted for any other award. All sources of work have been acknowledged and/or referenced.

Name _____

Date _____

Signature_____

ABSTRACT

Living long-term with Acquired Brain Injury in Ireland: Towards a Counter-Discourse

Irish literature on Acquired Brain Injury (ABI) is very scant and is mainly deficits and/or needs based. The focus is generally on how to manage the short term needs of the younger population with ABI. The starting position of my thesis is that people living long-term with ABI are important participants in developing knowledge about this social phenomenon, living with ABI while accepting that their brain injury does not determine them. Six mature adults with ABI[1] and their six significant others participated in this longitudinal study. Using a narrative approach in interviews, over twenty months, five repeat individual interviews with each of the twelve participants was held. From this I gained an understanding of their lived experiences, their life-world and their experiences of our local public ABI/disability services, systems and discourse. Along with this new empirical data, theoretical developments from occupational therapy, occupational science, sociology, and disability studies were also used within a meta-narrative informed by critical theory and critical realism to develop a synthesis of this study. Social analysis of their narratives co-constructed with me, allowed me generate nuanced insights into tendencies and social processes that impacted and continues to impact on their everyday-everynight living. I discuss in some depth here, the relational attitudinal, structural, occupational and environmental supports, barriers or discrimination that they face(d) in their search for social participation and community inclusion. Personal recognition of the disabled participants by their family, friends and/or local community, was generally enhanced after much suffering, social supports, slow recovery, and with some form of meaningful occupational engagement. This engagement was generally linked with pre-injury interests or habits, while Time itself became both a major aid and a need.

[1] Participants with ABI: four females and two males, over 40 years of age, living at least five years with ABI from urban or rural counties Cork and Kerry, Republic of Ireland.

The present local ABI discourse seldom includes advocacy and inclusion in everyday/every night local events, yet most participants sought both peer-support or collective recognition, and social/community inclusion to help develop their own counter-discourse to the dominant ABI discourse. This thesis aims to give a broad social explanation on aspects of their social becoming, 'self-sameness' and social participation, and the status of the disabled participants wanting to live 'the slow life'.

Tensions and dialectical issues involved in moving from the category of a person in coma, to person with a disability, to being a citizen should not demote the need for special services. While individualized short-term neuro-rehabilitation is necessary, it is not sufficient. Along with the participants, this researcher asks that community health and/or social care planners and service-providers rethink how ABI is understood and represented, and how people with ABI are included in their local communities.

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Many people have enabled me throughout this study. I thank them all, especially the following, for their support, ideas and their time, shared with me in so many ways:

The participants in this study enabled me to learn more not only about the topic of this study but also about many aspects of life and the various issues involved in research and the production of knowledge.

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PRESENTATIONS ARISING FROM THIS STUDY

Four R's in Research; research, realism, relativism and reflexivity.
Paper presented at the Association of Occupational Therapists of Ireland Annual Conference, Galway, 25 March, 2004.

Living with ABI in Ireland. Paper presented at the British Association of Occupational Therapists Annual Conference, Brighton, 22 June, 2005.

Poster presentation at Brookfield Inter-disciplinary Research Day, University College Cork, 17 November, 2006.

ACRONYMS

ABI	Acquired Brain Injury
AOTI	Association of Occupational Therapists of Ireland
BAOT	British Association of Occupational Therapists
BRI	Irish ABI peer-support and advocacy agency
BMA	British Medical Association
CORI	Conference of Religious in Ireland
COT	College of Occupational Therapists (UK)
CSO	Central Statistics Office
CVA	Cerebro -Vascular Accident (stroke)
DFI	Disability Federation of Ireland. Umbrella organization of organizations of and for people with disabilities
DoHC	Department of Health and Children
DRC	Disability Rights Commission
ECU	Equality Challenge Unit
EBP	Evidence - Based- Practice
HSE	Health Service Executive
NDA	National Disability Authority
NAI	Neurological Alliance of Ireland
PBF	Peter Bradley Foundation. Irish ABI service provider
PHC	Primary Health Care
RCC	Regional Co-ordinating Committee (HSE- South)
TBI	Traumatic Brain Injury
UCC	University College Cork

GLOSSARY

ACQUIRED BRAIN INJURY (ABI)

Any injury to the brain received during a person's lifetime and not as a result of a birth trauma (Headway Ireland, 2002, p.1). This includes traumatic brain injury and brain injury caused by internal events such as cerebro-vascular accident (CVA/stroke), tumours, viruses, or from lack of oxygen to the brain during a heart attack.

TRAUMATIC BRAIN INJURY (TBI)

Damage to living brain tissue that is initially caused by external mechanical forces (Headway UK, 2004).

CEREBRO-VASCULAR ACCIDENT

Medical term for 'stroke' - See Stroke below.

CLOSED HEAD INJURY

Closed head injuries are the most common type of head injury and occur when there is violent movement of the brain. If the brain is violently shaken around within the skull the various nerve cell connections within the brain are damaged (Headway UK, 2004).

HEAD INJURY

Injuries that impact on any part of the head or the face. NICE Guidelines define Head Injury as any trauma to the head, other than superficial injuries to the face (NICE, 2007). For example, data collection regarding head injuries may include injuries to the ears, nose and jaw.

OPEN or PENETRATING HEAD INJURY

These rarer injuries occur when an object fractures the skull, tearing the tough covering of the brain immediately inside the skull, enters the brain causing (relatively) localised brain damage (Headway UK, 2004).

IMPAIRMENT - DISABILITY

Impairment is used in this thesis as the essential and socially constructed difference at body-mind personal level. Disability is a complex social phenomenon dealing with internally and externally imposed restrictions on "factors relating to identity, experience, categorisation processes and group membership…always in process" (Fawcett; 2000, p.149). An issue at body level (impairment or health condition) is first required. Impairment is necessary but not sufficient therefore to have this form of disability.

BEST PRACTICE

A term used in business, health and education referring to procedures which are believed to result in the most efficient provision of a product or service. Occupational therapists believe that evidence-based practice (EBP) is a major element of what is now described as best practice (Canadian Association of Occupational Therapists, (CAOT) 1997).

ENABLING OCCUPATION

The process of facilitating, guiding, coaching, educating, prompting, listening, reflecting, encouraging, or otherwise collaborating with people so that they may choose, organize, and perform those tasks and activities of everyday life which they find useful and meaningful in their environment (CAOT, 1997). Refers to enabling people to "choose, organize, and perform those tasks and activities of everyday life which they find useful and meaningful in their environment" (CAOT, 2007, p.367).

EVIDENCE-BASED MEDICINE

Medical intervention which is based on the results of the most scientifically sound research applicable to the problem at hand, considered in light of patient characteristics and clinical judgment (CAOT, 1997).

EVIDENCE- BASED OCCUPATIONAL THERAPY

Client-centred enablement of occupation based on client information and a critical review of relevant research, expert consensus and past experience. (CAOT, 1997). Evidence based practice includes experiential, qualitative and quantitative evidence (CAOT, 2007).

REHABILITATION

Medical, vocational, social or neuro-rehabilitation for people with ABI usually means structured, person-centred goal-orientated team work, towards restoring, compensating, or re-learning basic everyday everynight required personal and/or social life tasks and activities. (The term rehabilitation is not mentioned in CAOT 2007).

OCCUPATION

For occupational therapists, the term occupation encompasses and enfolds all obligatory and self-chosen life tasks, activities, interests or work, from the mundane to the extra-ordinary. "Occupations are groups of activities and tasks of everyday life, named, organized and given value and meaning by individuals and a culture…"(CAOT, 2007, p. 369).

OCCUPATIONAL THERAPY

In disability sector, occupational therapists facilitate the person with the impairment gain the "ability to choose, organize, and satisfactorily perform meaningful occupations that are culturally defined and age appropriate for looking after one's self, enjoying life, and contributing to the social and economic fabric of a community" (CAOT, 1997, p.30).

OCCUPATIONAL THERAPY SERVICE USERS

Individuals or groups who use and receive occupational therapy services. They may include any persons with occupational problems arising from medical or health conditions, or from environmental barriers or from transitional difficulties. Service-users may also be organizations or community groups (CAOT, 1997). (Not mentioned in CAOT, 2007).

STROKE

Stroke is defined by the World Health Organisation as "a clinical syndrome consisting of rapidly developing clinical signs of focal (or global in case of coma) disturbance of cerebral function lasting more than 24 hours or leading to death with no apparent cause other than a vascular origin" (NICE Clinical Guidelines, 2008, p.11). The term stroke comes from the fact that it usually happens without warning, striking the person from out of the blue. A stroke is caused by a blockage of an artery supplying blood to the brain (cerebral thrombosis) or a bleed into the brain from a burst blood vessel (cerebral hemorrhage) (Irish Heart Foundation Council on Stroke, 2008).

CHAPTER 1 INTRODUCTION

This thesis is about personal experiences and social issues involved in living long-term with acquired brain injury in contemporary Ireland. The scope of this study was determined mainly by the twelve participants involved and their various lived and told stories over the two years, 2004 to 2006. The study explores some of the social processes involved in constructing disability and contentedness in their lives, when living with acquired brain injury. While improved individualised professionalised services are required, a change in public attitudes and public discourse on ABI is also required if people with acquired brain injury are to be recognised and to be included as citizens in local society.

Over the past five decades, disabled people have collectively challenged and renamed disability as a socio-political-economic construct, as much as a personal biological-psychological construct.[2] With three decades[3] of keeping people with severe acquired brain injury (ABI) alive, people with ABI, the focused population of this study, seek to be more involved in this search for equalisation of opportunities for all. People with ABI seek improved recognition, social inclusion and status like other disabled people and like all other citizens. Yet, most ABI literature documents the results of a patient's functioning against a standardised norm as measured, usually within the first year or two post-injury, following intervention in a specialised centre. The focus is on independence, self-awareness and self-adjustment of this new self or me now. Yet many aspects of the self are not amenable to adaptation in this short formal rehabilitation time-frame, as the brain can take many years before recovery is complete. Social issues causing additional problems for persons with ABI are seldom addressed by the rehabilitation team with the same importance, especially here in Ireland. Apart from basic home-based and respite care for the carer and/or family adjustment to this unwanted disruption in life, many ongoing needs remain unmet.

[2] Braddock and Parish (2001), Corker and French (1999) and Thomas (1999a). For other evidence in this process see Barnatt, Schriner and Scotch (2001) and Shakespeare and Watson (2001).
[3] Boake (2004).

The person with severe ABI is returned home from the National Rehabilitation Hospital in Dublin or Cork University Hospital and seen by their family as mad, strange, a stranger, and/or often kept separate from other people, including other disabled people. Public discourse on people with ABI is generally framed as if they are unable to learn or think, or should not be involved in disability issues or general politics. To add to all of this, attitudes of medical professionals can also be limited or negative, and even generic disability groups may exclude people with ABI. This study was carried out to explore some of these issues and to identify patterns and consequences of living long-term with ABI in southern Ireland.

This introductory Chapter will introduce the reader to the broad research topic involved in this inquiry, the research framework, the local context and the researcher. The first section introduces the research topic, research questions and aims of this inquiry. The definition of 'acquired brain injury' as used in this study will be given in order to provide boundaries, along with a brief comment about ABI itself.[4] In the second section I introduce my broad research framework, some local ABI research and the significance and justification for this study. In the third section, an introduction to the research setting, contemporary Ireland, is presented. In the final and fourth section, the reader is briefly introduced to the researcher and the development of my consciousness of disablement, and finally to the analytical strands and the Chapter plan of this thesis.

1.1 RESEARCH TOPIC, AIMS AND QUESTIONS

This study is based around people who have had a major disruption to their bodies, to their consciousness, and to their lived realities because of an injury to their brain. Advances in intensive care medical treatment and medical technology such as brain imaging technology, have enabled many people with severe brain injury

[4] See Glossary for a brief description of other concepts used in this study.

who would previously have died, to now survive.[5] ABI, especially from a traumatic brain injury, is still, however, "a leading cause of death and disability worldwide with most cases occurring in low-middle income countries" (MRC Crash Trial Collaborators, 2008, p.7). First, a brief introduction to the brain and brain injury is given to place in context the 'acquiring' of this injury.

The Brain

The brain has been described as a machine, a matrix, a jungle, or a desktop computer while the mind is noted as a container, multi-purpose tool or the self (See Fernyhough, 2005; Hale, 2002; Greenfield, 2004). But neuro-scientist Greenfield[6] claims that the 'jungle' metaphor is more apt to describe the physical brain rather than the more common metaphor of 'brain as computer'. The physical brain is very complex with many networks, but the functions are not so neatly located as many functions may be taken over by other areas. (See also Greenfield, 1997, 2000). Names, terms and classification systems for sub-structures of the brain are constantly changing as more is learned about the brain (Woolsey, Hanaway and Gado, 2008). Numerous sub-divisions of the brain are being mapped especially today with more accessible brain imaging scanners. For example, the hypothalamus in the central area is now known to be the size of a green pea, yet it is responsible for the regulation of all the major body functions. The main parts of the physical brain are the cerebrum, the brain stem, and the cerebellum,[7] with some including the diencephalon as the fourth main part.

The cerebrum, often called the conscious brain, is the largest part of the brain and where most conscious activity or thinking functions occur. The cerebrum has been described by Rhoton (2002) as "a remarkable beautiful and delicate structure" (p.51). The outside or cortex of this cerebrum is the most highly developed area of the brain as it contains the neural cell bodies and thus the most complex part of the

[5] See Boake (2004), Elliott and Walker (2005), Heary, Hogan and Smyth (2003).
[6] Greenfield interview on Irish radio Radio Telefis Eireann *The Dialogue Programme* by Andy O'Mahony, 14 August, 2004.
[7] Anatomists now divide the brain using the telencephalon, the diencephalon, the mesencephalon or mid-brain, the metencephalon and the myelencephalon (Woolsey, Hanaway and Gado, 2008).

human body. Higher functions such as language and information processing are based in this cortex. The cerebrum is divided into four lobes; frontal, temporal, occipital and parietal. (See Appendix 1). Each lobe is considered to be mainly or fully responsible for particular body functions. For example, the frontal lobe is responsible for reasoning, problem solving, moods and emotions, and some speech and movement. Some claim it is responsible for 'your personality' following the observations made by Dr. Harlow around 1848.[8] Neuro-imaging confirms this injury today, and frontal lobe injury causes a temporary or permanent loss of planning and problem-solving abilities, loss of attention, and a loss of inhibition and/or social nuance. The diencephalon**,** or central area includes the limbic system, the thalamus and hypothalamus. This area is essential for the processing of the senses, managing emotions, and for the co-ordination of hormones and basic drives such as sleep, hunger and sex. Parts of this region are also associated with memory processes (Greenfield, 2000). The brain stem, which links the mid-brain to the spinal cord, is responsible for many essential autonomic functions of our bodies. Some of these vital functions include breathing, blood pressure, body temperature, heart-beat and consciousness. Stroke or a lack of blood supply to this area often results in death. The cerebellum or 'little brain' is at the base of the brain and co-ordinates balance and movement. This area is very important in recalling learned skills or movements. Neuroscientists have now mapped the brain area that is responsible for skills used only or mainly by expert ballet dancers or professional sports players, the brain area 'where practice is made perfect'. Thus, it is suggested that even observation of past skills may assist retraining injured professional athletes or dancers even when they are physically unable to do the movement (Radford, 2005, p.10).[9]

[8]As noted in neurological texts and told at ABI seminars: Dr. Harlow noted the impact made by a three centimetre thick, one-hundred and nine centimetre long iron bar which went through the frontal lobe of the brain, skull and face of a railway worker, Mr. Phineas Gage. Phineas Gage survived this traumatic brain injury, recovered quickly and physically very well, but his character or personality changed.

[9] Based on research at the London Institute of Cognitive Science.

Acquired Brain Injury

The cerebrum and the other major components of the brain, along with the surrounding fluids and coverings, can be damaged or injured quite easily. This is called an acquired brain injury (ABI). There are many classification issues and controversies involved with the diagnosis 'acquired brain injury' and there are many types of ABI. The most common conditions often discussed within the ABI classification scheme include; brain injury, traumatic brain injury, head injury which may be open or closed, stroke, and viral infections. A brief general definition of these classifications or conditions is noted in the Glossary. One definition of Acquired Brain Injury (ABI) is "any injury to the brain received during a person's lifetime and not as a result of a birth trauma" (Headway Ireland, 2002, p.1). This is the broad definition of ABI used in this study as it was the definition used when recruiting participants as Headway Ireland[10] acted as gatekeeper for this study. The term ABI was kept broad also to allow for traumatic brain injury and for non-progressive neurological conditions such as stroke, because stroke is also considered an acquired injury to the brain. While the injury and the subsequent outcomes or consequences of either a stroke or a traumatic brain injury may differ, often only slightly, in everyday living for the people involved, there are many commonalities and collective ABI issues which are the focus of this study. The cause of brain injury was not of analytical concern in this study. Although having many common disability issues, this study does not include particular issues dealing with people with progressive neurological disease such as Parkinson's disease or Multiple Sclerosis.

ABI is called a modern silent epidemic because as mentioned above, until recent decades, most people died with such severe injuries. ABI remains "a significant cause of death and long term disability worldwide" (Baguley, Slewa-Younan, Lazarus and Green, 2000, p.505). While impairment may be a human constant (Sheer and Groce, 1988), certain social causes of ABI such as car crashes or wars

[10] Headway Ireland, the National Association for Acquired Brain Injury, was the main community ABI service provider based in certain parts of Ireland when I commenced this study.

are increasing. Cultural and socio-economic issues often affect the cause and type of brain injury one sustains. Globally, "road-traffic accidents are a leading cause of death, injury and disability around the world" (WHO, 2007, p.3). Motor vehicle crashes are the leading cause of death globally for those between ten and twenty-four years of age (ibid, p.3).[11] This is due largely with their risk-taking driving and social behaviour. War injuries and assaults are also major causes of ABI. In the United States, of the 1.4 million people[12] who sustain a traumatic brain injury each year, it is claimed that 50,000 people die.[13] Blackmer and Marshall (1999) state that native North-Americans "are more likely to suffer a head injury than non-native North Americans and alcohol is more likely to be involved" (p.627). Firearm injuries however are more common amongst the more deprived groups in USA affecting mortality rates and injury severity (Dunn, Henry and Beard, 2003, p.1063). All children in the United States who fall and hit their head are now recorded as having a head injury, thus North American research is presently "directed towards attempts to reduce the very large numbers of CT scans being performed" (NICE [14] Guideline 2003, p.25).[15] In Scotland, alcohol and assaults rather than road traffic accidents or falls were the main cause of the brain injury for people from the most socio-economic deprived areas (Dunn, Henry and Beard, 2003, p.1060).[16] Sports injuries are another major cause of brain injury and this does not include the obvious category of boxing. For example, Marchie and Cusimano (2003) state that bodychecking in the game of ice-hockey is a major

[11] The World Health Organisation (WHO) drafted a *Report on Improving Global Road Safety*, 24 March, 2008.
[12] Retrieved 15 February from http://www.cdc.gov/hiv/25.htm
[13] The International Brain Injury Association state that an estimated 5.3 million Americans are living today with disability related to TBI (www.internationalbrain.org/content.php).
[14] UK National Institute for Health and Clinical Excellence is responsible for national guidance on care or intervention of health conditions. Example: Head Injury Guidance 2007, Stroke 2008.
[15] National Institute for Health and Clinical Excellence (NICE) Clinical Guidelines 2003 updated CG56 Head Injury. 26 September 2007. Retrieved 11 April, 2008 from www.nice.org.uk .
[16] This population therefore presented to Emergency Departments 'out of hours', their clinical assessment was confounded by drug use, and as they self-discharged, they were less likely to be seen by a consultant in Accident and Emergency.

factor in the rising incidence of traumatic brain injury in Canada (p. 97 and p.124).[17]

Away from the playfields, roads and streets to the battle fields, the American Army and the British Ministry of Defence are debating what exactly constitutes mild traumatic brain injury (mTBI) (Taylor and Addley, 2007. p. 11). In the United States, a representative of the American Army stated that as many as twenty per cent of their personnel on the frontline of the Iraq war may be at risk of this injury which could be caused by shock-waves from explosions. The British defence officials are reluctant to agree with this, arguing that the classification of mild traumatic brain injury and the science is inconclusive. In addition, the British experience has been different (ibid, p.11). Diagnosing people with post-traumatic stress disorder occurs however more quickly and often quite easily in the United States, even before a normal grief reaction time to trauma has lapsed (Smith, 2003; See also Moynihan and Cassels, 2005, p.31).[18] Location at time of injury is another important factor because for many trauma incidents, the initial urgent body work starts at the roadside or in the home. For those with serious brain injury, it is urgent that access to emergency or intensive care is gained quickly (NICE, 2007, pp. 42- 44), yet many pre-requisites, such as brain injury awareness, are required at local level even before one gets to a major Trauma Centre.[19]

People with ABI in Ireland

The total population of people with ABI in Ireland is not known,[20] and thus the number for the focused area, counties Cork and Kerry, was not available at the start or at the end of this study. Using Hospital In-Patient Enquiry Scheme, 2002 data, Headway Ireland (2002)[21] stated that 10,163 people were admitted to Irish

[17] The age limit for body-checking in ice-hockey is now reduced from the age of eleven years to nine years.
[18] The British Army allow their personnel one month back home with friends and family before any assessments occur. Incidence of reported stress levels is therefore much reduced.
[19] Cork University Hospital is the only Level 1 Trauma Centre in Ireland.
[20] Population of Ireland is over 4.2 million (CSO, 2007). See p. 35.
[21] Headway Ireland was the main community service-organisation providing social and vocational training and counselling ABI services in certain parts of Ireland when I commenced this study.

Hospitals with traumatic brain injury.[22] But, only 3,323 of these people were coded specifically as brain injured. Another 6,471 were classified as people with stroke, brain haemorrhages or tumours. Headway Ireland state that:

> By studying the data from a number of other countries and basing it on the Irish population, we estimate that between nine-thousand and eleven-thousand people sustain a traumatic brain injury annually in Ireland, with a further seven thousand being diagnosed with a stroke. Additionally, we estimate that there are up to thirty-thousand people living in Ireland between the ages of sixteen to sixty-five with long term problems following brain trauma (Headway Ireland Website Homepage, 2008).

Peter Bradley Foundation,[23] another new ABI service-provider, state that in Ireland "over thirteen thousand people per annum acquire a brain injury and of these ten thousand are admitted to hospital with significant injuries" (PBF, 2008). Thus, the figure of ten thousand new people with ABI every year in Ireland seems to be the commonly accepted number used by service-providers, policy-makers and people with ABI. This remains a broad figure and good guess data and needs to be checked and analysed further for clarification. The coding processes involved between disease of the central nervous system, skull fracture and superficial head injury, etc., and the categorisation of hospital data, make this a difficult and contested project. Figures are therefore based more on hospital discharge figures than actual brain injury categorisations.

The causes of ABI vary. In Ireland, poor driving along with drinking or drug use, and the fact that provisional drivers are allowed to drive alone, have contributed significantly to the very high numbers killed or seriously injured on the roads. The Road Safety Authority state that pedestrian alcohol was also a factor in thirty-eight

[22] This scheme is commonly called HIPE data.

[23] See Appendix 3 for a brief summary on Irish ABI service-providers.

per cent of fatal pedestrian road crashes in 2006 (RSA, 2006, p.1). Three hundred and thirty three people died on Irish roads from June 2006 to June 2007 (RSA, 2007). Assaults to the head in gang or group fights, resulting in head trauma is another major change in contemporary social behaviour. Irish people on radio phone-in programmes discussing the violence on our streets on week-end nights, are frequently heard to say, *yes fights occurred in the past, but kicks to the head were just never done. If a guy was down, you didn't touch him*. In the small Irish midlands health area[24], Kiernan (2003) stated that each year, there are an average of six-hundred and twenty-five strokes[25], five-hundred and seventy road traffic accidents[26], with two-hundred and fifty traumatic brain injuries in 2001. In counties Cork and Kerry, the site of this research study, there is a total population of 481,295 in County Cork (with 119,418 in Cork City) and 139,835 in County Kerry (CSO, 2007). (See Map on next page). Extrapolating data from the state of Victoria, Australia, (as this state has a population of 4.5 million similar to that of Ireland), it is estimated that

> 1,250 additional people will experience ABI in Cork and Kerry this year [2007]… and eight per 100,000 (forty people in Cork/Kerry) will be within the severe-very severe range of ABI. (HSE (South) ABI Project Planning Group, 2007, p.12).

The debates about the classification of ABI, TBI, head injury and neurological disorders continue. But these controversies on terminology are not always made clear when discussing ABI statistics or issues. Different professional groupings use any of the available classification systems for various purposes. High numbers are often used when seeking new services and new specialists. For example, numbers with brain 'issues' often appear very high because people with migraine are included. Migraine headaches are now sometimes classified as a 'brain disorder' (Houston, 2007; McHugh, Murphy and Sobocki, 2007). Migraine, the

[24] ABI community services are now quite well developed compared to other parts of rural Ireland.
[25] Twenty-two point five per cent of these people with strokes are less than sixty-five years of age.
[26] The average age of people in these car crashes was twenty-eight years old.

commonest neurological condition in Ireland (Murphy, 2008), is included in discussions and awareness projects about acquired brain injury.

The Neurological Alliance of Ireland, co-ordinators of Brain Injury Awareness Week 2008, claim that there are "currently up to 700,000 people living with neurological conditions in Ireland" (NAI, 2008, p.1).[27] The focus in this study is on people who self-report enduring problems because of a sudden–onset serious injury to the brain, and live in Counties Cork or Kerry, Southern Ireland. [28] See map overleaf.

[27] Migraine now affects over 500,000 people in Ireland (Murphy, 2008).
[28] Sudden-onset conditions are one sub-category in the UK NHS *Service Framework for Long-term neurological conditions* (Department of Health, 2005, p. 9).

Figure 1.1 Map of Ireland highlighting Counties Cork and Kerry, the location of this study.

Source: Department of Geography, University College Cork.

Some Outcomes of ABI

There are many studies available on the outcomes following an ABI from the nano physiological changes in the brain to community reintegration. Women demonstrate a better early outcome than men (Slewa-Younan, Bagueley, Heriseanu, Cameron, Pitsiavas, Mudaliar et al., 2008), yet the outcome of ABI for both genders includes many changes. These include changes in the personal, occupational and sexual self (Abreu, 1998, 2006; Dombrowski, Petrick and Strauss, 2000; Fleming, Lucas and Lightbody, 2005; Gosling and Oddy, 1999; Krefting, 1987; Newman, 1984; Oliver, Ponsford and Curran, 1996; and Priganto, 1999). [29] The embodied self and the reflexive self undergo change, as for example, memory impairment impacts on daily occupation (Erikson, Karlsson, Borell and Tham, 2007), along with a difficulty coping with sarcasm (Shelley, Pellijeff and Rule, 2005). With the ripple effect, the family changes (Douglas and Spellacy, 1996; Heary, Hogan and Smyth, 2003; Hop, Gabriel, Rinkel, Algra and van Gijn, 1998; McCabe et al., 2007; Paskiewiez, 1988 as cited in Moustakas, 1994; friends change (McColl et al., 1998; Patterson and Stewart, 2002) and work-colleagues change (Rubenson, Svensson, Linddahl and Bjorklund, 2007). A small number of people with very serious brain injury may always remain however in a persistent vegetative state (PVS). According to Headway UK (2008), there are normally just less than one hundred people in the United Kingdom in persistent vegetative state at any one time. In a study by Berlins (2006), some people in persistent vegetative state have been 'woken up' for approximately two hours per day with the sleeping tablet Zolpiderm (Berlins, 2006, p.11). If this drug continues to 'wake-up' certain brain-damaged patients for longer lengths of time in the future, ethical health workers still have much to consider regarding their rehabilitation back into society and consider what kind of life awaits them (Singh et al., 2008).

[29] Many of the issues and needs of people in older studies are still relevant for people with ABI today.

Living with all these changes, requires many individualised interventions and services[30], some of which may be needed for a long period of time, along with work at family and community levels. Even after eight to ten years living with ABI, the self-reported symptoms specific to mild brain injury include dizziness (physical), difficulty dealing with people (behavioural/affective symptoms) and five specific cognitive symptoms, including reading, writing or doing maths; learning new information; being easily distracted; losing your train of thought and forgetting things you have done (Gordon, Haddad, Brown, Hibbard and Sliwinski, 2000).

The term 'brain injury' as with other diagnoses or labels can impact on social acceptance and the attitudes of others in the community. Although the diagnosis itself is not responsible for social consequences, Simpson, Mohr and Redman (2000) found that for a group of Vietnamese living in Melbourne, the label ABI brought shame. The perceived association of brain damage with madness brought shame not only upon the person with the injury, but upon all of the family. Thus the psycho-social responses to ABI are varied, reflecting the uniqueness of personal, social, economic and cultural situations. And with all acquired major impairments, it is important to remain flexible in interpreting a person's response or adjustment to ABI. The impact of an ABI is not static with much recovery possible over time compared to spinal injury or a limb amputation which, following recovery from trauma or surgery, are mainly fixed or stable body injuries. Other neurological disease such as multiple sclerosis is progressive with change occurring over time often experienced in a negative manner.

Research methodologies and ABI

Clinical research on the acute and rehabilitation stage of ABI dominates the ABI literature and although vitally important, this needs to be balanced with community and socio-political research projects, beyond the rehabilitation

[30] Details on clinical neuro-rehabilitation are discussed in Chapter 2.

environment and beyond studies using methodological individualism.[31] As it is quantitative research that dominates the world of medical and paramedical professionals, it is not surprising therefore that most researchers use empirical scientific standardized tests and/or assessments to measure the targeted activity, deficit area or outcomes being tested. The situated context of the patient, the test setting, issues that may impact on the standardisation of the test, differences in time and cultural place and contested meanings are generally explained away in statistical studies. Yet this search for prediction, full generalization and validity continues, even on practices in the community that may not require and are not suitable for such testing (Malec, 2004b). Statistical studies have much to offer aspects of disability research, but much that captures my attention in this project, does not fall in the control predictable arena, but rather the social, family, and political contexts of living with ABI. This balance needs to be redressed with more use of qualitative person-centred research, notwithstanding the lower position of such studies in the dominant hierarchy of evidence (Boyle, 2000; Hyde, 2004; Pope, Mays and Popay, 2007).

One seminal ethnographic study by Krefting (1989), *Reintegration into the community after head injury: the results of an ethnographic study,* highlighted the need for more personal narratives about the experiences of living in society with ABI. The told experiences of disabled people themselves helped develop the social model of disability, and how disability is represented, researched and responded to. As discussed later in Chapter 4, illness and/or disability narratives by disabled people are widely available today and not only within disability studies or sociology. These scripts or studies have a function not only for the narrator, but also to add to or challenge the evidence-base of professionals working in various disciplines. There is also a considerable amount of literature available today on methodological issues involved in disability research, narrative analysis and the analysis of narratives. (See Chapters 3 and 4).

[31] Methodological individualism is discussed in section 1, Chapter 3.

My initial broad research aims and questions

Having broadly discussed acquired brain injury, social causes of ABI, problems of categorisation, some of the outcomes of an ABI, etc., the aims of this exploratory research are to:

1. interpret narratives of personal experiences of disability from adults living with ABI;
2. explore theoretical issues linked with theorising disability and the application of this theorising for people with ABI; and
3. provide some new insights for policy-makers and service-providers in this sector.

To allow for participation of the participants in this research process, as much as was possible, I did not have one definitive starting research question, but rather many broad sub-questions. These included: how do people cope with or enjoy living with ABI here and now, many years after their brain injury? What are the trends and patterns contributing to the social construction of disability when living with ABI in southern Ireland today, adding to their body differences caused by the actual injury itself? [32] And how do people with ABI manage all this? This research also aimed to help challenge assumptions, fixity and over-essentialising of categories often used about people with ABI in much of the ABI literature.

In summary, my study links personal issues with collective issues, reinterpreting personal stories with/through public narratives. An introduction to my broad research framework and broad research themes are briefly described in the next section below, with details on methodology discussed in Chapters 3 and 4.

[32] The body-social or impairment-disability dualism is hotly debated today in various disciplines.

1.2 RESEARCH FRAMEWORK

This study aims to interpret the relationship between the individual lives of the participants and their social contexts, to identify general patterns and to generate insights and broad social explanations of the social processes involved in living with ABI. As much as possible, I have sought to include the socio-political discourse among disabled people, allies and activists, in reframing the experience of disability. Discursive practice in itself will not provide or change all that is required by the disabled person and their family. Discourse affects our words, language, meanings, categorization and boundary formations, thereby impacting on research, social mechanisms, public imagery and the understanding of how disability is produced and represented. The dominant discourse in assessments, policy documents and rehabilitation literature impacts on the evidence allowed for evidence-based-practice. This in turn can impact on the patterns and tendencies of the development of the personal identity of a disabled person. The researchers' theoretical, ethical and methodological positions are intertwined with and can impact on the ethical issues and findings of all research, especially disability-social research. Given the research topic under inquiry, my theoretical framework is broad and complex. This involves the self and the collective, tradition and change, individual agency and social structures, power and suffering, inclusion and exclusion. My overall theoretical framework involved working within three main areas:

1. theorizing social reality and knowledge;
2. theorizing embodiment of living with ABI embedded in Ireland today; and
3. theorizing disability, participation and disability services, especially occupational therapy.

Even though my aim was not to develop a theory, I do use, critique and contest many middle-range theories and the various ongoing debates within my own

profession and within the disability sector in general. My contribution to the above areas is located throughout this thesis, with a brief thesis plan outlined at the end of this Chapter.

Emancipatory, critical, participatory and empowering research were important key concepts in this research process. I have attempted to critique and hold onto many of the issues involved in such research throughout this particular study. I have enjoyed getting lost in the 'messy reality' with the participants, while at other times I got lost in the literature. Such abduction, similar to that sought by Canadian occupational therapists today in everyday practice (CAOT, 2007), [33] can be useful yet we cannot always work and research within fuzzy boundaries. While recognising the benefits and limitations of all research, I frame this within critical and emancipatory research work. Thus, this disability research, while not seeking improved definite practice guidelines, might be considered emancipatory, meeting the criteria for such research as indicated by the Irish National Disability Authority (NDA, 2004), Watson (2004) and others. This criteria state that a participatory research methodology within the broad social model of disability should be used if possible, and that a text-book response to the impact of impairment/disability in the lives of the participants is not assumed. While acknowledging that emancipation is not something I can 'offer' people, I did accept and use the latter criterion and allowed as much as possible for the former, given the demands of the academy and my personal situation**.** The theoretical social model of disability, even as contested, informs this study at a deep level, and not at the superficial level which Hammell (2007b) claims occurs more often by occupational therapists. The social model of disability is for me linked to the person with the impairment because 'the tired brain' or 'the leaky body' is always with us, even if disablism is not.[34] Further details on my research design and above issues are in Chapter 3. Humphries, Mertens and Truman (1999) state that there are four

[33] Canadian Association of Occupational Therapists.
[34] While the social causes of disability may be removed, physical body issues may remain (Asch, 2001).

elements in the framework for the process and outcome of emancipatory research. These are:

1. locate the self in the research process in terms of personal, social and institutional influences on the research and analysis;
2. explore the political power dimensions of empowerment;
3. be explicit about the tensions that arise in research and relate as much about how the tensions remain as about how they were resolved; and
4. link research to wider questions of social inequality and social justice. (p. 13).

Most of these elements are interwoven in this study, remembering that researchers not following such a methodology can also immerse themselves in the context of their research, explore the power issues involved and link their work to wider issues. Critical realism, the main metholodogical theoretical framework informing this study and the role of narrative is detailed in Chapters 3 and 4. Critical realism does not accept the incommensurability of various theories, thus I work on the assumption that shared meaning if not present at the start of a research project or in practice, can be developed or negotiated. Critical post-structuralism postmodernism also offered and continues to offer theoretical challenges which I admire and use at times. But inequalities, power struggles and the structure-action dialectic are very important to me. Thus, I do not replace substance with style, or reject political discourse or the possibility of radical social change (Aggar, 1991, p.198). Aggar claims these perspectives can and do occur in the world of possessive individualistic postmodernism. How people interpret my interpretations in the final text is in the hands and minds of the reader. This may not be 'emancipatory' or challenging enough for some people, while it may be quite challenging for others. But the use and dissemination of this research is also important. It is hoped that this study will challenge some of our existing stories and theorising about people with ABI and about neuro-rehabilitation. This is not

to discredit what exists, but to conserve and perhaps refine the processes “through the ongoing process of scientific elaboration and critique” (Norris, 1996, p.162).

Giving voice to oppressed or excluded people is not sufficient, because not all knowledge exists in the words of any category of research participants. But this is an important place to start accepting that people are not determined by their meanings shared in one research project (Skeggs, 1997; Smith, 1999). I grant epistemic status therefore but not epistemic privilege to the particular knowledge and experiences of the participants in this study. They are not expected to know vast areas about ABI only because they have, own, or live with this real injury. These participants are granted ontological status or depth because they have had to deal with their own brute facts and social facts about ABI. They have a very brute real injury, a major disruption in their adult lives which has caused essential differences to their lives. Their personhood was reduced by varying degrees and for varying lengths of time.

Some claim, however, that experience cannot be studied, and that only language or discourse (representation) is studied, because experience is mediated in or through language. But as Csordas (1994, p.11) has replied, “language gives access to a world of experience in so far as experience comes to or is brought to language”. Based on Hiedegger’s work, language ‘discloses’ our being-in-the-world, accepting also that collective embodied experience can be and is also discussed in communal life (Becker, 1999, p.13). People with severe cognitive and multiple impairments may be unlikely to get very actively involved in disability politics, but they or their advocates must still be included in our theorizing and in equality or justice work (Kittay, 1999, 2002). In this study, the participants’ injuries and experiences are not dependent on me labelling or naming them. They have been already named, just as certain historical and structural practices are handed to them, and not of their own making, as Marx told us. Plus their social reality is not created only, or totally, by discourse or social structures. Focusing only on these limits and demeans the agency of humans.

I am aware of the partial power I do have and that which I do not have over the final representation. Various power issues in the research process were minimised as much as possible starting with any words I used. Everyday language was used. Ongoing power issues between the participants and I were reflected upon often during this inquiry, but not on every social or subject positions that they or I possess (Smith, 1999). I could only try and control within reason where I am involved in their lives, i.e. a brief and intermittent research relationship, notwithstanding the rapport that developed through our multiple meetings.[35] This study therefore links in with the 'outside-in approach to disability scholarship and research' favoured by Barnes, Oliver and Barton (2002, p. 258). In this approach, the disability movement and the academy need to work together to improve knowledge about disability and the integration of disabled people in an inclusive society. Demands from the academy, including University guidelines for a PhD thesis, and from disability research ethics, personal finances, dependents, time and geography all played their part in shaping this inquiry, and therefore also had power over me and this inquiry. (See also Moore, Beazley and Maelzer, 1998).

Justification for the need of this study

The limited ABI research in Ireland focuses more on needs assessments of people with ABI or professional-led knowledge construction for evidence-based clinical-rehabilitation practice. Most resources are placed within acute clinical or neuro-rehabilitation practice issues: that important first stage of care in the ABI pathways of care. Needs assessment studies in Ireland have been carried out by the Midland Health Board (Kiernan, 2003), the North Western Health Board (Keenaghan, 1999), and ABI planning reports such as South Eastern Health Board Report (SEHB/HSE 2004). The local Health Services Executive (South) have, through their ABI Planning Project Group, completed in January 2007, their first plan[36] for future community-based ABI services. A National Rehabilitation Plan for people

[35] I meet four of the participants regularly through my involvement with BRÍ. BRÍ is a new Irish ABI advocacy support group established in Dublin in 2003. See Appendix 3.
[36] On behalf of BRÍ Cork, I was a member of this ABI Project Group for the duration of the project, i.e. throughout 2006 to February 2007.

with ABI is under discussion also. Other major studies in Ireland include *Living with an ABI during Childhood and Adolescence: An Irish Perspective* (Heary, Hogan and Smyth, 2003) and an epidemiological study on people with traumatic brain injury at Dublin Hospitals one year post-injury (Gaigean, 2005). Major service-providers such as the National Rehabilitation Hospital, Headway Ireland and Peter Bradley Foundation carry out their own internal audits and reviews and publish some needs assessments and self-help materials.[37] Most of the above studies are within the framework of a needs analysis within a bio-medical framework, although carer and sibling studies are emerging. This is reflected in the small but growing number of requests received by BRÍ from post-graduate psychology students seeking participants for their research.

As mentioned above, qualitative research, beyond needs assessments, is required where the focus is more on issues starting from people's own accounts and their agency. Self-report studies by people with ABI themselves are however still regarded as suspicious or not reliable while, almost from the start, explaining qualitative research itself was also an important part of this research journey. At my first formal meeting with a high profile leader in the ABI sector in Ireland to discuss and negotiate this research, the first question asked of me was, what was I testing? (I was not testing). There is also a lacuna in local academic literature about the nuanced complexity of long-term living with ABI that could include positive stories as well as stories of oppression or discrimination. I have not located any local study with a longitudinal aspect, using such a methodology framed within a disability rights perspective. Therefore, the research story on ABI in Ireland today, limited as it is, needs to be balanced with additional studies such as this one, inquiring about life beyond the first five years of living with ABI.

This study and all of the above work is written within the context of progress or otherwise within ABI services and ABI discourse in Ireland today. As this thesis is about particular issues based on the told and lived stories of a small number of

[37] A brief introduction on these main service providers or agencies is in Appendix 3.

Irish people living with ABI, some generic contextual issues of contemporary Ireland, the location of this study, are presented next.

1.3 THE LOCAL CONTEXT OF THIS RESEARCH

This section aims to give a snapshot of the rapidly changing society in which the research participants and the researcher live. I introduce some points about Ireland in general and then some disability issues in particular.

Ireland, now in 2008, a member of the European Union, with a population of 4,234,925 persons at the last census, has moved into a more vibrant intercultural society. The main new immigrant group of people living in Ireland are those from Poland, 62,674 people in 2006 (CSO, 2007).[38] Ireland also has an increasingly ageing population, with eleven per cent of the population aged sixty-five and over in 2006 (CSO, 2007). Yet, Ireland still has the lowest proportion of its population aged sixty-five and over among European Union countries, and is well below the European Union average of nearly seventeen per cent. Male life expectancy is catching up with female life expectancy.[39] Therefore, once the age of sixty-five years is reached by Irish men and women, we have higher life expectancies than the European Union averages, in spite of all the controversies regarding our present health care services. There is at present a sense of general malaise in our health services, especially in the Emergency Units, in accessing hospital beds, and in the early detection of breast cancer. These are three of the most topical problematic health service issues and they have been a major topic of national debate throughout the winter of 2007 and the spring of 2008. (See also HIQA, 2008; Perry, 2008). Lack of clinical therapists created the opening of three new

[38] 2006 Census of Population Report.
[39] For males aged sixty-five, life expectancy has risen from 13.8 years in the 1990's to 15.4 years in 2001-2003, while women at age sixty-five have a corresponding increase now up to 18.7 years CSO, 2007).

Irish schools of occupational therapy in 2003, but yet, this same issue still makes headlines in the public media.[40]

Meanwhile, Ireland is/was one of the fastest growing economies in the developed world with our economy now transformed from being agrarian and traditional manufacturing to one based mainly on internationally traded and hi-tech services (ESRI, 2007). Unprecedented economic growth and social change, especially in the latter half of the 1990s, caused Ireland to be named the 'Celtic Tiger'[41] akin to the earlier Asian Tigers of Singapore and Taiwan. (See below for some current changes). Based on this boom, there is now an 'Irish social model' of development (Layte, Nolan and Nolan, 2007). Instead of emigrating, Irish people and thousands of others migrated in large numbers for the increasing employment opportunities. Better housing, greater participation in education, along with reduced absolute poverty and long-term unemployment are according to some writers indicators of recent social progress and economic growth in Ireland (See Ruane, 2007). Ireland moved rapidly into the ranks of being the fifth wealthiest country in the world (ESRI, 2007). Certain authors claim that there were five definite ingredients for our economic miracle. These five factors are European Union membership, foreign direct investment, low company taxes, social partnership and an abundant young English speaking workforce.[42] But Allen (2008) argues that these points could be rephrased "to suggest that US corporations came to Ireland to establish a base inside the European Union single market, and choose a location where taxes were low, wages were cheap, and the unions did what they were told" (p.75). Fiscal policies such as very generous tax incentives for entrepreneurs and artists also assisted our economic boom. Economic development was expected to drive and manage all other required change. But much of our wealth was based on our Gross

[40]For example, 'State failing Down's syndrome girl'. O'BRÍen, *Irish Examiner*, 11 April, 2008, p, 1.
[41] Term coined in 1994 by Kevin Gardiner of the US investment bank Morgan Stanley, cited in Smith (2005, p. 37).
[42] For example, Sweeney (2008). *Ireland's Economic Success*.

Domestic Product (GDP)[43] figure which includes those substantial profits made by foreign multinationals, much of which is repatriated. Thus, the real figure based on our Gross National Product (GNP)[44] figure, gives a more realistic picture (ESRI, 2008). This lower figure also explains why our open economy is very influenced by global markets and trading, especially by events occurring today in the United States economy.

The above economic and social development was informed by and dominated by one single version of economics however, the neo-liberal model (Higgins, 2006). Neo-liberal economics stress the supremacy of markets as mechanisms of social distribution of goods, services and incomes which involves privatising public companies, including health care.[45] Most of these are the elements which have been and are promoted by the present government, who have been in office for the past eleven years. Glavanis-Grantham (2008) states that this neo-liberal agenda "has been actively pursued and its logic deepened in Irish society" (p.103). Regarding health services, the privatization project of health care is one such strategy currently being pursued by the Minister of Health and Children (Mary Harney, TD) and the Health Service Executive. This is often referred to in the media as part of the overall Boston-Bonn debate.[46] While Ireland always had a certain amount of privatisation in health and social care services, including the use of public beds or surgeries for private patients, etc., the present major co-location of hospitals project, is, "a developer's dream" (O'Connor, 2008).[47] Other opportunities within the Department of Health, for those not suffering sickness, but for developers, include accessing tax breaks for building Nursing Homes, encouraging, perhaps, some rogue traders and managers. The entrepreneurial

[43] GDP a problematic economic measure often used as a measure of a nation's income. (See Fahey, Russell and Whelan, 2007).
[44] "GNP adds factor income received from the rest of the world to GDP, and deducts factor payments flowing from Ireland to abroad" (Nolan and Maitre, 2007, p. 28).
[45] For more details see Clarke and Newman (1997), O'Hearn and McCloskey, 2008.
[46] This is a common metaphor used in local media to describe health planning, on a socialised Bonn model or the American Boston private model. For details, see Tussing and Wren, 2006.
[47] Marie O'Connor (2008). '*The project of privatization of health care in Ireland'*. Paper given at University College Cork, Ireland, 5 March.

activities of private voluntary hospitals, consultants and the use of the National Treatment Fund,[48] also impact on public monies, and therefore need to be included in this debate (O'Connor, 2008).

This debate about for-profit private-public health care stresses higher productivity and deeper managerialism, which generally attacks the costs, effects and the problem of the welfare state itself, including public medicine (Clarke and Newman, 1997). And in the name of improving quality, detailed accountability and increasing bureaucracy are sought, which also impacts on all public services. While some of this may be desirable, Perry (2008) states that with regard to the health sector, "the quality revolution will, paradoxically, require us to confront the limits of health care" (p.2). When appraising quality of the health service, Perry reminds us to include the incidence of medical errors and the fairness of the system, as well as the feedback from the patient's experiences of the system. Layte, Nolan and Nolan (2007) do agree that there are "[c]onsiderable improvements in health of the Irish population in terms of indicators such as death rates and life expectancy" (p.122). This sentence continues by these writers to state "but this trend began well before the onset of the economic boom".

For Tussing and Wren (2006), the "inequalities in [the Irish] health and life experience are mirrored and compounded by a health care system in which access to care is determined [generally] by income rather than need" (pp.40- 41). But in comparison to the situation for people in the United States who have no health insurance, as presented lately in the documentary film *Sicko* (2007),[49] at least accessing trauma care within the Irish acute health service is fairer. All people here can attend at any Emergency Department and are given medical attention regardless of income. Waiting time for less-urgent cases is problematic, however. Equity throughout the rest of the health system needs to be improved and is one of

[48] This agency was introduced in 2002 to reduce waiting lists for public patients awaiting surgical procedures. This fund manages the sourcing of treatments in private hospitals.
[49] A nuanced documentary movie on the American health care system by Michael Moore, American Film Producer.

the main elements of the programme for change and quality (DoHC, 2001). The above researchers Tussing and Wren claim however "that the Irish services [are] in crisis" (ibid, p.331). And the Boston model being actively pursued to improve the quality of our health services, may also create some unintended consequences while bringing in certain improved outcomes. For me, increasing managerialism, accountability, profit-making and professionalisation of rehabilitation services and of the everyday life-world, may not enable people with ABI in their community participation.

With all the recent developments and current plans within neo-liberal development, many social and equality issues are neglected here (Combat Poverty Agency, 2007). While Ireland may have greater numbers in the higher income brackets, in further education, and in employment, at least at this time of writing, inequality and the actual gap between the 'haves' and the 'have-nots' has increased. Today, seventeen per cent of the population (777,000 people) are at risk of poverty and seven per cent (290,000 people) in consistent poverty (Combat Poverty Agency, 2007).[50] Certain social groups, e.g. lone parent families, people with impairments or immigrants, have higher poverty rates than the rest of the population, but at least the situation for older people has improved[51] (Combat Poverty Agency, 2007). Improved education of the Irish population was also an important mechanism for the above transformation. There are more people in Ireland today with PhDs (Higher Education Authority, 2008),[52] yet one quarter of our population between the ages of sixteen and twenty-five, are functionally illiterate (CORI, 2008; O'Brien and O'Fathaigh, 2005, p.8). Rural communities and small medium enterprises were not enabled either in the past as much as the multi-national corporations or millionaire tax-exiles (See Fahey, Russell and

[50] Poverty Threshold is sixty per cent of median income equal to an income of below €202.49 per adult per week in 2006.
[51] The risk of poverty for older people has fallen from twenty per cent in 2005 to fourteen per cent in 2006, while the rate of consistent poverty for this group has decreased from four per cent in 2005 to two per cent in 2006
[52] The Higher Education Authority state that there were five hundred and fourteen graduating doctorates ten years ago. Over one thousand doctorates are to be awarded for the first time, in 2008.

Whelan, 2007; Higgins, 2006 and the homepage of the Department of Community, Rural and Gaeltacht Affairs website).

The numerous intended and unintended consequences of modernisation, individualism, urbanisation, and materialism on personal, family, and community life, impacts on people living here with ABI. Some of these issues may be noted throughout this thesis, but most are beyond the scope of this thesis. They are well documented elsewhere. (See CORI, 2008; Fahey, Russell and Whelan, 2007; Hyde, Lohan and O'Donnell, 2004; Kirby, 2002, 2005; Quin, Kennedy, O'Donnell and Kiely, 1999; Quin and Redmond, 2003; Wren, 2003). Yet, many questions remain.

Ireland may indeed be doing very well on many indicators of 'development', but what then can be said about the 'quality of life after the boom' asks Fahey, Russell and Whelan (2007, p. 3). Are all boats lifted up or only those of millionaires or the very rich? Is it better that we reach or aim to reach management targets and global best practice in various domains of service, but do not have time to talk, laugh and/or cry together in our homes?[53] It is hard to give a definite answer to this question and this thesis does not need to, but according to Fahey et al. there are many difficulties involved when trying to decide about the costs and benefits of our Celtic Tiger. First, there is the 'cultural relativity problem' as to what really constitutes social progress. For example, is it best for us that the role of religion has reduced or that we have a more liberal attitude to sexuality today? Second, there is the 'apples and oranges problem' when trying to balance the different dimensions of progress. Education for all has increased, but crime figures have also gone up. Third, there is the 'ambivalent good problem'. People now have access to their own car for personal mobility, but this causes congestion and negative environmental factors. Finally, Fahey, Russell and Whelan (2007) state there is the 'ignorance problem'. We may be actually ignorant of what really did

[53] See Leahy (2008) *Wasting Time with People*? in which a cross-section of contemporary Irish figures write about the importance of spending time with people during our lives and not only in retirement or on our death-beds.

happen before the boom. Thus, it is hard to say if there has been much change or progress in Ireland and if so, how much. In summary, and as these writers conclude, "at a minimum, Ireland now has the least worst of times- things may not be good everywhere, but on balance they are not as bad as they used to be" (p.10). The Conference of Religious Groups in Ireland (CORI, 2008) report that by including poverty indicators, Ireland is ranked eighteenth out of the nineteen industrialised countries as reviewed by The United Nations Human Development Index (2007). (See CORI, 2008).

The Celtic Tiger appears to be downsizing today to becoming a celtic kitten, a process that is actually required according to dominant economic theory.[54] And with globalisation, multi-national companies, like the absentee landlord of long ago, with little or no commitment to local issues, can now move on to new cheaper under-developed economies, without little if any local regard. Our unemployment rate is now on the increase while our industrial sector is in major transition as our construction industry, the main stay of our economy from 1997 to 2007, has slowed down. The current lull in house prices may be welcome relief for many trying to enter the housing sector, but not for those employed in this sector, and/or for our Minister of Finance. Many of the above trends have occurred or are occurring on a larger scale in other industrialised countries, and therefore Ireland is considered to still have a good quality of life. In the Quality of Life Index by *The Economist Report*, Ireland gained first place in 2005, which attracted many people to migrate here. However, many downward economic changes are occurring nationally and globally at the time of writing.

Ireland continues to have a good network of local communities, parishes which underpin community living for thousands through church membership or GAA[55] membership. This local unit of socialisation provides thousands of people with a

[54] Standard economic theory cautions against continuous raising of the cost of living. And as house prices in Ireland were spiralling 'out of control', a lull or dip in this market was required.
[55] Gaelic Athletic Association is the organization responsible for managing the traditional voluntary Irish sports of camoige, hurling and gaelic football.

sense of place and a sense of belonging which is must sought after by other countries (Putnam, 2007). Many migrants feel at home here, sometimes because of the link with the catholic church. Ireland comes out high on international happiness and quality of life surveys. There are considerable new social movements here enabling social inclusion, such as anti-racism, environmental and gay mobilisation (Connolly and Hourigan, 2007). Ireland also has had a history of direct or indirect action through many 'old' social movements, such as the Credit Unions, Irish Countrywomen's Association, the GAA, and social action by the main church organisations. Social Partnership Programmes[56] between various population and employment groups and government agencies are aiming to provide fairer social development for all. For everyday leisure, for example, in Cork city there are now projects working on Access for All, Art for All, and/or Playgrounds for All projects (See homepage of Cork City Partnership website; Community and Entreprises / Community Development links). Aspects of the social partnership programmes and processes, especially those linked with sustainable long-term real change, are critiqued by numerous community development workers, activists and/or theorists. (See Allen 2000, 20007; Combat Poverty Report 2006; Connolly and Hourigan, 2006; O'Donovan, 2000).

Disability Sector

This is also a time of major transition for the disability sector in Ireland linked with the tensions, difficulties and the benefits involved in the above changes in society as well as in the operationalising of disability legislation, for example, The Disability Bill.[57] (See more on this sector in Chapter 8). Counting disabled people in Ireland commenced in the Census 2002. Census 2006 reported 390,153 persons (CSO, 2007), although Layte, Nolan and Nolan (2007) state that levels of disability have fallen significantly between 2000 and 2004 for the Irish population aged sixty –five or more (p.112). The required two-pronged approach to managing the assets and needs of disabled people aims to provide both the required

[56] For Partnership Projects in Cork City see www.corkcitycouncil.ie

[57] After years of debate, the Disability Bill was finally accepted by the Oireachtas, Houses of Government in 2004, and became a legal instrument on 5 June, 2007.

individualised services, while also seeking to or improving inclusive opportunities or services. Implementation of the Disability Bill is today only required for children from birth to five years of age, but improved funding for other major developments in the intellectual disability sector has commenced.[58] Independent or supported living units, care packages, etc., although still insufficient, are becoming more available and/or the norm in our disability sector and practice today. The new Irish Mental Health Act (2001) is also bringing about slow but important changes for people with mental health needs. Further legal developments include improved access to information, and to peer advocacy for all disabled people in Ireland.[59] (This is discussed further in Chapter 8). Problematic areas remaining are defining 'disability', managing complex appeals systems, the lack of a disability audit in all government departments, and finally, insufficient funding and problems in accessing scarce specialist support services. The prohibitive costs of meeting all rights of all disabled people as citizens block the inclusion of rights-based legislation in the present Disability Bill. Instead, incremental progress and enforceable entitlements are the focus of service developments.

Brain injury services

Regarding brain injury services in particular, there are certain support services in existence, but most are all underfinanced and understaffed, thus offering only a limited and generally a disjointed pathway of care. People with acute ABI from the six[60] southern counties go first to the neuro-surgical ward in the Cork University Hospital**.** Other acute brain injuries are treated in Beaumont Hospital, Dublin. Acute basic rehabilitation is available unofficially for a very short period in such units as "an acute surgical ward is not appropriate for those needing rehabilitation" (Marks, 2003).[61] Regarding clinical rehabilitation, Mark Delargy, Senior Medical Rehabilitation Consultant in the National Rehabilitation Hospital[62], once stated

[58] Major financial investment has been made in the intellectual disability advocacy, housing and education services (See Comhairle, national advocacy agency. www.comhairle.ie and Chapter 8.
[59] The Citizen Information [Advocacy] Bill (2004/2007).
[60] Counties Cork, Kerry, Limerick, Waterford, Tipperary and Clare
[61] Charles Marks, Consultant Neuro-surgeon, Cork University Hospital.
[62] Dr. Mark Delargy, retired from working in the National Rehabilitation Hospital in 2007.

that "the first thing he has to offer people with ABI in Ireland is a queue" (Headway Ireland Conference, 2003, p.3). The Rehabilitation Hospital is the only residential medical rehabilitation centre in the Republic of Ireland for people with serious and ABI, spinal injuries and amputations. This hospital or rehabilitation centre[63], situated outside Dublin City, provides medical-neuro rehabilitation to people with complex disability aged up to sixty-four years only. However, only twenty-five per cent of people with ABI get the opportunity to go to National Rehabilitation Hospital (NRH, 2000), even though it is also the case that not all people with ABI need to go there. But for many people with ABI, especially those in Bri, it represents a place for a cure. For those who do get to benefit of the services of this centre, much of that benefit is often considered lost on discharge to home due to the lack of follow-up or few community support services. Their survey (NRH, 2000) reported that twenty-three per cent (n=16) stated that they received no treatment in the community. And, "seventy-eight per cent (n = 55) reported that they did not receive the precise range of services that had been recommended following discharge from the unit" (NRH, 2000, p. 9). This is to be expected given the small numbers of community therapists, social workers or personal assistants, available to carry on individual care planning, especially in rural Ireland.

Vocational and social rehabilitation programmes are also very limited here with work and pre-work training opportunities[64] available only in some of the main cities. However, new regional and community services are being developed with Headway Ireland, Peter Bradley Foundation and HSE services. (See also Headway Ireland,1987). These agencies provide specialised services, but a debate continues as to whether all staff in these agencies must be trained specially to work with people with ABI. The numbers of ABI resource-workers are also improving slowly with more advocates, social care workers and therapists in training and in employment. But many of these health or social care workers may not be

[63] This is a one-hundred and twenty-three bed medical rehabilitation centre.
[64] Headway Ireland, Rehab care and National Rehabilitation Hospital provide vocational training.

employed because of over-spending and/or mis-management of our health services, a daily topical point of public debate in our public media. To add to this, there is also scant public awareness on ABI in Ireland, with very limited localised information packages for new families today with ABI in their family.[65]

The above paragraphs provide a brief but relevant introduction to life and living in Ireland today, especially regarding the focus population of this thesis. Within the Irish disability movement, people with ABI appear silent or removed, whether by their own choice or by design from within, or perhaps this situation arose purely because of the historical specificity of this *new* impairment group. This absence was one trigger for this study as advocacy and everyday social living of people with ABI were seldom written about in 2003 when I commenced thinking about this study. The formation of new agencies along with developments in Headway Ireland may help to develop the public political voice of people with ABI themselves, but time, financial resources, management of inter and intra-disability group politics will also determine how these agencies proceed. And similar to the women's movement, and the disability movement, there is not one ABI voice. It is thus a very exciting time to be involved in this sector as many positive events or plans are happening, at least on paper, with the above. A little more about myself is now mentioned in the final section of this Chapter before providing the plan for the other Chapters in this thesis.

1.4 INTRODUCING THE RESEARCHER AND MY THESIS PLAN

Positioning myself in this study is only mentioned briefly as more about my personal perspective is discussed later when I talk about my chosen methodology and how analysis was carried out, as suggested by Fay (1996). Here the focus is more on how my consciousness of disability emerged and how I developed my conceptual commitments. Equalisation of opportunities was part of my everyday

[65] Peter Bradley Foundation and BRÍ held twelve national public awareness days in 2006/2007.

living growing up, although asking why such inequalitites existed was not always discussed in my middle-class home life and schooling.[66] But, action to reduce or remove inequalities is at least, one important aspect of Freire's conscientization process, his praxis for change. From my teenage years, volunteering with disabled youth and older people on monthly and annual clubs and holidays enabled various relationships to develop. Our joint visits to tourist sites, art galleries, pubs, church events, beaches and dancing were not patronizing caring situations, but pragmatic caring about and for each other in fun. Throughout my occupational therapy undergraduate education, and often with the same disabled people, and other various professionals and advocates, I participated in formal special interest disability advocacy monthly meetings, seeking social and political changes. This advocacy work, along with the fun work, was carried out within a voluntary agency of and for disabled people, one branch of the important emerging disability movement in Ireland at that time. Then, for four years from 1981,[67] when the Disabled People's International was formed, I had the privilege of working with one of the founding members of this international movement, Liam Maguire.[68] He and others in the disability movement, in the women's movement, and in the civil rights and development activists were my formative heroes.

Then, prior to commencing this PhD study having spent some years working in developing countries, and then as a full-time parent, I spent six months as a locum occupational therapist working with people with acute ABI in Cork University Hospital. This experience reminded me of and made me value the benefits of biomedicine. Many lives were 'saved' here while much caring and respect were also shared in this unit. However, the limits of individualised biomedicine and the lower status given to community health and social care, however, also became apparent during this time. Following a person's neuro-surgery or initial emergency care, and once able to almost walk and/or almost talk, our patients were often

[66] Participating in action on reducing inequalities for all were expected in my family home.
[67] The United Nations International Year of Disabled People (IYDP).
[68] Maguire was once Chairman Wheelchair Association and thus head of my employing agency where I worked as a community based occupational therapist/disability worker. Details on Liam Maguire's role in the disability movement in Drierdger (1989) and Toolan (2003).

expected to go home. For the neuro-surgeons, week-end visits home often assumed automatic discharge would or could follow. Perhaps this is why the Headway Ireland newsletter (Summer 2003) stated that neuro-surgeons may need to receive training in rehabilitation. It was during this short time in this hospital, that I often wondered, how do people with ABI manage and enjoy life in the long-term? At the end of this locum experience, when I chose to learn more, I swapped the busy corridors of this hospital with their crying, whispering and some laughter, for the quiet spaces and study privileges of a university.[69]

I now present the plan of this thesis, one of the main outcomes of my study.

Thesis Themes and Plan

There are four key themes in this thesis. They are i) social becoming or identity with ABI, ii) beyond assumptions and dominant narratives in ABI rehabilitation, iii) opportunities and barriers for participation, and finally, iv) living a slow life. These themes guide my personal thesis and this text. This thematic scheme emerged out of the participants' stories and from the analytical strands used in Seymour (1998).[70] It likewise has some links with the global disability framework, the International Classification of Function, Disability and Health (WHO, 2002). These themes are interlinked, but located and discussed separately within various Chapters. The first theme relates to identity and social becoming with ABI**,** and links with disruption from literally having been out of this world in a coma, to being allowed back in this world, with self-sameness. This is akin to the theme of "second chance" used by many writers when working with and studying people with stroke or spinal cord injury as in Seymour's study (1998). For most people who acquire an ABI, neuro-rehabilitation plays an important role in the beginning of their ABI career. Thus, my second theme addresses the assumptions and dominant narratives embedded in ABI neuro-rehabilitation, while seeking to go

[69] Being a self-funded post-graduate student studying out of personal choice also highlighted the many public and hidden small and large privileges available to non-fee paying students and staff.
[70] Seymour, an Australian physiotherapist - sociologist, has written much on the body and people with spinal cord injury.

beyond them. My third theme addresses various open and hidden opportunities and barriers for participation in local community, the material and social resources required or available for social inclusion. The fourth theme is about ongoing long-term living with ABI, living a slow life in a fast world; the slow life.

This thesis is contextualized within particular background literature and applied middle range theories highlighting particular debates or antecedent issues which are presented in Chapter 2, although theoretical literature is used throughout all of my Chapters, including the findings Chapters. The categories chosen for this literature Chapter are from broad background theory, important for underpinning this study and important in the lives of people with ABI. The main methodological theories and decisions which informed this study are discussed between Chapters 3 and 4. Special attention to our social reality is discussed in the ontological section of Chapter 3 as the concept of multiple realities is not accepted in this thesis. This Chapter also includes broad details on my research design and on why the narrative approach was used in interviews. The importance and benefits of narrative self, narrative identity are explored then in Chapter 4 before introducing the six disabled participants, the focus people in this study. Finally, details on my final interpretations and on how my themes and Chapters were constructed, organised and developed are also discussed in Chapter 4.

My findings, based on the data co-constructed with the participants, their narratives of disruption, along with ongoing literature and policy-development locally are presented and discussed in Chapters 5, 6 and 7. The essence of Chapter 5 is on body issues, identity and self-sameness while Chapter 6 is more about social and environmental barriers when living long-term with ABI. Chapter 7 is about collective status citizenship issues, giving and living with difference and with sameness. My concluding Chapter 8 summarises the research findings and my final interpretations, before I open out with final discussion, recommendations and ideas for future research.

CONCLUSION

This Chapter has introduced the research topic, the research framework, the research context and the researcher, all informing this research study. It should be evident from the above pages that ABI is now very topical in Ireland, as many of programmes were only established in the past few years. Compared to the generic disability population, the balance between individual impairment service needs and collective disability issues are at an early stage of development for the Irish ABI population, while social issues are seldom considered. And for many people with ABI, especially in the southern region, where this research occurred, individualised services are even more scant and removed from those closer to our capital Dublin. The present distribution of financial resources may mean that little will change in the community, regarding social issues. Funding of community services, advocacy and self-help groups is under-resourced compared to the funding of the individual focused vocational or allied health services. While a limited number of disabled people have benefited from various development and equalisation of opportunities projects available here, many people living with ABI are only commencing on this path in a journey of social inclusion. Few people with ABI feel part of our body beautiful, knowledge and/or leisure society. I am not claiming that their ABI or their self-identification as a person with ABI determines them, but it is the case that this ABI can make a major real difference to their lives, with many issues added because of our disabling society and the social construction of disability.

The next Chapter therefore discusses some literature regarding both body/personal and social issues relevant to and/or impacting on living with ABI in contemporary Ireland.

CHAPTER 2 EXPLORING BACKGROUND AND LINKED DISABILITY / ABI LITERATURE

Theorizing disability, equalisation of opportunities, social inclusion and development are located through many sites of knowledge or disciplines such as disability studies, occupational therapy, sociology, and social theory. Literature from many disciplines provides the contextual framing for this research, and therefore for this Chapter. The body, individual and collective needs are forever intertwined, especially with regards to living with ABI, the salient focus of this thesis. Linking a sociological perspective with occupational therapy is vital, yet this linkage only commenced in the last two decades. Around the time the 'social environment' was being incorporated more into occupational therapy literature, *the body* was gaining prominence in sociology texts and discourse (Turner, 1992; Seymour, 1998). Yet, disabled scholars and activists were theorising the body and the disabled body in society for two decades by then, albeit focusing on disablement linked with physical impairments. Theorists from various continents such as Abberley, Finkelstein, Heath, and Zola in the emerging disability movement in the 1960s and 1970s challenged the medicalisation of their everyday living whether by medicine, medical sociology, and/or the allied health professional disciplines (See Driedger, 1989). This was the start of the global voice of disabled people's international and formal theorising of disability from the users' perspective which has had a major impact on how disability is represented, researched and discussed today. Although this thesis comes mainly from within a clinical therapy discipline, namely occupational therapy, I do not wish to over-medicalise the lives of people with ABI, but neither do I wish to over-socialise their lives. Fortunately, certain elements of occupational therapy are within that space between the medical and social aspects of living.

While all Chapters in this thesis include much literature, the aims of this particular Chapter are to provide background knowledge or identify theoretical issues underpinning this study and to highlight certain debates and areas of empirical

weakness relevant to this study. Certain factors considered relevant to various stages of the phenomenon of living with ABI, e.g. social practices in neuro-rehabilitation, and community participation or inclusion issues are introduced. Thus, four sections are used in this Chapter to present data on ideas or antecedents relevant to this research, helping also to build up arguments developed throughout this thesis. First, I introduce a broad discussion about the body and embodiment linked with theorizing disability. Second, as the benefits of bio-medicine enable people with ABI to live, I present an overview of neuro-rehabilitation as a social practice and explore certain problematic processes linked therein. In the third section, I consider the work of occupational therapists with people with ABI in general, with particular attention given to self-awareness. These two middle sections focus on individualised rehabilitation, an important first step in re-embodiment (Seymour, 1998) especially for people with severe ABI. Finally, literature linked with social participation and community integration, especially for persons with ABI in the social context, is discussed. Literature on many of these and other related concepts, including advocacy, difference, recognition, justice and citizenship, are discussed further in later Chapters.

2.1 THE BODY AND DISABILITY

Various disciplines are debating the body, body-mind, and the brain-body-self in society. Even within a uni-disciplinary perspective such as sociology, "[i]t is obviously a mistake to assume that different approaches to the body are talking about the same 'thing'" (Turner, 1992, p. 26). With this in mind, I proceed with a brief discussion about the body, impaired bodies and disability from my perspective informed by various theorists including disability studies (Abberley, 1995; Thomas, 1999a, 2004), medical sociology (Lupton, 2003; Frank, 1995, 2004), neuro-psychology (Broks, 2003; Harre, 2002), neuro-science (Greenfield, 1997, 2000), occupational therapy, (Primeau, 1996; Thibodaux, 2005), philosophy

(Edwards, 2005), psychology (MacLachlan, 2004; Yardley, 1999) and sociology (Seymour, 1998; Turner, 2001, Frank, 2004a), to name but a few.

The body, whether the commodified body as in our consumer society or the disciplined body as sought by public health authorities (Lupton, 2003), is seen today mainly as a project. It is as if our bodies, our selves, our identity, are all part of life as a project, a social project (Sahil with Butler, 2004), taking place "in a life-world that is already social" (Turner, 2001, p.260). For many today, especially postmodernists, 'the body is all', and our-selves, our identities are linked with what we make of our selves and our bodies. In reflexive individualised societies where tradition, religious and community routines are or have changed, Miles (2001) states that "we are not what we are, but what we make ourselves across time and space"(p.96).[71] But as Skeggs (2004) states, the "working class [and many within the disabled population], are not allowed access to resources and technologies required for self-production" (p.91). Thus, the body impacted by socio-cultural and historical factors, discourse, technology or prosthetics "can no longer be considered as a brute fact of nature" (Csordas, 1994, p.1). But can this be so for all bodies?

Having a body and being a body are also often discussed using Merleau-Ponty's concept of embodiment and modern phenomenology (Crossley, 2005, p. 15). This having and being a body are the two aspects of embodiment (Edwards, 2005). In the first aspect, the person 'is' the body, and an identity, with a changing identity suggested between the person and their body (Sarup, 1996, p.28). The body is viewed here more as "capacity" with potential **(**Seymour, 1998, p.12). In the second aspect of embodiment, the housing model, the body imprisons or houses the person. The person and their body are seen here as somewhat separate and the body is seen as a "constraint" (Seymour, 1998, p.12). But both constraint and capacity are part of the lives of and well known to and lived by, the participants in this study. Because of their time in coma in different states of consciousness, while

[71] See also Beck, 2002; Giddens, 1990; Lloyd, 1999.

also emerging from these states, they and/or their families had to live with the fragility and constraint of the body. As Becker (1999) stated, such "[n]ear-death experiences heighten awareness of the fallibility of the body" (p. 48). The participants also know now, however, about the capacity of the body. Within Disability Studies and writing from a postmodern position, Iwakuma (2002) defines embodiment as "taking one's body image into account unconsciously" (p.81). He claims that embodiment cannot be complete for disabled people as long as a disabled person is conscious, for example, of "pushing a wheelchair for transportation or is making an effort to flip a page while using a prosthetic arm" (p.81). Yet, in our body conscious society today, and not only in rich nations, it is hard to avoid hidden or subtle messages about your body and the need for that perfect body. The ever growing beauty industry, including cosmetic, fashion, health, and nail shops, and the media, especially celebrity magazines and the internet, remind consumers about the need for working endlessly on 'your body'. So, contrary to Iwakuma's words above, the majority of people today appear to accept being constantly conscious of their bodies. They are actually asked to be body conscious by health services when stressing an individualised approach to health management. Plus many disabled people need to be very aware of their object bodies, especially their skin, in order to prevent risk situations.

Embodiment is a complex concept. Thirteen aspects of embodiment are listed by MacLachlan (2004) in a collage of different ways of 'being' in the world today. These range from the Body Social, Body Emotion, to Body Plasticity. But Csordas (1994, 1999) claims that "studies about embodiment are not about the body per se, but rather they are about culture and experience…bodily being-in-the-world" (p.143). For him, embodiment is about cultural phenomenology, experience and subjectivity, where the body is at once tool, agent, and object rather than essence or behaviour. This links in with Broks (2003) statement, "we are not only physically embodied, but also embedded in the world around us"(p.101). Theorising or discussing embodiment is not sufficient therefore in my opinion when seeking a better quality of life for people with ABI, unless such theorising is

linked with their particular material reality and/or cultural phenomenology. It is important to remember, however, that some things are more socially constructed than others, and that some topics are more politically charged than others (Turner, 1992, p. 26). Many causes of ABI itself and of disablement are socially constructed in Ireland today while the ABI sector is also becoming more politically charged now, thus, being embodied with ABI and embedded are a major part of this thesis.

Impaired Bodies, Disability and Models of Disability

The "biomedically constructed body" is one of four main ontologies of disability (Williams, 2001, p.129), although many disabled theorists seem to focus only on this one ontology. The other ontologies of disability are in the person's relationship to the lived body, between the person and the people with whom he or she comes into contact, and finally, between the historically formed society[72] and the person as a member of that society. Historically, disability was articulated as an individual problem, a personal tragedy because of personal impairment. Those individualistic models, including the Medical model, Deviance[73] and Deficit approaches, focused on the person's body, loss and deficit, usually treating the person as an object. The majority of responsibility for change and adjustment to this difference or deviance was left to this disabled person and perhaps their family. But individualised body work cannot manage to explain or to change the common collective experiences and recognition requirements of people with disabilities. Mainly through the disability movement in the 1960s to 1980s, disability theorists, funded by favourable agencies and governments, developed the social model of disability. This model incorporated Finkelstein's Administration model[74] and the Social Death model of disability.[75] Initially, the

[72] This encompasses political, economic, welfare, culture and ideology issues in society.
[73] Deviance framework informed work on controlling atypical bodies, which violated cultural norms.
[74] Administration model disability necessitates "interventions by able-bodied professional and lay-worker who then 'administer' the cure or care solutions" (Finkelstein, 1991, p.27).
[75] Here society defines disabled people as socially dead and in need of care until physically dead. (Miller and Gwynne, 1972, as cited in Finkelstein, 1991, p. 21). Many disabled people refuted the end part of this assumption as they were engaged in struggles to change their lives.

social model focused mainly on material reality and social inclusion, both theorised within the social construction of disablement. Included in this reality was, and still is, the material relations of production, unemployment, poverty, access to health care services, social relations, lack of education, negative discourse, citizenship rights, discrimination, the lack of choice, and/or lack of voice in their daily personal or social lives. Today, there is no one fixed social model of disability as there are many variations on a theme. Shakespeare and Watson (2001) claim that the British social model depends on changing society in general, while the American minority group approach seeks to "raise the status and situation of an identified constituency of disabled people" (p.556). The history, debates and theorising on disability models are well articulated in disability studies literature (Barnes and Mercer, 2004; Corker and French, 1999; Fawcett, 2000; Oliver, 1990, 1996, 2004a; Shakespeare and Watson, 2001; Thomas, 1999a, 2004, 2007).

This social model and activism ensured that "the essence of disability was transformed from physical or mental deficit into a matter of exclusion and discrimination" (B. Hughes, 2002, p.64). For post-structuralist theorists, the social model conceptualised disability mainly as a structural process. Others stressed the importance of language as a key dimension in this issue of disablement or disabilism. Like Thomas (2004), I do not agree with "postmodernists and poststructuralists who reduce everything to language in the final analysis" (p.26). For neo-Marxists such as Oliver and Barnes, key theorists on developing the social model, social relations were not and are not their priority. They challenged and continue to challenge even deeper relations, such as the relations of production and the impact of capitalism on people with impairments in their societies. As a model of its time, identity and/or representation were not over-privileged or fore-grounded (see Corker and French, 1999; Oliver, 1996, 2004b). This model was developed mainly on the collective experience of disablement and not about "the limitations that our functional impairments impose upon us" (Oliver, 2004b, p.23).

Identity theory links in here as there are three pre-requirements in defining a disabled person: the presence of impairment, the experience of externally imposed restrictions and the self-identification as a disabled person (Oliver, 1996, p.5). Not all persons with impairments need to or want to identify as a disabled person and not all people with an impairment experience disability; other markers may be more salient. Impairment is, however, necessary, but not sufficient when discussing disability.

Critics have stated that this model over-socialises the needs of people with impairments or disabled people, while others state that the realities and the subjective experiences of both impairment and disability are almost sidelined here (see Corker and French, 1999; Thomas, 2004; Williams, 2001). Yet this model of disability emerged from, and can include issues arising from the personal experiences of individuals with impairments, i.e. personal body issues. As Oliver,[76] who has held positions as Reader in Sociology and Professor of Disability Studies, but seldom speaks about his personal body issues, stated recently,

> in more than forty years since I acquired it [his high-level spinal cord injury] I have been aware of it every waking moment and I have even trained myself to wake at night should a blocked catheter or awkward sleeping position put my health, and even my life at risk
> (Oliver, 2007, p. 232).

Thus, individualised body issues and body work are accepted as urgent and important for a certain time and place, but how individuals respond to most of these body issues are different and separate from the collective socio-political disablement issues. Other criticisms of this model came from Wilson and Beresford (2002) who claim that people with mental health needs and/or those

[76] Oliver was one of the first in the 1980s to articulate a formal theoretical social model of disability, stressing this model is only a working tool.

with cognitive impairments were initially excluded in this social model. Disabled feminists claim that women's views were excluded from earlier theorising on disability (Corker and French, 1999; Fawcett, 2000; Thomas, 2004), while gender or race issues are sometimes added on as double or triple oppression. But, as Edwards (2005) shows, gender or racism cannot simply be added on to disability theories, because "[d]isability, in contrast to race and sex, is always accompanied by impairment" (p.39), thus, real yet strategic non-essentialised differences have to be considered. Feminist perspectives and those from people with mental health needs and cognitive or learning differences are now well developed or are being developed within the social model perspectives. Oliver (2004b) hopes that the social model of disability may in time even incorporate these markers or "other social divisions" (p.23) further or deeper beyond naming them as additional oppression.

A final criticism of the social model is that the cultural values positioning disabled people as 'others' is ignored (Oliver, 2004b). But both Oliver and Barnes, as material theorists, claim that identity or issues about 'othering' are less important in a time when material deprivation is a greater problem for many disabled people in the world. Disability politics is/was not exclusively about 'representation' or identity, even if redistribution of justice and of material needs are closely linked with recognition issues.

In an attempt to merge the individualistic and the social models of disability, work continues on the (Nordic) Relational Model of Disability (Corker and Shakespeare, 2002; Reeves, 2006; Thomas, 2004). This model aims to focus more on the 'complex' psycho-emotional and interactional issues between impairment and disability, and on relationships between impaired and non-impaired persons (Krisjana and Kermit, 2007, p. 279). This social relational approach to disability is very important to disabled people regarding 'who we are' or 'who we can be' (Thomas, 1999a, p.45). But while relational issues are important, people with ABI, for example, want more than "warmth, care and respect" in professionalized and

general services stated Oliver (2007, p. 232). The Norwegian writers mentioned above, Krisjana and Kermit, state that the Nordic countries have had several social models since the 1960s, conceptualizing disability as "complex and contextual/relational, an interaction among individuals, environments and society" (p. 281). This (new) relational model also "has much in common with …the relative interactionist perspective" writes Traustadottir (2007, p. 216). Thus, while this relational model may be useful for many, the longer established social model can also incorporate further theorising on identity, including more about language and culture issues (Thomas, 2004). The debate continues, but should work continue on a theory of disability as Barnes (2006) suggested, rather than developing numerous models of disability along with a theory of impairment.

While also aiming to link individual and social needs and impairment/body functions with disability, The World Health Organisation (WHO) have developed a bio-psychosocial classification tool of or for impaired function and/or disability, The ICFDH, 2001[77]. This tool claims that all people are temporarily able-bodied, as all people could become, or are, potentially, disabled persons, because we could all be knocked down crossing the road, acquire a spinal injury and then have to use a wheelchair. This concept or the converse, the 'universalism of disability', was also developed to manage the disability identification problem and to seek inclusion for all. Occupational therapists are even told by Vrkljan (2005, p.59) that they "should support the implementation of social policies that are based on universalistic principles as such policies ...assign value to the broad abilities that fall along this ability-disability continuum." But this universalistic perspective of disablement brings its own problems, discussed further in Chapters 7 and 8.[78]

With the focus today on function rather than on impairment, all older people can be considered 'disabled' if or as most old people do living a little slower. Low

[77]This International Classification of Function, Disability and Health, while not accepted by many disabled people and health workers, is a useful planning document for nation-states developing health and social care services.
[78] See also Hammell, 2004a.

(2003) wonders if this development is really for an inclusive society or is it more for political correctness? And to push the logic of this universalism even further, Edwards (2005) wonders should fewer births occur, if we all have the potential of becoming disabled. The collective experience of disability pride has challenged and changed disability discourse in many cultures today, and in the clinical and political discourse of the WHO. This changed discourse may also help many people in their personal and social adjustment to living and/or celebrating life with certain health conditions. But this is not so for all people at all moments, especially if a serious acquired impairment is in question. For some, their suffering, their loss, their leaky bodies, and their immobility are not for celebrating, perhaps never, or perhaps only on seldom occasions.

Going beyond impairment as personal and disability as social (B. Hughes, 2002) suggests a synthesis, stating impairment may be social and disability embodied. While this may be a neat synthesis with the blurring of boundaries, the old body-social, micro-macro, agency-structure, impairment-disability dualisms remain. Managing individual needs along with changing social structures and processes by individuals and groups continue to be a real issue. Using the social model need not and does not mean essentialising the differences linked with impairment or that their 'real' differences will be over-emphasised.

I accepted some of the above criticisms of the Social Model of Disability and, at one time, welcomed the development of a new model of disability. Having moved away from the social model and towards the relational model, a little, I return though to the social model. This social model underpins adequately for me the issues linked with managing difference, discrimination and incorporates sufficiently social relational issues between different sectors of our population. Through the concept of citizenship[79] this model allows for work on sameness, too.

[79]Erikson (2007, p.270) discusses the importance of and links between the civil, political and social rights of individuals and individual groups in the development of a national democratic society. As with many writings on citizenship, his starting frame is Marshall's (1950) *Citizenship and Social Class*.

(See also concluding Chapter 8). Working with difference involves working with sameness, but it is important in our specialised world to delineate in some way collective responses and social policies rather than blurring everything. With our ever-growing number of professionals working with disabled people, keeping impairment separate at a conceptual level, allows 'individualised services' working on individualised impairments and 'impairment effects' to develop, without clinically professionalising all of the lives of disabled people. I also look forward to a social theory of impairments which aims to theorise and reduce disabilism in the lives of disabled people.

Conclusion

Participants in my study do not speak about 'embodiment' or their 'embodied selves', but they are very conscious of their bodies and aware of the issues involved with living with a brain injury to their body. They are also very aware of being-in-the-world with ABI, especially when discriminated against and treated as either too disabled or too special. They are not ill, and seldom have a chronic illness, as per sociology or population health discourse, although some may have pain at times. Tremain (2002) using Foucauldian themes claims that "allegedly 'real' impairments must now be identified as the incorporated constructs of disciplinary knowledge/power that they are" (p.42), and that rehabilitation is part of normalizing technologies today, a disciplinary mechanism. But without some of these disciplinary mechanisms, many people with ABI would not live.

The following section looks at neuro-rehabilitation because a career for most of those with ABI starts here. Most people with brain injury require neuro-rehabilitation in order that they may join the disability (pride) collective rather than the silent dead majority**.** Although I may be critical about how this process is sometimes organised, and the social practices within, I am also aware of the problems that exist if neuro-rehabilitation is not available and/or the wrong label is given.

2.2 NEURO – REHABILITATION

With the development of neuro-science, the term 'neuro' is widely used today and adds focus and/or status perhaps to specialists within professional groups and their tasks. Neuro-rehabilitation is that domain of medical, clinical, cognitive, communication, social, occupational and vocational generic rehabilitation used when working with people with injuries or damage to the brain. The social organisation and social practices including the tests and assessment scales used in neuro-rehabilitation, both positive and problematic, feed into the lives of people living long-term with ABI, the focus of this research[80]. Some of these processes often determines whether a person will live or not with ABI. Thus, this second section of this Chapter discusses neuro-rehabilitation in general that occurs for the majority of people with a new serious ABI in most rich nations. The initial focus in rehabilitation is generally on recovery, restoration, remediation and rehabilitation. McGrath (2004) names these as *Models of Restoration* stating that they focus too much on the past, all with the prefix '*re*'. She seeks instead a Model of Transformation for Clinical Rehabilitation. While I agree in part that transformation may emerge through 'suffering', for most people with serious ABI, this 'transformation' may occur only on completion of a certain level of urgent recovery and rehabilitation 'body work'. This section is about this important body work.

Brain injury rehabilitation, once called Head Injury rehabilitation, now neuro-rehabilitation, originated in specialised centres in Germany and Austria during World War 1. Boake (2004), a neuro-psychologist, who has written on the historical aspects of neuro-rehabilitation, claims that seventy-seven per cent of people with brain injuries died in one campaign during World War 1. By the time of the Vietnam War (1970), this number was reduced to eleven point two per cent. Up until 1979, people with severe brain injury did not survive, but with improved

[80]See Appendix 5 for a list of titles of common scales and measurement available.

acute physical care, drug medication, and brain imaging (MRI scanning), this is no longer the case. However, the outcome for many people with ABI is still not that great, so it is most important that minimal brain damage occurs at the outset (Smith and Godfrey, 1995). Medical diagnostic tools used initially in the intensive care unit (ICU) are often used to determine the severity of the brain injury and to predict functional outcomes weeks after the event. The outcomes sought usually include typical functioning, independent living, vocational and/or occupational satisfaction, along with today, a growing concern on identity and behaviour. The most common tools used at the acute stage are the Glasgow Coma Scale (GCS), the Length of Coma (LOC) and Post Traumatic Amnesia (PTA). These measures generally determine whether a person's injury is classified at this stage as mild, moderate, or severe brain injury. Although all pose their own difficulties in measurement, my discussion will focus on the Glasgow Coma Scale.

This Coma Scale defines and quantifies the depth of coma[81] (Heary, Hogan and Smyth, 2003, p. 9). It was or is generally assumed by most people that the greater the depth and length of coma, the poorer the prognosis for recovery. But this is not always the case. Asikainen, Kaste and Sarna (1998) claim "that a low Glasgow Coma Scale score at the time of hospital admission and a prolonged period of impaired responsiveness, are not necessarily incompatible with good recovery and restitution of cognitive functioning" (p.98). This scale is also known to be not very precise or suitable for coping with subtle changes (Malec, 2004b). Sheil, Horn, Wilson, Watson, Campbell and McLellan (2000)[82] developed the Wessex Head Injury Matrix (WHIM),[83] which, unlike the Glasgow Scale, allows for nano-changes in behaviour. This has meant, however, that many people with ABI have been wrongly diagnosed as being in a vegetative state (Sheil, 2004). In addition, this British Wessex ABI rehabilitation centre is now known to fail to save the lives

[81] On the Glasgow Coma Scale, fifteen is normal, with the person able to open eyes, move and speak. Eight or less means the person is comatose.
[82] Wilson is a world expert neuro-psychologist working in neuro cognitive rehabilitation. Sheil is now Professor of Occupational Therapy, University College Galway, Ireland.
[83] The WHIM, a reliable and valid behavioural scale, is constructed following observations and recording behaviour and real life skills during assessment.

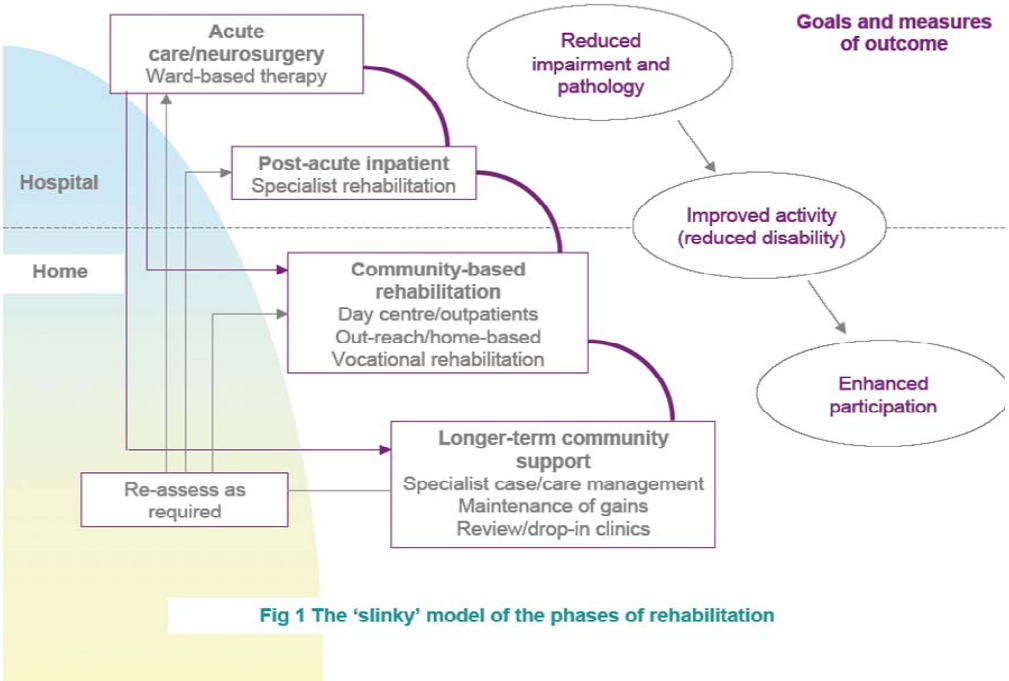
of (only) below ten per cent of new coma patients in their care, yet nationally this number is approximately twenty-per cent (Vulliamy, 2007, p.27). Yet it is not all high-technology that is required, for such improved life-chances, but often the 'will to care'. Because there is often widespread nihilism at the initial acute phase, with the notion that nothing can be done, care is often withdrawn, and giving up becomes a self-fulfilling prophecy (ibid, p.25). This adds to claims made by Smith and Godfrey (1995, p.150) about their earlier study in the mid 1980s which found that the pessimistic expectations and values of staff also impact on the community re-entry of people with ABI.

For most of those people with serious ABI who stabilize, medically and neurologically, regardless of difficulties in precise measurements, the acute individual medical model of rehabilitation then commences. Rehabilitation focuses on informing and/or training the person on compensatory methods, assistive devices, and/or environmental modifications that may be required to manage living with their impairment. This staged programme can include specialised cognitive and/or behavioural rehabilitation, along with vocational and home and/or community based rehabilitation. Wilson (2004b) has commenced work on developing a Comprehensive Model of [Cognitive] Neuro-Rehabilitation. This is a mix of the three main rehabilitation models amalgamated because, as Wilson claims, no one model can do all the required work.

The Slinky Model of ABI services (see overleaf) illustrates the various broad phases of rehabilitation. But, as Pickard, Seeley, Kirker, Maimaris, McGlashan, Roels et al. (2004) state, "the reality of the process is much more complex and three-dimensional than [this] model suggests"(p. 388).[84]

[84] See Appendix 6 for a list of guidelines or policy documents available for informing multi-disciplinary neuro-rehabilitation including some uni-disciplinary guidelines for occupational therapists.

Figure 2.1 The UK Slinky Model: Phases of ABI rehabilitation services



www.cot.org.uk/specialist/neurology/events/conference/pdf/8a.pdf

(See Pickard, Seeley, Kirker, Maimaris, McGlashan, Roels et al., (2004))[85].

Rehabilitation is all about learning and this process seeks errorless re-learning or re-training usually of numerous body needs. These can range from swallowing, eating, standing, walking, communicating, undertaking everyday self-care tasks, to managing orientation, attention and information processing needs, visual perceptual work, and community living, using occupational, educational, spiritual, social, leisure and sexual opportunities. Self-awareness work, which some claim to be pivotal to benefiting from neuro-rehabilitation, is discussed separately in Section 3. The multi-disciplinary rehabilitation team involved usually includes the consultant doctors, the dietician, the medical social worker, the psychologist, the nurse, the occupational therapist, the physiotherapist, and the speech and language therapist, along with all assistant and support staff. Others such as psychiatrists, orthopaedic surgeons, laboratory technicians, etc., may also be involved. Team

[85]This figure of The Slinky Model of ABI services retrieved from both sources.

work occurs most times, but organisation and professionalisation issues often dictate the rehabilitation process and overall time actually allowed for this process. Ysiklaver and Feeney (2005, 2006), American neuro-psychologists,[86] lament the daily forty-five minute treatment sessions that are generally used to plan and provide uni-disciplinary rehabilitation provision. These short sessions with varying personnel place additional time pressure on the person with ABI, while fragmenting the body further, and reducing the person to numerous sub-goals (Ysiklaver and Feeney, 2000, 2006). At discussion time at a Headway UK Conference, Wilson (2004a, 2004b) cautioned the professional workers testing in neuro-rehabilitation today, to remember that '*rehabilitation is about people and not about testing the test'*.

The overall focus in rehabilitation team practices changes with time. Klonoff, Costa and Snow (1986) are quoted as being "among the first to have analysed the predictors and indicators of quality of life after traumatic brain injury" (as cited in Koskinen, 1998, p.632). At that time in 1986, great emphasis was on the effects of the severity of the injury, and in particular the effects of the main residual motor deficits. Ten years later, based on a major study with people living ten years with ABI, Koskinen claimed that "managing behavioural and emotional issues are the significant correlates of life satisfaction" (p. 645) rather than mobility or cognitive issues. Today, greater attention is placed on re-establishing identity (Vulliamy, 2007, p.28), while theoretically at least, cognitive, behavioural and emotional issues are addressed in an environment as close to real life as is possible.

Identity issues and identity politics, major issues for other disabled people in recent decades, are slowly being assimilated into all rehabilitation work, although many people with ABI have a pre-identity stage to work through because of loss of consciousness (See next section and Chapter 5). Vocational rehabilitation, also required by many, is de-emphasised within the dominant traditional rehabilitation

[86] I have heard both speakers in Dublin, Ireland at two PBF and BRÍ ABI Education or Awareness Events in 2005 and 2006. I also listened to Ylislaker at the Headway UK Conference, 2004.

programmes (Asikainen et al., 1998; Headway Ireland, 1997; Skeel, Bounds, Johnstone, Lloyd and Harms**,** 2003). Studying vocational issues for disabled people five years post-injury, Askinainen et al. (1998) found that thirty per cent of people with severe ABI in various age ranges could not return to work (p.100). But it must be remembered that if people were not working pre injury, as many of the young people involved in this population are, they may not seek or even wish to work after their injury. Also, vocational rehabilitation and work issues need to be considered within the context of welfare societies today in rich nations, the importance given to leisure in our leisure society today, and that many people with severe ABI gain compensation funding.

Reinstating autonomy and control as quickly as possible to the patient and family are part of this rehabilitation work today. This collaborative work of the person her/himself or the family is sought as early as possible for issues ranging from care, information, general outcome, sexuality or empowerment (Douglas and Spellacy, 1996**;** Kosciulek and Lustig, 1999; Man, 1999; McColl et al., 1998, 2001; Wallace and Bogner, 2000). One of the main critical writers within occupational therapy literature today, Hammell (2007a), claims that this dogma of 'person centeredness'' may be however more rhetoric than real. She claims that occupational therapists "are often complicit in perpetrating oppressive institutional practices" (p. 266), an issue which is also part of this thesis (see Conclusion Chapter 8). Negative attitudes may still be present among rehabilitation workers even at later stages of rehabilitation although scant literature was found on this point. The fact that Skeel et al. (2003) and Woods (2004) called for a more favourable discourse amongst rehabilitation workers and to check against any form of ageism suggests that staff attitudes are still important and critical, but seldom researched within neuro-rehabilitation.

Outcome Factors and Plateauing

The benefits of neuro-rehabilitation are well documented in a plethora of ethical, medical, occupational, paramedical, political, social and vocational literature. But

working from an economic perspective, McGregor and Pentland (1997) state that "there is a paucity of reliable and methodologically sound evidence on the cost-effectiveness of rehabilitation services for TBI individuals" (p.302). The general belief and practice are that neuro-rehabilitation is best provided as soon as possible following injury for improved functional outcomes. This may be contested as the needs of people with slow-to-recover traumatic brain injury may be best carried out in slow, low-pressure rehabilitation, one or two years post injury (Eames, Cottrill, Kneale, Storrar and Yeomans, 1995). Eames et al. claim that such a non-confronting approach, enabling change rather than demanding change, is required in rehabilitation systems, as much as the fast track rehabilitation systems. But where people wait for a place in a residential rehabilitation centre in the meantime can lead to other problems. This team found that a dependency relationship is more likely to occur when young adults wait for too long at home with their mothers, awaiting their call-up to rehabilitation. This waiting is a common situation for many families in Ireland, where only one in four persons access a bed in our National Rehabilitation Hospital, as noted in the Introduction.

However, numerous pre injury factors impact on outcome as well as the actual injury itself. These pre injury factors noted from the literature and conferences named throughout this thesis include personality (although often over stressed by some), education, drug-taking, guts, social networks, social supports and spirituality. The rehabilitation procedures and social processes required and/or available after the actual event or injury, including time itself also impact on the outcome. Age at time of injury, for example, affects reaction time to formal cognitive-reaction tests (Heatherington, Studd, and Finlayson, 1996). This may be due to the "decreased plasticity of brain to recover from severe injury", according to Asikainen et al. (1998, p.104). Yet, older people will have other adaptive skills, perhaps spirituality, experience of ageing and life, etc. Cultural attitudes to disability and the politics of the rehabilitation worker all add to the mix in devising a personal response to ABI. Outcome issues are also linked with personal

rehabilitation readiness which may in turn be linked with self-awareness as well as available or given services.

While the best starting time for rehabilitation needs to be flexible, so too is deciding if and when there is a plateauing of recovery or relearning. The dominant view used to be, and is still held no doubt by many professionals, that the "majority of recovery after severe head injury occurs in the first six months post-injury". This time-frame developed from results of a 1976 study cited in Heatherington et al. (1996, p.482). But recovery, especially in neuro-cognitive functioning, continues to take place after a six-month 'deadline', albeit at a slower pace. (See Pepin, Dumpont and Hopps, 2000). Work by Asikainen et al. (1998), Newbigging and Laskey (1995), and Oliver, Ponsford and Curan (1996) shows that the final outcome following an ABI is not always possible to determine until years after injury. As Gray (2000) states, studies with "longer follow-up periods call into question the concept of plateauing of recovery and the widely accepted notion of maximal functional recovery occurring within two years after injury for at least the slow-to-recover severe TBI population" (p.1008). Fleminger and Ponsford (2005) also found that many long-term studies show "surprisingly good outcomes" (p.1419), thus highlighting the importance of studies over the long-term. Actual recovery is hard to predict.

It is not surprising, therefore, that the predictive outcome measurement tools for brain-injury have only minimally advanced in the last twenty-five years (Malec, 2004b). The MRC CRASH Trial Collaborators (2008) are now developing an international practical prognostic model for use in clinical decision-making.[87] Therefore, predicting outcomes for people with ABI is difficult, perhaps even dangerous I believe**,** given the numerous factors involved in a person's response to/with their ABI. The transference of learning from cognitive rehabilitation training to home-community living is also limited (Erikson, Karlsson, Borell and

[87] The Medical Research Council (MRC) International CRASH Trial on corticosteroid randomisation after significant head-injury, is co-ordinated by the London School of Hygiene and Tropical Medicine.

Tham, 2007), thus the need for community and/or home-based rehabilitation services. Even though community rehabilitation and disability services are only available in a few parts of Ireland, the USA efficiency model of twelve weeks specialist neuro-rehabilitation is now being introduced in our National Rehabilitation Hospital.[88] (See also Chapter 8).

Although ongoing learning and recovery may occur for years post-injury, some people with mild ABI live with self-reported symptoms specific to ABI for eight to ten years post injury (Gordon, Haddad, Brown, Hibbard and Sliwinski, 2000). The physical and behavioural symptoms noted here were dizziness, difficulty dealing with people, and five specific cognitive symptoms, "reading, writing or doing maths; learning new information; being easily distracted; losing your train of thought and forgetting things you have done" (p.28). These symptoms were not linked with awaiting compensation, a common assumption or issue which often causes some professionals to consider people with ABI as malingerers.[89] There are also always a small number of people who remain in the medical category of 'severe brain injury', even following intensive rehabilitation programmes. Their symptoms include serious and enduring amnesia, cognitive, emotional, functional and relationship difficulties. People within the category acquired brain injury are not homogenous, and unlike a fixed injury, such as spinal cord injury, the majority of people with ABI change over time within a recovery model.

Conclusion

This section has highlighted the many positive and certain problematic issues that can arise in neuro-rehabilitation. Most aspects of the minutiae of neuro-rehabilitation are studied by the various specialisms today. Person/family-centred team work are key words used in neuro-rehabilitation texts today, yet efficiency,

[88] This statement was made by a nurse from this NRH in discussion time at the ABI Peter Bradley Foundation /BRÍ Conference, Cork, 22 August, 2007. Deeper managerialism and/or targeted rehabilitation policies within the Irish health services are shortening length of stays in the NRH.
[89] This may be linked with the sick role as theorized by Talcott Parsons (1951). Parsons regards the sick role as a form of deviance, a threat to that social order of performing expected roles (Blair, 1998, p.47).

control and predictability in order to manage costs are also prevalent research topics. Improving the sensitivity of tests is named as an ongoing research need, yet after twenty-five years of research, the predictors of neuro-rehabilitation are still broad and varied.

Managing the balance between natural ongoing recovery, slow recovery, and re-learning from rehabilitation towards some form of personal and social adjustment is important. Numerous scales and measurements are available for professionals, but as is common in much social research, the researcher or tester can often impact on the test result, as well as on the actual timing of this testing.[90] Many of these issues, along with the scales etc., are part of the working domain of occupational therapists working within neuro-rehabilitation. The next section discusses an overview of some of this work.

2.3 OCCUPATIONAL THERAPY ~ SELF-AWARENESS

Occupational Therapy is one of many enabling, therapeutic, training, and caring professions. Within the profession it is known as "the art and science of helping people do the day-to day activities that are important and meaningful to their health and well-being through engagement in valued occupation" (Crepeau, Cohn and Schell, 2003, p. 28). Occupational therapists work within formal acute and specialised centre-based neuro-rehabilitation teams as well as in the community. Their focus is to work on enabling meaningful engagement in everyday living as much as possible through apprenticeship procedures in real-world contexts, providing context-sensitive and meaningful feedback (Ylvisaker and Feeney, 2006). This section of the Chapter focuses on the work of occupational therapists in general and on their work in self-awareness re-training following a severe brain injury in particular.

[90] Many scales are also available for people with ABI, and for their families, partners or carers.

Following an ABI, people may have a combination of behavioural, cognitive, emotional, functional, physical, occupational, social, self-care, and sexual difficulties. For occupational therapists this means that "all occupational areas and client factors can be affected, depending on location of lesion and type of injury" (Pulaski, 2003, p.768). It must be remembered that for this discipline, every activity in daily life is now considered 'occupational', including sleep and rest. The British Association of Occupational Therapists (BAOT), Specialist Section Neurological Practice Annual Conference (2006)[91], covered topics ranging from Assessing and Treating Executive Problems, Understanding and Managing Fatigue following brain injury, Returning to Work, Use of everyday Memory Aids, and Sex - are you thinking about it enough? Occupational therapy enables individuals to learn skills for independent living (McLean and Potts, 2004; Trombly, Radomski, Trexel and Burnett-Smith, 2002), enable the habit-body (Erikson, Karlsson, Borell and Tham, 2007), reduce stress (Gutman and Schindler, 2007), and regain vocational and written communication skills (Phipps and Richardson, 2007), to name but some benefits accrued to occupational therapy.

At the acute stage of neuro-rehabilitation, occupational therapists work mainly within a biopsychosocial medical discourse. Their main focus is usually on perceptual evaluation of attention, executive functioning, sensory awareness; cognitive skills, motor evaluation, passive or active range of movement-pre-requisites for personal self-care needs and functional daily living skills (see Collins and Dean, 2002). Over time, and with the team, the occupational therapists work on endurance, insight, problem-solving, sequencing, along with values, habits and motivation on some required activities. All of these named concepts are occupational components**.** The occupational therapist as part of the goal-focused neuro-rehabilitation focuses on meaningful or productive goals or activities relevant for that moment in time. Significant others, such as family or a friend, are often involved at this early stage while the person has limited capacity to make a

[91] Power-point presentations from this conference are available electronically to professional members of the B.A.O.T. Retrieved from www.cot.uk members link on 5 November, 2006.

goal, or to plan or negotiate their rehabilitation (Conneeley, 2004). Occupational therapy interventions can include adapting the environment, the task, or working with the person on components of awareness-adjustment work, self-care needs or social interests. At a later stage, work whether formal, informal, paid or voluntary, plus pre-requisite activities required for access to and engaging with community living are generally part of intervention.

Occupational therapists use a variety of techniques, strategies or approaches when working in cognitive rehabilitation with individual people with ABI. Blundon and Smits (2000) describe the two broad approaches as the cognitive remediation-restorative approach and the cognitive adaptive approach. This second approach focuses on using compensatory strategies to facilitate successful performance in everyday living, rather than the former approach which focuses more on remediating underlying cognitive skills required for various tasks. Many clinicians question the first cognitive remediation-restorative approach because of the difficulties in transferring learning from graded table-top exercises used in a specialised rehabilitation setting to home situations. While it is generally accepted that retraining for functional outcomes should take place in as near a life situation as possible, this is not always possible given the social organisation of rehabilitation practice. Fisher[92] (1999) developed a structured evaluation tool that could be used by occupational therapists with service-users in various settings. This tool, the Assessment of Motor and Process Skills, commonly named The AMPS, allows occupational therapists to assess or measure "the impact of impairment on the client's occupational performance" (Chard, 2000, p.481). A wider debate continues between occupational therapists as to the possibilities of being occupational or not within specialised rehabilitation centres. Yet, for many service-users, this is where that person (P), in that environment (E), may need enablement and time to work on urgent basic occupations (O). This is the broad

[92]The Assessment of Motor and Process Skills (AMPS) developed by Fisher requires five days training and clinical work with ten clients before independent clinical use is allowed (Chard, 2000).

PEO triad of concern for all occupational therapists, but hospital work is not always seen as sufficiently occupational in a post-modern holistic perspective.

The great numbers of occupational therapy models for neuro-rehabilitation may explain the complexity and scope of this practice, or alternatively show how creative occupational therapists are with their professional craft knowledge (Titchen and Ersser, 2001). A summary of the main models used by occupational therapists in cognitive rehabilitation over the last two decades is presented by Lee, Powell and Esdaile (2001). The temporal and special features of each model highlight the scope of work in this area. Certain models are only for particular stages of neuro-rehabilitation, while others, for example, The Neurofunctional Approach by Giles, can be used throughout all the rehabilitation stages as noted above (See also Giles, 1998).

Another model claiming to be suitable throughout all stages of neuro-rehabilitation is The Quadraphonic Holistic Approach (Abreu, 1998), yet this is not listed by Lee et al. (2001). Abreu claims this approach is more holistic and suitable for all people with cognitive impairment throughout the continuum of neuro-rehabilitation, as equal focus is placed on teaching-learning, information processing and neuro-developmental biomechanical evaluations, along with re-training for community living. The micro and macro perspectives of rehabilitation are integrated here along with individual and group work as appropriate for the person(s) involved, with the focus always on community re-entry.[93] However, this Quadraphonic model is not mentioned in the list referred to above, although an earlier model developed by Abreu and Toglia (1987)[94] is listed by Lee et al., along with Toglia's (1991) Multi-context Treatment Approach. [95]

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[93] Abreu presented an interesting qualitative meta-analysis of collaboration between persons with brain injuries and occupational therapists at the 2006 World Federation Conference, Sydney.

[94] The Model of Cognitive Rehabilitation (1987).

[95] This omission may only be editorial space issue but it may also be an example of one of the issues involved in the sociology of knowledge production impacting on what is published or not in professional journals.

One common component of occupational performance found or required to varying degrees within all of these models above, is insight or self-awareness. Professionals claim that a lack of self-awareness causes the disabled person to have reduced motivation to participate in rehabilitation and it may also have an adverse effect on functional outcome (Fleming and Strong, 1999, p.4), thus impacting on living with ABI. Self-awareness is the focus of the rest of this section.

Self-Awareness…annoyed, embarrassed or in denial?

Self-awareness has been defined as "an emergent brain function that by its nature integrates thinking and feeling" (Priganto, 1999, p.154). The issue of self-awareness of deficits or its opposite, the denial of deficits, plays a major part in rehabilitation work, and occupies much space in academic research on living with ABI. (See Priganto,1999; Simmond and Fleming, 2003; Wallace and Bogner, 2000). In the past, professionals and relatives usually assessed the disabled person's overestimation of abilities as refusing to admit to difficulties or as a means of coping by denying their disability. Until 1999, this denial of disability was represented by many rehabilitation workers as a psychiatric disturbance. Then Priganto, the neuro-psychology expert on self-awareness, called for this notion "to be abandoned" (1999, p.155). Four syndromes of partial or complete self-awareness were then identified for psychologists to use in individual client work, and to make inferences about the disabled person's "level of functioning and disability" (ibid, p.156). This change of label is to be welcomed, although the effect of the past diagnosis on professional and carers' expectations could have materially and psychologically affected the lives of numerous people with ABI. It is also possible that some professionals may not have abandoned the former psychiatric definition.

Today, the two broad types of self-awareness, a motivated lack of awareness and an organic lack of awareness, are considered overlapping and not mutually exclusive (Giles, 1998). There is no single discipline responsible for evaluation

and treatment of cognitive-perceptual impairments (Kohlmeyer, 2003). The occupational therapist has a major role to play here because of the impact of self-awareness limitations on activities in everyday and everynight living. Occupational therapists and psychologists generally used and still use a pyramid model[96] or hierarchical model of three independent levels of self-awareness. The three levels are Intellectual Awareness, Emergent Awareness, and Anticipatory Awareness. Intellectual awareness, the lowest level, refers to "knowledge about the existence of deficits and how they may interfere with functional performance" (Simmond and Fleming, 2003, p.448). Emergent awareness occurs when the person is able to recognise a difficulty as it is actually occurring, while anticipatory awareness refers to the person's ability to self-correct before the difficult or risk behaviour, action or movement occurs. The lack of anticipatory awareness is considered to be a good predictor of the level of supervision required for community re-entry (Abreau, 1998). Compensatory strategies requires the client to recognize that they have a limitation with functional performance These levels of self-awareness are mapped on to occupational performance as per Lucas and Fleming (2005) and discussed more in Chapter 5.

The hierarchical model above was challenged also by those wishing to "highlight the dynamic rather than [the] hierarchical nature of self-awareness" (Lucas and Fleming, 2005, p.162). Thus, a Dynamic Comprehensive Model of Awareness was proposed by Toglia and Kirk (2000) to stress the dynamic relationship between all the factors involved in this phenomenon (knowledge, tasks involved, context, etc.). A collective term, online awareness, was also established to refer to "self-evaluation of emergent and anticipatory awareness collectively" (Simmond and Fleming, 2003, p.448). The well-established hierarchical model is still much used in practice, however, because assessments are available to measure the various 'levels' of self-awareness such as The Self-Awareness Deficits Interview (SADI) developed by Fleming, Strong and Aston (1996).

[96] This pyramid model was first developed by Crosson, Barco, Velezo, Bolesta, Cooper, Werts et al., (1989). Awareness of compensation in post-acute head injury, *Journal of Head Trauma Rehabilitation*, 4 (3), 46-54.

The self-awareness hierarchical model has been adapted and modified by various rehabilitation workers. Acceptance of ABI is now linked to self-awareness, now called the awareness and adjustment model. (See Appendix 7 for a diagrammatic representation of this adapted Model). Acceptance or personal adjustment is graded now from 'none to full', alongside the changing degrees of awareness. Here full acceptance is noted as the final goal, thereby neglecting the many social or sociological issues involved in the construction of disablement. Such issues include cultural attitudes to people with cognitive or physical differences, social discourse on ABI in particular and the given public funding for health and social care services to people with these 'real' differences. Also, it may be questioned whether a person should or could 'fully' accept their brain injury if caused by a dangerous driver driving carelessly into you while driving or when walking, or because you were a passenger in a friend's car and she walks away unhurt, because a car manufacturer did not correctly label the new oil filters used or inform consumers about this change, or because a tyre burst in your new company car and your employer gives you little support? These are the causes of brain injury among the participants in this study. However assessed, the question remains and a debate continues, 'is the person unaware of her/his limitations or in denial?'

A recent differentiation was made by Prigatano[97] depending on whether a person uses non-defensive or defensive coping methods. According to Katz, Fleming, Kere, Lightbody and Hartman-Maeir (2002), "only defensive coping methods relate to denial, while non-defensive methods relate more to neurologically based unawareness" (p.283). While a lack of self-awareness or denial of impairments may be organic for some, others claim it may be partly linked with the person trying to preserve self-esteem while aiming to cope with the reality of her/his changed situation. A seminal study in occupational therapy with people with self-awareness difficulties by Krefting (1987) found that family members were also

[97] Prigatano, a neuro-psychologist who has published widely on awareness or denial, has developed the Impaired Self-Awareness and Denial of Disability Clinician's Rating Scale.

embarrassed rather than being in denial about specific limitation. Giles (1998) also asked if people are more embarrassed rather than being in denial about specific activities, because she found that this denial "response style is common among a patient's family members" (p.131). Krefting actually named this lack of awareness of abilities in this situation more as a blind spot. The actual timing of this self-awareness assessment impacts on results. Gray (2000) concurs with Fleming and Strong (1999), who accept that self-awareness does "improve in most functional areas during the first year post-injury" (p.14). Yet, for tasks or activities including a large cognitive and socio-emotional content, e.g. managing finances and communicating with loved ones, continuing impairment often exists for more than a year. Therefore, Fleming and Strong (1999) claim that "individuals who are considered unsuitable for intensive rehabilitation because of poor insight could be reassessed over time and given the opportunity to receive services at a later stage if appropriate" (p.15). Dirette, Plaiser and Jones (2008) studied the pattern of recovery in self-awareness training to conclude that incorporating participation in familiar occupations into clinical practice and time is important. Yet, Pepin, Dumont and Hopps (2000) question the use of continuing cognitive rehabilitation after the initial three months post-injury, although these researchers did follow their participants for only one year post-injury.

It is becoming more accepted that people with a disorder of self-awareness may lie anywhere along the unawareness-denial continuum measured by using scales such as the Impaired Self-Awareness Scale or the Denial of Disability Scale. Today at least, while the above assessments continue, more importance is granted to the disabled person's self-reporting. Problematic difficulties continue, however, for me because of the various social processes and social organisations involved. These include the amount of time allowed for assessment, the test environments and the possibility of test sophistication. Is fatigue prevented in the process? Is the development of shared meaning adequately allowed for during the short assessment periods? Do the team consider the patient's overall day, moving between the various team members? How is chronicity or the length of time post

injury managed in various studies? All of these factors impact on the outcomes of the test, yet the outcome is then often used to decide the long-term future of a person's life.

Self-awareness does generally improve over time (Eames, 2004; Fleming, Lucas and Lightbody, 2005; Smith and Godfrey, 1995), yet living with a limitation in this area need not determine the lives of the people concerned. Time, and empowering enabling supports which focus on the social causes of disablement and not just on individual impairment issues are required for personal and social learning and adjustment to occur. Self-awareness is also an important ethical issue, because improved self-awareness is linked with the emergence of distress and depression. This issue is being debated, but like Eames, speaking at the twenty-fifth Anniversary Conference Headway UK[98], I hold that this distress is linked more to being assessed against an almost perfect norm and having to live in our disabling society. (See also Chapter 5).

Improving self-awareness may occur naturally, but with professional intervention it may develop at an earlier stage. This is important because as mentioned above, there is a link between improvement in self-awareness about abilities and limitations with increased dissatisfaction, emotional distress and/or the emergence of depression. In a New Zealand study, Smith and Godfrey (1995) found that the disabled participants developed greater insight or awareness of deficits a short time earlier than without this intensive work. But these writers claim that the notion of "increased awareness is causally related to worsening distress" (ibid., p.154). They also claim that the "return of insight eventually occurs even without therapeutic intervention and is inevitably associated with mood disturbance" (ibid., p.155). These findings are echoed by Fleming et al. (2005), Gordon et al. (2000), and Koskinen (1998). Koskinen[99] found that people who were more self-aware of their deficits following an ABI were less satisfied with their lives. There may

[98] This conference was held in Stratford-upon-Avon. England, 9-10 September, 2004.
[99] Koskinen presents the views of fifteen people living with severe ABI injuries for ten years, and their relatives.

however be various reasons for this dissatisfaction, starting with organic cognitive impairment for some. Others may dislike the special or community rehabilitation practices in which they are involved, or they may be acknowledging life in a disabling society. Although more self-aware about their abilities, they may be unhappy because they participate more, in social activities encountering situations in which their cognitive deficits are revealed more, but not accepted by others. Cultural variations exist also on whether competencies or deficits are allowed to be self-reported or hidden (Man, 1998; Simpson, Mohr and Redman, 2000). As Gordon et al. (2000) state, some people may also feel lucky to be alive and thus feel they have less right to 'complain' (p. 32).

Clinicians and researchers have debated for some time now about how to cope with these issues of poor insight and unrealistic expectations. Ethical issues always existed for me if services for people with ABI always focused on limited individualized work, often with unwanted, even if unintended, consequences. Is ignorance more blissful if our rehabilitation systems, socio-political systems and society in general are not doing more to balance the social and community needs of the individual and those of his/her family? As with other disabled people with major impairments, there is a need for many collective responses to their lived experiences as per the social model of disability. Yet, it is only in very recent years, that occupational therapists are asked to be cautious and careful with the ethical issues involved in assessing and/or planning interventions to improve self-awareness (Lucas and Fleming, 2005; Fleming, Lucas and Lightbody, 2006). Lucas and Fleming (2005) state that therapists need to assess "whether the benefits of improving a client's self-awareness outweigh any likely emotional distress" (p.163). Poor motivation in rehabilitation is cited as one of the reasons given for the need to improve self-awareness. I believe that there may be other factors to consider. The choice, style and discourse of rehabilitation on offer, rehabilitation readiness of the person and of the unit for that particular person, and the focus on seeking a better quality of life in other areas beyond functional abilities may also be linked to the disabled person's poor motivation to participate in rehabilitation.

Conclusion

This section has explored certain positive and problematic issues linked with occupational therapists working in neuro-rehabilitation. Particular problematic issues are the social practices and assessments linked with self-awareness which may link with an increase in distress. It appears that adjusting, coping and accepting could be linked with being allowed to self-report, which may in turn actually impact on accessing services. Many of these social factors are seldom addressed in Ireland as the focus is generally on individualised services, especially assessment. While improvements in individualised services are required, the need for collective responses to ABI also exists and is an important part of my thesis. Improving a person's quality of life when living with ABI is what all this body-work, rehabilitation and therapy programmes are about. Conneley (2003) warned that "[f]unctional status measures alone should be used with caution, since they may not be good indicators of quality of life" (p. 441). And as shown here, developing a greater self-awareness will not always facilitate an improved quality of life.

In the next final section of this Chapter, using the concepts of social inclusion and community integration or participation, I explore other issues linked with seeking a better life or 'quality of life' when living with ABI.

2.4 SOCIAL INCLUSION - COMMUNITY PARTICIPATION

Living with ABI embodied and embedded in society is not easy. Many disabled people, especially with ABI embodied, are often "moulded, even constituted by societal factors" (Lloyd, 1999, p.116). Whatever level of agency the person has or has not over or with their body, they have to try to manage the web of meanings and discourses in which they find themselves. There is much talk today in social development and social policies of social inclusion, social networks and shared citizenship between people with various identity markers (Putnam, 2007), but are

people with ABI part of these social networks? As the sociologist Putnam states, we all need bonds or ties to people "who are like you in some important way… and bridging ties to people who are unlike you in some important ways" (p.143). This is akin to the claim of Rorty (1991) that we all need to meet and mix with like-minded people in 'your club' as well as mixing at the market bazaar of life, even if, I add, that people with ABI may only stay at the bazaar for shorter lengths of time. With the growing kinds of diversity today, even within the disabled population, ensuring social opportunities for all involves negotiating many divides between interests linked with inclusion and others related to identity (Baker, 2006). This section focuses more on inclusion and participation in general public activities for people with ABI in general.

Participation in everyday living in the local community for many disabled people is not an individualised issue, a health or social care issue, nor the domain of any one professional grouping. Life itself and the process of social participation or integration-inclusion, for me, commences with a relational self and not an isolated individual as per Husserl (see Crossley, 2005, p.173). And for people with ABI, there are many pre-requisites to partaking and participating in social life or community living, beyond the material needs such as functional abilities, money, transport, and physical access. One major pre-requisite is a sense of recognition and belonging to some network. Honneth's Theory of Recognition claims that there is a need for recognition at three levels, emotional, personal, and collective (see Honneth, 1999, 2001). The three areas are mapped out as follows: human beings need love, played out in family and personal relationships; human beings desire formal equality, played out in collective groups, social movements or citizenship; and finally, human beings desire 'individual distinction', a status or personal statement (Crossley, 2005, p.262). While all three elements of recognition helped organise this thesis and are discussed more in Chapters 5, 6, and 7, issues linked with the first two for people with ABI are first introduced in this section. To be recognised or to gain this recognition in the home or in the local community, many people with ABI have to be enabled or allowed to be involved and included

in their social network or ‘community’. Thus the terms community integration, social inclusion and social participation are used somewhat interchangeably here.

People are constantly in the process of social becoming (Crossley, 2005) and not just becoming as an isolated individual. This is very appropriate for people with ABI and incorporated in the recovery model and theories of learning, change, and advocacy. But participating in ‘society’ or local community is difficult if your community or local society hold major misconceptions about the particular impairment and disability issues impacting on your life. Swift and Wilson (2001) claim that the British public hold many misconceptions about ABI, leading them to often misidentify ABI as a mental health or learning disability problem. The British public did not know about the long-term nature of ABI, or the diversity of possible problems a person with ABI may experience. At a more personal level for many adults who acquire a serious impairment (e.g. spinal injury, multiple sclerosis), a loss of pre injury friends is often reported. This can lead to high levels of psychological distress.

In a Finnish longitudinal study with people living with ABI for ten years, the loss of friends and the reduction in participation in leisure activities, and dissatisfaction in togetherness with their partners or a lack of partners added up to major social isolation (Koskinen, 1998, p.632). Callaway, Sloan and Winkler (2005, p. 257) found that the “loss of friends and social isolation are common outcomes” of ABI. This is articulated as strained day-to-day relationships and strained friendships post ABI, by Patterson and Stewart (2002). People with brain injury are also found to have “spent more time alone and less time with family than the general population” (Winkler, Unsworth and Sloan, 2004, p.78). Methodological issues, although described in a minor way in this latter paper, need to be mentioned here. People with ABI were timed and coded differently in their time use compared to those without ABI. Developing shared meaning over categorisation of activities caused further discrepancies. Plus, people with ABI often require and need to

spend more time alone to manage fatigue and noise (Winkler, Unsworth and Sloan, 2004).

Re-integration into the community by people with severe ABI and their families is a hot topic today for occupational therapists. This was studied in that much cited seminal ethnographic study by Krefting (1989) mentioned above. Krefting, a Canadian occupational therapist, identified three major recasting strategies to articulate how participants managed this task, namely concealments, blind spots and redefinition. This last strategy, where people understated their problem(s), is of particular interest in the Irish context. Providing one example of redefinintion of independent living, Krefting discusses how a mother in her study redefined 'independent living' by stating that "she could visit [her son] every other day and put food in the freezer" (p.75). This is analysed and named by Krefting as one recasting strategy following ABI. Yet, many Irish mothers continue to do this food preparation for their sons and daughters, whether able-bodied or not. In addition, now nearly twenty years after this study, many young mature European adults enjoy living in the family home and not always because of the cost of housing. Pure or full independence must have been sought by Krefting, although interdependence may be more useful or realistic. The concept of full independence is still sought by many therapists and families, and by many disabled people themselves, although the latter group may be responding to external pressures to be so, in order to be accepted.

From 1993, studies by rehabilitation workers focusing on community integration often used the Community Integration Questionnaire developed by Whiller, Rosenthal, Kreutzer, Gordon and Rempel (1993). Using a fifteen item scale and focusing on behaviours, this scale focused on home integration, social integration, and productivity. Scoring was based primarily on the frequency of performing activities or roles in the above domains. Trombley, Radomski, Trexel and Burnett-Smith (2002) state that this community integration questionnaire is a measure of

‘handicap’[100] specifically for persons with traumatic brain injury (p. 492). But the concept of handicap was dispensed by disabled people themselves in 1976 when the Union of the Physically Impaired against Segregation (UPIAS) proposed a twofold classification only, impairment and disability (Oliver, 1990, p.11). However, based on this questionnaire and on other scales, Fleming, Tooth, Hassell and Chan (1999) found that social and community integration for people two to five years post brain injury, could be predicted by age, disability level and cognition. But as Doniger et al. (2003) state, this questionnaire “fails to consider the individual’s interests and the types of premorbid activities performed” (p.74).

In their systematic review of the literature from 1980 to 2005 on community re-integration following ABI, McCabe, Lippert, Weiser, Hilditch, Hartridge and Villamere (2007) conclude by saying that the definition of community reintegration is not clear. They claim, however, that determining which of the various diverse supports is most effective is vital. They focused on five major aspects of community reintegration, namely independence linked with social integration, caregiver burden, satisfaction with quality of life, productivity and return to driving. Assessing and discussing community integration for people with brain injury today is generally replaced by the Community Integration Measure (McColl et al., 2001). This measure was developed following an ethnographic study carried out by these Canadian occupational therapists. Based around two main concepts, belonging and social participation, these writers claim that the indicators of community integration for people living with ABI are:

1. living in a place that encourages autonomy and independence;
2. orientation to one’s community;
3. having close and diffuse relationships;
4. conformity, knowing what it takes to fit in and the skills to do so;
5. acceptance, perception of being accepted by one’s chosen community;

[100] Within the old WHO IDH classification, impairment, disability and handicap, the term ‘handicap’ was regarded as the social participation aspect of living.

6. being involved in leisure and productive occupation; and
7. having a sense of purpose and structure to one's day, receiving respect.

Yet, many people without ABI may have no orientation to their community, no wish to conform and fit in, may not feel accepted by that 'community', and are not involved in leisure. McColl et al. (2001) state that independent participation is not a sign of greater integration than is mutual co-participation (p. 430), yet they continue to hold on to the label 'independent participation' in their Tables and in their discussion. But not all disabled people seek independence in all activities. As with rich citizens, personal assistants and paid carers are often employed by disabled people. Other disabled people may not wish to participate independently or otherwise in event or task x, preferring to maintain energy for participation in other more satisfactory areas of living (Desrosiers, 2005). This Measure claims to be a 'client-centred measure', but similar to the Questionnaire earlier, this interview-assessment scale can be completed in about ten to fifteen minutes with brain injury clients using a personal or telephone interviewing. Somewhat similar to McColl et al.'s findings on belonging and social participation, Winkler, Unsworth and Sloan (2004) claimed that social support and occupation are important sub-constructs in community integration for people with severe brain injury in particular.

Reistetter and Abreu (2005), however, claim that there is "little evidence to support the use of the Community Integration Measure" as it is "client-centred and provides a subjective qualitative insider's perspective" (p. 208). They seek more randomised controlled trials (RCT's) on community integration, linking in with the dominant discourse in clinical and medical elite journals. Reistetter and Abreu also state that "the construct of community integration is beyond the disability perspective" (p.208) and there is a need to include social, economic and political factors. For them, community integration "corresponds to larger global issues shaped by society's perceptions of persons with brain injury who should be recognised as active community participants" (p. 208). But this is precisely what

disability and the social model is about, yet many clinical professionals continue to interchange the word impairment totally with disability, ending with or implying that community integration is beyond the disability perspective.

Participation is assumed, expected and involved in all of the above, but what is participation?

Participation

Recently occupational therapist scholar Desrosiers (2005)[101] claimed that "[p]articipation is a relatively recent concept that is still not clearly understood or measured" (p.195). She did acknowledge, however, that more theoretical work has been carried out on this construct over the past two decades. Yet, since before the 1970's, the disabled people's movement have sought opportunities for greater real participation in everyday life. For decades the disability movement sought to reduce ablism and discrimination in their societies - in many African, American and European nations. *Equalisation of Opportunities* was the theme of the United Nations International Year of Disabled Persons in 1981. Many changes, benefits and outcomes emerged from this Year (See UNDP and WHO country reports, and Disability Studies literature). Twenty-five years later, *Equal Opportunities for All* was the theme again for the European Union for the year 2007, and the theme also of the European Network of Occupational Therapists in Higher Education Conference.[102] Here, Johnsson (2007) sought to problematise the concept of participation and suggested that this concept is a synthesis of 'social interaction and doing'. This is similar to McColl et al., (2001) and Winkler, Unsworth and Sloan's (2004) work on constructs required for social or community integration.

Participation is also an important component of the revised International Classification of Functioning, Disability and Health (WHO, 2001). In this bio-psychosocial classification tool, adapted from an earlier bio-medical model, the

[101] Muriel Driver Memorial Lecture on Participation and occupation, presented to the Canadian Association of Occupational Therapists in Canada, and published in the *Canadian Journal of Occupational Therapy*, 2005. See Desrosiers, 2005.

[102] This European conference was held in University College Cork, 19-20 October, 2007.

WHO define participation as 'involvement in a life situation', classified using personal and/or social activities. Thus, much of the old meaning of social handicap is held on to, but now both the capacity and the performance of participation are to be measured. This classification system is welcomed by many individual occupational therapists, the global World Federation of Occupational Therapists and many national associations. Caution is requested though with use of this classification of function, disability and health (see Hammell, 2004a; Hemmingsson and Jonsson, 2005; Kjeken and Lillemo, 2006). I believe there is much need for caution. Although this International Classification has many benefits, participation is still assessed against a norm, rather than the person's subjective desires or needs. As Hammell (2004b) stated, participation may be passive or active, independent or supported, virtual, for short-term, long-term, or directed through paying others. Determining the levels of participation by disabled people may be difficult, even problematic, if assessed against a non-realistic norm.

A recent study on social exclusion-social participation for disabled people in Ireland showed that "Twenty-two per cent of severely disabled people are not participating in all [the] four levels" assessed in this study (Gannon, NDA/ESRI 2004).[103] The following four indicators were used: Talking with neighbours; Meeting People; Afternoon/evening out; Member of Club or Association. Yet, many people do not talk with their neighbours and people may attend a meeting but not feel included or allowed to participate. Occupational therapists are encouraged to join in this search for the "the best predictors of participation" (Desrosiers, 2005, p.199), including satisfaction with that participation. But in many domains of life, participation can be both a process and a product, authentic or artificial, weak or strong, assisted or independent. Can we predict all of this? Do we want to? As noted earlier, the predictors of outcome following an ABI have included numerous factors from pre-injury such as age, education, personality, social networks. In addition, the outcome following an ABI may also depend on

[103] This study incorporated both the Disability Survey (CSO, 2002) and Living in Ireland Survey (CSO, 2001).

the location and level of injury, the length of coma; duration of post-traumatic amnesia, rehabilitation services, informal supports and public discourse on disability. The usefulness of predicting life events or participation in life even if possible would be problematic and unethical perhaps and will always include the need for action at various levels. More occupational therapists are using self-report surveys and assessments to collaborate on social participation issues with service-users (see Hemmingsson and Jonsson, 2005; Thibodaux, 2005). Still the search for the best standardised measure continues. Many professional groups including the United Nations statisticians continue to search for and examine aspects of participation that are not covered in their current surveys (Madans, 2004).

Measuring Social Participation for people with ABI, the MPAI-4 Rating Scale, designed by Lezak and Malec (2003), uses nine items, namely initiation, social contact, leisure/recreational activities, self-care, residence, transportation, work/school and money management. Again, some of the screening questions used for assessing or measuring participation may be contested. For example, initiation involves answering a question about problems getting started on activities without prompting. Two marks are attained if one has a mild problem in this area – interfering with activities five per cent to twenty-four per cent of the time. Yet, many shy or very sensitive people may have a mild problem in this area, while many cultures use alcohol or some other socially accepted drug, for example, tea, to prompt or initiate social interaction. Social contact is assessed on social contact with friends, work associates and others who are not family, significant others or professionals. Significant others are not allowed to be a person's main social contact. This appears to lessen the importance of participation in life events with extended family, important in many cultures, even within the USA. The individualisation of American culture today lurks under the questions used for residence, as the highest achievement is *independent living without supervision or concern from others*. Full independence at a normal pace in eating, dressing, bathing and hygiene is again the gold standard for self-care. Mildly slowed completion of self-care or use of assistive devices, incurs a score of one, and three

scores are attained if moderate assistance is required. It is therefore quite easy and quick to reach a ceiling of 'disabled person' when assessed against a very high norm. Yet, Lezak and Malec devised this scale because of their conceptual and clinical difficulties in using the other popular Disability Rating Scale used frequently to assess levels of disability or disablement among people with disabilities. Using this rating scale, Malec (2004b) stated that he himself could quickly be categorised as disabled, as he does not do the shopping or cooking in his home. This situation could also arise with the MPAI-4.

Social participation or community integration, while being a major goal of body work and cognitive rehabilitation (SCR, 2005), does not necessarily lead to being really included in a social network or having a good quality of life. Quality of life is that term often used to cover well-being, feelings of social inclusion, etc. Quality of life "…is about the goodness of life, and in relation to health is about the goodness of those aspects of life affected by health" (Bowling, 2005, p.7). However broad, useful or otherwise this concept is, people living with ABI seek like everyone else a 'good' quality of life, however conceptualised.[104] Hop, Gabriel, Rinkel, Algra and van Gijin (1998), who studied the quality of people and partners after having a sub-arachnoid haemorrhage, named three positive points raised by their middle aged respondents, but seldom noted in the literature. Firstly, most people were glad to get a 'second chance' at life. Secondly, they appreciated their social relationships more than before and thirdly, some actually felt less stressed than prior to the haemorrhage (p.803).

It must be remembered that "not all people enjoy a good quality of life prior to injury" (Conneeley, 2003, p.442), a point that is also often neglected in the literature. Factors linked with a poor quality of life such as poverty, are often the cause of their injury. This is especially so for those injured by friends when joy-riding, or in gang fights using head-kicking assaults, knives or guns. In

[104]Linked with the above discussion regarding predictive measures, Brown, Gordon and Haddad (2000) seek a model for predicting the subjective quality of life among people with brain injury.

Conneeley's study[105], post injury, the personal loss of control or a restriction of personal autonomy were the main factors impacting on the participants' perception of their quality of life (p. 445). Yet, according to Huebner et al. (2003), increased community participation did allow adults with ABI, approximately two years post injury, to feel they had a greater quality of life even if they experienced limitations in decision making, and were often depressed or withdrawn.

Conclusion

Yes, participation of various populations engaging in life events involves many mechanisms, structures, and social processes (Desrosiers, 2005). If studies and/or services continue to focus on the views or changing behaviours of isolated individuals, trying to predict and measure this changing community integration or quality of life is perhaps an impossible and unethical task. Using Husserl's isolated individual is problematic, because in agreement with Crossley (2005), I accept that our "individual subjective life is fashioned from the materials of an intersubjective domain" (p.175). Both the social and others always play an important part in community integration. As noted above, some of the main components of community integration for people with ABI were around the constructs of belonging and participation, especially in decision-making, and not always independent functional abilities. Yet, social and community integration as developed by politicians and professionals seems to be accepted as being a state, considered non-problematic, and mainly up to the individual to achieve. The term inclusion is considered more politically correct, and links more with the reality of a process and a negotiated partnership claims disability studies scholars, Swain, French, and Cameron (2003). But, like the concept of assimilation, they are not theories, they are simply concepts. But they are concepts we can ill do without (Brubaker, 2003).

[105] Conneeley's (2003) study was carried out with eighteen people with ABI only one year post-injury which is acknowledged as "a relatively BRÍef period in terms of recovery from TBI" (p.445).

CONCLUSION

Seeking improved capabilities, fun, meaning, and/or social engagement in life is the ultimate goal of rehabilitation, when embodied with ABI and embedded in Ireland today. This Chapter has highlighted a small sample of some of the many real 'brute' facts and the socially constructed facts involved with or hidden behind a career with ABI, both within the specialised rehabilitation centres and in local society. I have demonstrated that bio-medicine can now work generally quite well on the 'object body in a coma', but enabling the disabled person (with ABI) in local society, where most of living with ABI actually occurs, or should occur more, is only beginning to receive the attention it requires and deserves. The art of medicine, as well as the science of medicine, is seldom highlighted, unless the medical personnel involved are passionate and ethical about qualitative disability research, power-sharing and our shared humanity. Quality individualised rehabilitation at the right time, in the right place, is urgent, even if many of the assumptions underpinning neuro-rehabilitation processes and assessments may be contested. But what is the best time and where is the best place for neuro-rehabilitation or is all of life post-injury to be considered 'rehabilitation'? Should the focus of neuro-rehabilitation be on cognitive rehabilitation or on behavioural rehabilitation? Should the priority be on motor function or on identity?

As noted above, the priority of neuro-rehabilitation may have changed over the eras, yet for many people, all elements are required and are still included to varying degrees. With much writing on identity in society today, identity is also very topical in neuro-rehabilitation. For the people under consideration in this study, neuro-rehabilitation at an individualised clinically functional (table-top) perspective, is vital, is necessary, but it is not sufficient. Neuro-rehabilitation, especially self-awareness work, is limiting if the focus is on clinical and specialised interventions. Much relearning and recovery takes place through everyday community living, which is slowly being discussed in ABI literature. The dominant ABI discourse claims plateauing at an early stage with little focus

post year one or two, but this is based more on traditional fast track neuro-rehabilitation. Within the dogma of evidence-based practice today, there is an on-going search for more control trials to show evidence for efficacy of neuro-rehabilitation. And within the professionalizing projects of various rehabilitation disciplines, there are demands for all professionals involved to show stronger evidence for their effectiveness. Occupational therapists, for example, have to show evidence that greater physical independence or improved management in managing cognitive components or activities, or participation in vocational and/or leisure goals is attained.[106] But randomised control trials are not suitable for the ultimate goal of neuro-rehabilitation, which is according to many writers, community integration. But real community inclusion is not at the discretion of the individuals with ABI or their families.

As noted above, self-awareness generally improves more over the long-term, yet the broad social context, the space and place, within which the person is expected to 'accept the new me' and adapt, is seldom asked to change. There are few ABI public awareness projects in Ireland[107]. Yet, public attitudes and values play a major core role in where, when and how the person 'adapts' and learns about their own ABI. As Seymour (1989) stated,

> amidst the energy and enthusiasm of the rehabilitation program it is seldom considered that the real concern for the...patient today is not that he or she will die but that he or she may have to live (p. 65).

As Seymour suggests above, there is great energy and enthusiasm within teams working in the golden moments of high-tech intensive care, neuro-surgery and neuro-rehabilitation. There is now a growing high-tech focus with fast through-

[106] Within recent clarification in Irish employment legislation, the word 'work' was replaced with he term 'occupation' for agencies funded by the HSE. This differentiates funding and programmes funded by the Department of Health from Department of Trade and Employment. (Personal communication with senior HSE official, January 2007).
[107] An annual Brain Injury Awareness Week was recently introduced. This week is co-ordinated by the Neurological Alliance of Ireland.

put. But neuro-rehabilitation need not always be located in a specialised centre. Retraining and relearning everyday living through and with slow and natural recovery in or near the person's home has many advantages for all concerned.[108] As with other single-impairment groups in the past, the clinical perspective or clinical discourse dominates community living. But this could be because fewer people in society or scholars in other disciplines were ready or interested in acting on community integration.

The purpose of my research was to study how people manage long-term living with ABI in the early years of this new century. As with most evidence-based practices, whether in education or health, 'evidence' will, or may depend, on why, and how evidence is constructed, who is involved and what is counted as evidence. There is little evidence in Ireland about adults living long-term with ABI on their own terms. The rest of this thesis is therefore about how and why I proceeded with this research and about how some disabled persons live with ABI in local society. The Chapters based on data generated with and from participants living with ABI follow my Chapter on methodological considerations, which is next.

[108] See Dirette, Plaiser and Jones (2008). *British Journal of Occupational Therapy* 71 (2), 44-51.

CHAPTER 3 METHODOLOGICAL CONSIDERATIONS

"Methodology is itself theory" (Skeggs, 1997, p.16).

While working through the various theoretical and methodological assumptions linked with this research, I remained cautious about methodologicalism and 'research recipe books'. Instead, I sought "a theoretical space in which multiple answers are situated" (Wagner, 2001, p.129). From within this space, my interpretations about this social phenomenon in question, living with brain injury in Ireland today, were developed. My findings are documented in later Chapters. In this Chapter, therefore, I explain how and/or why required methodological decisions were made within a framework of particular existing social theories, research ethics, and pragmatic needs. Details on the research design, and how new data was co-constructed to construct new knowledge, and more questions, are also presented here. Rather than documenting all the complexities and uncertainties involved in this research study, this is, as Alvesson (2002, p. 9) stated, the simple version of the complex research process, written in forty pages.

In the first section, I present my theoretical, ontological and epistemological position, and why weak critical realism within a critical methodological pluralism was chosen as the overall methodological framework for this thesis. In the second section, my research design and methods used in this study are detailed. The co-construction of data and data audit and how and why my analysis and interpretation proceeded as they did in practice are presented in the third section. The fourth and final section discusses issues dealing with claims made about this data including relevance, generalisation and reflexivity. Although this Chapter is written in a somewhat linear, chronological order, much interweaving, abduction, to-ing and fro-ing, and deep interpretation occurred in practice. Relevant details for this Chapter were decided by balancing the need for details of research events and issues with ethical considerations, along with the requirements of the reader,

academic requirements, and what may be required for any related inquiry. It is accepted that a replication of these findings is not possible, but the broad research design and methods used may be replicated. Many details are in Appendices 8-20.

3.1 MY ONTOLOGICAL AND EPISTEMOLOGICAL POSITION

For me, what I say or can say about the world, ontology, is linked to how I choose to find out or know about it, epistemological decisions. Things act and exist in life independent of our descriptions of them. As Crossley (2005) states, the world, our reality, and especially the social phenomena in this inquiry and other inquiries, pre-date our knowledge of them, considerably, "and will in all likelihood outlive [them]" (p. 300). For some, especially relativists and standpoint theorists, ontology is a theory of being, and 'being' is accepted as equal to 'knowing'. Such thinkers generally claim that just by being a woman or a disabled person provides "epistemic privilege" in studies. With other critics of standpoint theorists, I do not accept that 'being' is equal to knowing. Yes, there is a link between ontology and epistemology, but as the feminist sociologist Skeggs states, one need not determine the other. Knowing requires more than being (Fay**,** 1996) while solipsism is of limited help in social science. Human thought(s) or meanings yes are a necessary condition for social 'facts', a component of social reality, but they are not sufficient. Language and social contract or conventions are also included. Yet, people holding very strong constructivist principles "…seem to imply that human agents can shape social facts at will by agreeing on how to describe them" (Collins, 1997, p.110). Realism, but of the non-naïve type, is for me an ontological position. It provides me with a framework about what exists, rather than a theory of knowledge of what we can and cannot know. For non-naïve realists, whether subtle, critical, pragmatic, or complex, "the world does exist and we can know it although the process of knowing is a social process with social content" (Byrne,

2002, p.3).[109] (For more on non-naïve realism see Carter, 2000; Hammersley, 2002; Mattingly, 1998; Porter, 1998). This does not mean accepting the 'epistemic fallacy' whereby the nature of the social world is reduced to what can be seen, measured or observed. This empiricist epistemology or 'fallacy' is removed in non-naïve critical realism by Bhaskar, Giddens, Habermas and others, and is one reason why this meta-theory informed this inquiry[110]. Such an ontological position accepts and can use a constructionist epistemology, because 'the world and our knowledge of it are two quite different things and we should not confuse the two" (Crossley, 2005, p. 249). Davies (1998), however, claims that this separation and acceptance of things 'out there' in the world, independent of their descriptions, is just a device "to cement their own legitimacy as realists" (p.145), against relativists. Relativists generally claim that there are as many ways of describing or theorising a social phenomenon, as there are theories, or conceptualisations. I accept and enjoy the fact that post-modernism or late modernity celebrates diversity and plurality, and that multiple paradigms interact and co-exist today. This freedom is important to me, but not if it leads to an unfettered relativism ending with a focus on the celebration of difference only. This result may lead to the loss of any sense of sameness or any sense of shared humanity beyond individualised discourse.

With critical realism, communication across different social theories and perspectives is possible in our social reality and not incommensurable as many others believe. But not all knowledge is of equal importance. Therefore, non-naïve realism accepts yet limits relativism, especially particular types of relativism. Critical realism accepts epistemic relativism, but not judgemental relativism which claims that there are no grounds for assessing knowledge claims. Various criteria may be used to review or assess results of inquiries, including emancipatory,

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[109] Non-naïve realism, unlike simple naïve realism, does not accept that research can just '*tell it like it is'*. Pure relativism is not accepted either when co-constructing data, delving into and beyond complex everyday realism, but without reifying the social.

[110] Unobservables are important in this ontological position, and "what can be said about the nature of the world (ontology) is [not] reduced to what can be known by means of a particular (that is, empiricist) epistemology…"(Stones, 1996, p. 28).

historical, or instrumental while each knowledge discipline develops their own dominant criteria for appraising quality in their related studies. Emancipatory research[111] aims to show relevance between social practice and theory in public life, rather than romantic intellectualism (Chouliaraki and Fairclough, 1999, p. 34). Historical criteria within an explanatory-factor framework, identify relationships between background or underlying preconditions and triggering events, or in value-neutral explanations, the focus may be on situational history, causes, or on specific break points in history (Hall, 1999). Instrumental or technical criteria, could, for example, include a focus on critical 'practical principles', for example, in development work, education or health or social care (Finlay and Ballinger, 2006; Kemmis, 1996).

Multiple perspectives may be had and are required on our shared world, but in agreement with theorists such as Crossley, Hammersley, Porter and others, I do not accept that we live with multiple realities. There are, I believe, only various perspectives on our one reality, our time, our space, our one world that we inhabit, not multiple realities. Multiple realities are claimed by relativists who accept individualised contexts and individualised meanings, asserting that there is no unique truth, there is instead "the post-modern emphasis on truths, rather than Truth" (C. Hughes, 2002, p.178). The meaning of the word 'truth' in critical realism allows for debate and change, but slippages of meaning are not always beneficial or wanted, especially by air-pilots, surgeons or by people in a soup kitchen seeking food. But non-naïve realism is not similar to positivism as so often claimed. They differ in three main ways, namely, the nature of causality, the presence of unobservables, and in the nature of the social scientific method (Crossley, 2005, p.246). These are important issues in this study, although I was not searching for one 'cause and effect'. Critical realism also incorporates the differentiation and stratification of reality. Reality is differentiated by three ontological levels or domains; the real, the actual, and the empirical. The real

[111] For example, many working in this genre seek more explicitly to reduce suffering or oppression and improve tolerance in our world. See Barnes, 2003; Mercer, 2002.

(causal) domain is the deep dimension made up of mechanisms; the actual event is made up of all events, whether experienced or not, and all that caused that event to occur, while the empirical event is made up of experiences (Danermak, Ekstrom, Jakobsen and Karlsson, 2002; Outwaithe, 1987; Porter, 1998). If we focus only on the latter, that which was measured, witnessed or heard in empirical research, although very important, the terrain of ontology is 'flattened'. There is then little or no reference to, or search for, unobservable social relations (see Willmott, 2002, p. 227). And as Danermak et al. (2002) state, critical realism "…repudiates a science that reduces knowledge to knowledge about the directly given or observable" (p. 96). Unobservables and unintended effects of events, norms, or policies are also important as they play a role in determining explanations which are required in social research because interpretativism on its own is one-sided (Fay, 1996). [112] While non-naïve realists accept that we cannot get in touch with much of reality, we can access many indicators of those unobservables. For example, continuous empty food cupboards and low welfare cheques act in Ireland as good indicators of poverty or unemployment. Hidden mechanisms, such as power and money, are accepted as important generative mechanisms in life events for critical theorists. It is often these hidden mechanisms that may link 'a and b', or "…highlight that there is something about the nature or essence of a and b which constitute the causal relationship between them" (Crossley, p. 246). There are also often many reasons or deep mechanisms causing the event(s) in question to occur, while certain links may be identified which may cause b not to happen, even if the tendency is generally the opposite. Critical theorists also use a relational differentiation of reality, because it is only in the interaction of the differential powers between mechanisms and subjects in an open system that a result is produced. Our world or reality is also stratified for critical realists between structure and agency, or "…between the 'parts' and 'the people',

[112] Unlike the natural sciences, interpretativism in social research, involves researching the meaning and understanding of social phenomena, and therefore, these are necessary and urgent but they are insufficient. A social science, including health care research, requires also a search for underlying causes or mechanisms, and/or an explanation, thereby going beyond participants understandings and meanings.

necessarily related but irreducibly distinct" (Carter, 2000, p.65). I would claim that our increasingly specialised knowledge society is creating even more strata.

In social research, and especially for this study, it is important to gain the understanding and stories of people living with ABI, remembering that their accounts were constructed for this particular study. Critical realism is not about 'telling it like it really is' as that is too naïve, as if narrative simply represents experience (Mattingly, 1998). Thus, narratives here are the important starting point of this study seeking to listen to people's own told stories, using their personal meaning frame. Then, I go beyond individual experiences using the double hermeneutic[113] of social science to present their views, meanings, or experiences. While their individual stories are very important to me, we need more than experiences and greater understanding, to change problematic social structures, even if gaining shared agreement on meaning can sometimes be difficult. Salient theoretical issues regarding narrative in general are discussed in the next Chapter, together with further details on holistic or final data interpretation involved in this study.

Different foci of methodologies used in social theory

Methodological individualism[114], strong or weak, is the methodological framework used when the needs and desires of isolated individuals are expected to explain our reality. Oliver (2002), one of the authors of the social model of disability, dislikes the frequent use of naïve strong methodological individualism in disability research. Oliver claims that many individuals with disabilities are over-researched, while the organisations and policy-makers are not studied sufficiently and/or are not expected to change. For other social theorists, the study and explanations of social phenomena are based more in a more holistic 'systems-down' approach, as if social structures determine all individuals. Relationalism, however, entails that

[113] Unlike natural science, social science involves studying other people's interpretations of their world or their reality. Then, using the double hermeneutic, researchers offer new knowledge, social science explanations of everyday social or common sense.
[114] This insists that facts about social phenomena can be explained solely in terms of facts about individuals (Willmott, 2002, p. 227).

we take neither individuals, society nor parts as fixed entities to explain aspects of our social worlds (Crossley, 2005). The focus is therefore on interactions and relationships between the various agents and social norms and practices. The different foci of methodologies are depicted next in Figure 3.1.

Figure 3.1 Individual, Society and Social Relations

METHODOLOGICAL INDIVIDUALISM	HOLISM	RELATIONALISM
Society ↑ Individuals	Society ↓ Individuals	Society ↑ Interactions / Relations ↓ Individuals

(Source: Crossley, 2005, p. 267).

The relational self rather than the isolated self was also my starting point as I focused on ongoing and changing selves. As relationalism and the relational logic are used in non-critical objectivist social science research, a dialectical logic with or from a relational logic is also required. This is considered more important in critical research methodology (Chouliaraki and Fairclough, 1999, p.32). Dialectical logic acknowledges the ongoing struggle and activity are being formed by, and often limited by, our discourse, language and/or social relations in social practices and patterns, while simultaneously trying to change them. Just as there is a dialectical relationship between this research, researcher and given structures, our unequal health or social care systems include both “the precondition of social action and the products of action” (Chouliaraki and Fairclough, 1999, p.32).

A difference also exists for critical realists between the transitive objects and the intransitive objects of reality. The transitive objects of reality, those many theories of our knowledge, continue to change, yet many intransitive objects in society which do not occur at random, are fairly stable and slow to change. Critical realism accepts that it is very important to research and identify the power and mechanisms of these intransitive objects of social science, especially when discrimination, poverty, hunger or oppression are present. It is important therefore in empirical studies, to search for those wanted and unwanted generative mechanisms and the consequences of such mechanisms for demi-regularities.[115] Although social interaction implies constant movement and change, yet "that which appears relatively static does so only in virtue of ongoing interactions which perpetuate its relatively stable form" (Crossley, 2005, p. 266). That may be one reason why even the best formulated plans for social change may not work.

Because the mechanisms involved in social processes in real life may not appear at random, or in pure form, many theorists have adopted Bhaskar's philosophical realism for a sociological critical realism. (See pp. 83-85 above. See also Archer, Bhaskar, Collier, Lawson and Norrie, 1998).[116] This study used much from such sociological adaptation to manage social relations and issues between parts and people, whether individual actors or collective agents. Layder (1998) was used because of his affinity with critical realism and critical theory, and because of the importance he gives to "…the analysis of power and domination in society as an essential part of the endeavour of social research" (p.147). Layder accepts the power of discourse, but claims that this does not exhaust the analysis of power in social life, plus not everything in life is discursive. The concept of power and the fact that power exists in all moments were accepted as a given in this study, including the power, real or assumed, that the disabled person has over their partner. Disabled persons are often depicted as powerless, yet, like all people in

[115] Demi-regularities are those patterns that change very slowly in society such as gender, class and ethnicity patterns (Chouliaraki and Fairclough, 1999, p.166). Thus, it is possible to link disability with class, ethnicity or sexism.

[116] I was also informed much by Carter (2000), Danemark et al. (2002), Layder (1998), Hollis (1994) and Porter (1998).

social situations, many disabled persons do often hold certain open and hidden power relations over their family and/or their partner.

Critical theory also informed this research as noted in Chapter 1, although I learned much from other people's use of the blending of various theories rather than accepting all or none. For example, Chouliaraki and Fairclough (1999) "do not accept postmodernist social theories that abandon the project of social struggle …or ontologies that conflate the social with discourse nor with epistemologies that advocate a 'just gaming' position for theoretical practice" (p. 89). Such theorising, with little or no application to everyday life, is not of interest to me. The writers above work within post-structuralism, but without adopting either the post-structuralist reduction of the whole of social life to discourse. Like them, I do not accept post-structuralist judgemental relativism which claims that all discourses are equally good or bad constructions of reality. While discourse is important in life, and in this study, it cannot be considered capable of representing or solving all things, especially since not all social interaction is discursive. As Aggar (1991) has stated, "word choice cannot do our thinking for us, nor solve major intellectual controversies" (p. 28).

Conclusion

Weak critical realism was the meta-theory used in this study as I was not aiming to provide pure theoretical explanations as with strong critical realism. This allowed me to go beyond a flat ontology, to include tendencies, patterns, unobservables, relationships, relations and power linked with told stories on living with ABI today in Cork and Kerry. Non-naïve realism also allowed me to consider some of the underlying mechanisms and dialectics involved in certain empirical experiences of people with ABI. I held onto a moderate social constructivist argument believing we are not determined fully by the social construction of reality, yet accepting that people and parts are interlinked. This framework gave me adequate space for holding on to some realism while discussing many interpretations of the diversity, fluidity, and uncertainty involved in living with ABI. Details on the main applied

aspects of this research design, methods, and claims made about this study follow in the next three sections.

The table 3.1.below presents an overview of my methodological framework.

Table 3. 1 Framing my Methodological Framework for this Study

ONTOLOGY	EPISTEMOLOGY	THEORETICAL PERSPECTIVE	METHODOLOGY	METHODS
Non-naïve critical realism	moderate Critical Realism moderate Social Constructionism	Critical Theories Critical Realism	Pluralist/hybrid Critical Methodologies relationalism emancipatory	*Narrative approach in interviews *Analysis of narratives *Identification of patterns, themes and possible mechanisms *Critique *Interpretation

3.2 RESEARCH DESIGN USED

This section discusses sampling, inclusive and exclusive criteria, and how and why a narrative approach in interviewing was used in this study. My chief data source were people living long-term with ABI, along with academic and grey[117] literature, and my own theoretical ethical position. This second section is discussed in phases to delineate the main stages of research.

Phase 1 The construction of research categories

In my initial proposal submitted in January 2004, I sought people from the rural parts of both counties Cork and Kerry in southern Ireland.[118] A rural focus was made at the start, as I did not wish to be a researcher who focuses only or mainly on urban needs and issues. But the rural-urban boundary was not required for ontological or analytical reasons in this study. Assuming these two counties had much in common, the research population was sought from Cork and Kerry. Plus, many public services are planned or organised specifically for these two counties. Initially, romantic notions or assumptions were held about the rural-urban category. I assumed that disabled people in rural areas, although having difficulties living away from specialised urban disability services, attend local events, such as 'the pub', church, or Gaelic hurling and football matches more often than urban disabled people. I also assumed that rural dwellers would interact with their neighbours often out of need or duty more often than urban dwellers, or because they have more time for 'chatting'. Finally, I also assumed that rural dwellers with ABI may live with more boredom during 9 am - 5 pm on weekdays. Access to limited ABI services in Ireland is a problem for people with ABI living in urban settings, while many people living with ABI may not require special individualised services. Hidden assumptions implied that because a person lives in a rural area, they accept or adopt a rural identity. Although change may occur slower in

[117] Grey literature, from conference material to local radio or newspapers, was also very useful in this study.

[118] Different plans for involvement of 'new' residents, i.e. people from Nigeria or Poland living in Cork or Kerry, were not made, although they would have been welcomed and included if they had chosen to volunteer.

particular practices in rural Ireland, this may be linked to religious, cultural, financial or mobility issues, rather than only the location of home and/or the provision of specialised services.

As rural living does not imply only one particular way of living, and as I chose not to exaggerate a rural-urban divide among people living with ABI, this specific inclusive criterion was removed. Social class and gaining access to money for additional paid help, or to assist in the additional costs of living with a disability, could be a bigger issue than geographical location. The social phenomenon under study here is to be found in the social practices of people living with ABI in any part of these counties, accepting that I cannot be in all contexts even within these two counties (Mason, 2002a).

Also, at the start of this study, six 'couples' or six 'sets of two' were sought with the researcher open to any combination of two adult persons living together. Initially, I assumed they would be living under the one roof, but as McCluskey (2004) has stated, "living separately need not signal the end of family relationships" (p.72). The legal, residential, and social issues involved in determining a family, a couple, or even a household highlighted numerous definitional difficulties. Thus, this initial category, couple, was also reviewed, and along with the category 'rural' was also eliminated as it was not essential to this inquiry. Recognising the problems relating to my initial categories allowed me to become more aware about my object of study and how all of these issues might affect those who were to participate in this study (Mason, 2002a; Stanley and Wise, 1990). The required analytical categories for this study were ascertained and non-essential inclusive criteria from original sampling requirements were removed. Criteria for inclusion in this study finally focused on the object of study, *Living long-term with ABI in Cork and Kerry.* A representative sample of people with ABI was not sought, but rather a sample of participants who could offer a sense of the 'core' population of this research. These are, people living with ABI, even if they self-represent and were self-chosen. Who and how participants were

recruited and some reasons why people chose to join this inquiry are discussed next.

Phase 2 Sampling and Criteria for Participants as data sources

Purposive sampling was used and six participants were accessed through Headway Ireland (Cork)[119], the main community service for people with ABI existing in Cork in Spring 2004. Despite the limitations of accessing participants only through this one agency, they did have a local counsellor who agreed to assist with any issues participants or I would like to discuss during the research process. The services of this counsellor were not required throughout this study. Within limits set predominately by convention in the academy, and formal University requirements, I was in a position to shape the research in a pragmatic, ethical manner. Small numbers were sought to allow for more in-depth interaction with the participants, along with time for learning and critical thinking. As Steward (2006) states, "more does not mean better" (p. 42). Research planning, which involved allocating time for repeat interviews and transcriptions by the researcher, enabled me to decide on twelve people as the optimum number of participants for this study. Time for slow speech, for writing out certain words during interviews, and for managing or preventing fatigue was also incorporated into the design of this study. This design was to allow for as full inclusion of persons with ABI as was possible in our meetings. The empirical design of this study included interviewing twelve people individually, six times, in various locations, over a period of approximately two years. Through this gatekeeper agency, I sought six people with ABI, five years post-injury in the age group forty to sixty-two years for this study. (More details on the recruitment of participants follow below).

The first four rounds of data generating interviews were planned to have approximately three months between each meeting. Following a longer six month time gap, Round 5 was planned and used to share my interpretations with

[119] Headway Ireland is a voluntary self-subscribing organisation for people living with or interested in ABI who happen to hear or know about this agency.

participants and to share discussions about the final thesis. The sixth official meeting was planned to allow participants to see or hear more about the final thesis and for closure, a final thank you courtesy meeting. The writing up phase was delayed for some months as I commenced employment in the academy, but I continued to meet with three of the participants with ABI almost monthly. In reality, I met five of the disabled participants many times following the fifth interview even before and during the writing-up phase. The final Chapter plan and the one page pen portraits of all the disabled participants[120] were distributed to and/or discussed with the participants with ABI in November 2007 as the sixth round of formal communications. Full closure with all participants is unlikely, but a final formal appreciation will be made when the official process is completed.

Inclusion Criteria

The theoretically significant population categories in this study are:

1. adults with ABI, living at least four years with continuing problems from their ABI; and
2. approximately forty to sixty-two years of age.

The cause of their ABI was not relevant here.

About years post-injury

A specific number of years of living with ABI was not essential here once people were about four-five years post-injury. As noted in Chapter 2, recovery from ABI, if it does occur, is often slow and long-term. Some chronicity or years post-injury assumed that much recovery and some personal-social adjustment would have occurred. I also assumed that the people with ABI and/or friends and family would have built up their own form or pattern of home-living, their own tacit knowledge and that they would hold positive and negative stories or experiences available for inclusion. As Claire, a participant, said to me in our first telephone communication "*you need people like me. If you don't get them how will you know*?" This was an insightful remark from a person with ABI on the predicaments of the lone scholar!

[120] Pen portraits on the disabled participants are presented in the next Chapter.

About age range requirements (40 – 62 years)

By focusing on mature adults, I assumed that they had their own independent life pre-injury, with some of that spent away from the family home. The lower age of forty years was used assuming that the majority of people have settled down by this age. They would have decided on their views about commitment in a relationship or not, and most people, especially females, would also have decided whether they would have children or not, or they would have had children. An upper age limit was considered so that people would not be transferred to a geriatrician during the study. A person aged sixty-five, with a stabilized ABI in acute hospitals, in a neurosurgical unit in Cork at least, may be clinically transferred from a neurosurgeon to a geriatrician for medical care.[121] Also, at the age of sixty-five years, placement in or access to a Nursing Home is somewhat easier in Ireland, and often encouraged.

About speech, memory or other requirements

As the main avenue of eliciting participants' stories was through very loosely structured one-to one audio-taped interviews, speech was required. The ability to speak or converse was required, but perfect speech was not required. This decision was made simply by asking myself, is it possible to have a chat with this person and can I understand what this person is saying. As our meetings were audio-taped for data analysis and interpretation by me, the researcher, their voice production needed to be at a level at which it could be audio-taped. To be in a position to convey stories and personal experiences, the ability to recollect and process thoughts was also required. As all people can have amnesia about certain events or periods in their lives, the participants were not required to have perfect memory. Their level of personal independence, emotional status, mobility, co-ordination, employment situation, level of participation in any social or religious organisation, and certain other social factors were not specifically factored in or out.

[121] Such transfers of patients occurred between medical specialists in Cork University Hospital in 2003, where I worked for six months with people with acute ABI as a locum part-time occupational therapist.

Why I included interviewing with a partner

Each disabled person was asked to name and ask a significant other to take part in this study, but not a parent or son or daughter. I wanted participants from the same generation if possible without the parent/child or child/parent role. As Hollway and Jefferson (2000) claim, "significant others can provide, or fail to provide, reliability in external conditions, containment and holding" (p.138). Separate individual interviews were sought with this partner or friend, because firstly, they were or are in this situation together, and secondly, the person with ABI may talk about them. Thirdly, if the person with ABI had major memory problems, I could check non-problematic, less intimate data with this person, for validation but only if really warranted. The stories from both were expected to "illuminate and reflect upon each other like gems of a necklace" (Betraux and Delcroix, 2000, p.74). Much disability research focuses on the physical capacities of the disabled person(s) for participation, speech, memory, etc., often assuming that the non-disabled partner(s) have perfect bodies and abilities, including literacy. In this study, the other participants were also required to have good enough speech, memory, and time for inclusion in this study.

Data generation with chosen data source(s)

Rorty's pragmatic question 'what is it that you want to find out about' helped me focus on the purpose of the inquiry and that which it may serve, rather than worrying excessively about a "methodological-ontological debate" (1991, p.96).

The table below based on Mason (2002a, pp. 28-29) links my broad research questions with data sources and/or research methods and purpose in this study.

Table 3. 2 Chart linking Research Questions and Methods

RESEARCH QUESTIONS	DATA SOURCES / METHODS	JUSTIFICATION
How people live with ABI here, years after the event?	* Narrative approach interviews with participants * Observation	*Repeat interviews will provide ambiguous, but useful representations of lived experiences.
What are the trends and patterns contributing to the social construction of ABI in southern Ireland today adding to the real differences caused by the ABI?	*Interviews with participants *Public documents on disability services and ABI services in Ireland today * Attendance of ABI meetings	*Interviews will highlight particular trends on coping with their ABI and local social construction of disability.
How do disabled participants find enjoyment or personally meaningful occupation today or otherwise?	*Interviews with participants	*Repeat interviews open to positive aspects of living and not only needs or problems.
How do their narratives relate to rehabilitation literature and practices here today?	*Interviews with participants *Academic and grey literature	*Deeper interpretation of all my data sources will help me to see whether needs and reality 'fit' and from which I can develop my argument.
What is the interface between their '*stock of knowledge*', my research and theorising about disability today?	*Interviews with participants *My analysis and interpretation	*My analysis of their 'whole narrative' with me, literature and my interpretations provide the basis for this. *Reflexivity.

(adapted from Mason, 2002a, pp. 28-29).

I accepted that I could find out more about participants' lives, beliefs, and desires through what they say over time, in whatever way they say it, or however long it takes to say things in one setting. Therefore, talk was my main means of

generating data, although much was learned through observation and non-verbal communication. How the respondents focused their stories or identified themselves was not up to me. If they all had presented with happy stories about their lives, with ABI only playing a very minor role, much significance and delight would have been placed on such findings. Having the advantage of shared everyday language, ABI language, and many shared cultural assumptions, I knew that I would, and did, "gradually pick up the knack of understanding (them) without conscious puzzlement or inference" (Rorty, 1991, p.108). Further theoretical issues linked with narratives are explored in Chapter 4.

Much time was spent on designing this study to allow the main issues to come from the participants, but which were linked with the original broad research questions. Time was incorporated for a longer 'self story' or 'told story' to emerge Therefore, a narrative approach in repeat interviews was planned to allow this to develop and to include time, and to manage the limitations of interviews. (See section 3 of this Chapter). Interviews are problematic as they assume a stable reality, fixed meanings, while assuming that what people say corresponds with what people do in their lives according to Silverman (2000). But over two to three years together in dialogue, a 'gestalt' even if limited, was expected to develop in this study and it did. Repeated interviews "usually result in closer rapport and may be useful when change over time is of interest" (Mathieson, 1999, p.121). Such interviews were used here not to record change, but to allow for the development of rapport, "that surprisingly ill-defined concept given its centrality to social research" (ibid, p.128). Repeat interviews were also used to allow me to gain a deeper interpretative understanding of the participants' lives, to allow us to work in slow time, to allow time to seek clarification on any issue, and as mentioned above, to allow participants to cope with any fatigue. Although Mathieson (1999) claims that "repeated interviews can be seen as problematic methodologically" (p.129), she states that such interviews are important to obtain depth of information and when interviewing people with chronic illness.

As noted in Chapter 1, and in section 1 of this Chapter, my aim was to work within an emancipatory framework as much as possible, in designing and carrying out the study, but also in assessing the knowledge claims made. This was noted above as one of the criteria that can be used to appraise the results of studies. This study therefore sought participants' involvement in the research process as much as possible, within the demands of the academy and my personal situation. Participants were given the freedom to meet, talk and drop out of this study whenever they wished, to decide what was said or not said, to make comments on transcripts, and to review my final interpretations. Albeit not an action group research, individually participants decided the basic content of this study, and they were also involved in prioritising issues and needs. Researcher responsibility is taken however for going across and beyond their stories as this study was not a phenomenological study based on methodological individualism. I was a little uncomfortable with pure self-talk or the "tyranny of narratives"[122] (Reissman, 2002a), where the self is almost reified and where the positive or negative from local cultural public narratives and social structures are absent. The limitation of personal narratives in research was in my mind long before I accessed Reissman's paper in October 2004. But this research design, however, allowed for any changes required when working with 'messy reality' and the uncertainty in the lives of the thirteen participants[123] involved in this study (Becker, 1999; Chamberlayne, Rustin and Wengraf, 2002; West, 2001).

Ethical approval for this research was sought and granted first by the University College Cork Clinical Research Ethics Committee in January, 2004, and by the chief clinical psychologist in Headway Ireland Dublin and the Southern Manager in March, 2004. It was acknowledged that participants as members of Headway Ireland may have had additional supports not available to non-members. However, this membership was of limited benefit to most participants at the time of our

[122] 'The 'tyranny of narratives' does not allow for much or any social linkages or critical debate on a personal narrative. Rather like psycho-therapy, deeper reflection does occur, but usually only inwardly and individualised. See Reissman (2002a).
[123] The thirteen focus participants in this study includes the twelve 'external' participants and myself, the researcher.

interviews, although four people had benefited to varying degrees at earlier times. One person still attends Headway today. The local Headway counsellor also agreed to my request to accept referrals for any counselling if participants required or requested this during the research process.

Phase 3 Recruiting Participants

Following discussion with the local Headway Ireland Manager, a one page reader-friendly information letter was prepared. This used a small amount of text in simple English with some graphics. (See Appendix 8). A full-text recruitment letter was also prepared and delivered with the above (See Appendix 9). In April, 2004, this flyer and letter were distributed through the Headway Ireland magazine to approximately seventy members[124] in counties Cork and Kerry. A postal strike in Dublin impacted on the first week of the distribution of this newsletter. The local Headway Ireland manager also distributed my information letter to some of her community-based workers. My request for volunteer participants was also noted on the Headway Ireland website www.headway.ie although an error was present in the email address printed out.

Seven people living with ABI replied directly to me, with six people fulfilling my inclusion criteria.[125] Telephone communications initiated the start of our ongoing dialogue. Four self-volunteered participants stressed their role in helping me in my study "*in order to help others*", while Joe participated partly to give him "*something to do*". Four of the six disabled participants, Annie, Claire, Joe, and John, stressed their role in helping me understand more about ABI, and directly or indirectly, that they could help others with ABI. One person, Claire, wanted "*to get it [ABI] more out into the open*", because as another person, Annie stated, "*we are a forgotten race*". The six disabled persons, Annie, Claire, Sinead, Vivienne,

[124] Many people join Headway Ireland, as I did, because they are interested in the work of this agency.

[125] The seventh person, although not eligible for this study, wanted to highlight the needs of her dying bachelor brother who had a brain tumor. Her two main issues were transport difficulties accessing radiotherapy services in Cork city, and the underlying assumption in our health and social care services which appear to be planned for married couples or 'the family'.

along with Joe and John, are introduced in the following Chapter along with their significant others, partner or friend, respectively, Mary, Pat, Paddy, Helena, Elizabeth and Brid. (For some basic details on the participants, see Appendices 12a and 12b).

No material gains were offered to participants, and no promise or plan to change or 'fix their situation' was offered, although long-term social change was implied. It is claimed that in health and social research, interviewees often manage their talk or participation in the hope of obtaining additional benefits (Hill, 2007). Participants in this study were informed that I was not employed by any agency and not a practising occupational therapist. (Employment was taken up in the academy in September 2006). Not being an official employee of any agency, but rather a self-funded private student during the active fieldwork stage of this study was an advantage as I was, almost, an 'independent researcher'.

At the start of our first official interviews, informed consent was sought and given without hesitation by all disabled participants. (See Appendices 10 and 11 for a copy of the consent information and Consent Form used). After our first meeting, I asked the persons with ABI to name an other, a person in their personal and social life who may be interested in taking part in this study. Waiting until this stage to recruit other participants was also useful because the disabled persons knew more about this study and about me, with a sense of trust, respect and rapport commencing. One husband and one wife of two participants with ABI, with whom I had met briefly, had expressed interest, and by this stage they knew about the study. Two single people named a friend rather than a sibling, while the other two named their partner or ex-partner living elsewhere. These other six participants also gave their written voluntary informed consent without hesitation to take part in this study.

3.3 CO-CONSTRUCTION OF DATA and DATA AUDIT

I present here details about the co-construction of my new empirical data with the twelve participants. Their verbal meanings were those words that "transform colourless movements and lifeless physical objects into human reality" (Collins, 1997, p.224), accepting that these meanings did not determine the essence of the participants. Their meanings were constructed within social systems, structures, and languages available to them and linked in with their experiences. There are two aspects to the term 'meaning' (Fay 1996). Firstly, there is the personal meaning of the experiences and told stories for the participants themselves, and secondly, the significance of people's meanings and experiences for health and social care workers and policy-makers. Narratives were used in this study to reference participants' lives rather than searching for deep meaning in their stories or experiences. Thus, the second aspect of meaning is used in this thesis.

The matrix used for the co-construction of data in this study is noted next. This matrix is based on that used by Hollway and Jefferson (2000).

Matrix for the generation of data included:

1. the narrative or texts from the participants and other empirical data;
2. supervision, feedback and theoretical discussions with my supervisors;
3. academic and grey literature on ABI in general, and on knowledge, social, disability research and on concepts involved in this study;
4. national policy documents on disability, equality, inclusion, and ABI;
5. many shared cultural assumptions on exclusion and disability issues; and
6. my interpretations and knowledge of the above, aided by the use of research journals, discussion with colleagues, and disability meetings.

Certain methodological assumptions linked with narrative are noted in this Chapter, while finer theoretical assumptions and issues linked with narrative and

the narrative self are documented in the next Chapter, Chapter 4, before the participants and my findings are introduced.

The co-construction of new empirical data took place from April 2004 up to January 2006. Appendix 13 documents the dates of individual interviews.

New empirical data for this study includes:

1. Data from five interviews, using the narrative approach, with twelve people in ten locations around Cork and Kerry;
2. Full transcripts hand-written and then typed up by the researcher from the taped interviews in days following each of the first two interviews, - others typed up directly;
3. Notes made in a research field notebook per person;
4. Written up detailed notes during or following interviews;
5. Observations and telephone calls; and
6. Reflective and theoretical memos in three hard-covered A4 Research Journals. **See overview of data generation in Appendix 14.**

At least five formal interviews using the narrative approach were held with all twelve participants, but in reality, many more meetings took place. Two telephone interviews were held with two named 'others' because either they or a family member was ill. As this was near the end of fieldwork, these two participants had little to add to my narrative about their friend with ABI.

The narrative approach in interviewing

The narrative approach in interviewing was used in this study because there is a link between people's experiences and their stories. This is the logic of narrative, which assumes that people have a story to tell and this will emerge given the opportunity, time, and a person who will enter into dialogue with him or her. Participants in this study were informed that they could tell or share what they chose on answering the opening question *can you tell me about living with ABI*

here now? This opening question was used following a pilot interview to practise active listening and to decide the best opening question for me. The other opening question considered was from Sacks (1982) *"How are you? How are things?"*, two sub-questions really. Although deeply philosophical questions, these two short questions were considered too broad and too abstract, leaving this person wondering where to start. The five repeat interviews held with the twelve participants over two years always started with a variation on this opening question above; *can you tell me about*…? From this simple opening question, pages and pages of transcripts were gained. Notes from observations and telephone calls were also included in my data set, if relevant. To facilitate the production of the participants' meaning-frame, four principles recommended by Hollway and Jefferson (2000) were used. These were: use open-ended not closed questions; elicit stories; avoid 'why' questions; and follow-up using respondents' ordering and phrasing. Some of the participants assumed I would have many particular questions to ask them. For example, before our first meeting, Paddy said, "*you ask me the questions there, and hope I'll have the right answers"*. When I told him I have only one general or broad question, he went on to talk for nearly one and a half hours.[126] The location of research interviews is also important and is discussed later.

Which story participants told about their own living with ABI was their choice. Issues involved with certain other markers of their life, for example, being a vegetarian, was not my salient focus, therefore 'unstructured structured' interviews and processes were maintained as much as possible. Obviously, certain markers overlapped, e.g. being a mother, a wife, a neighbour, a member of Group X; this is to be expected rather than expected to be new or amazing (See Alvesson, 2002). Thus, we shared that 'conversation with a purpose', accepting that searching for or allowing for great openness can sometimes be seen as intrusive by some people or as subtle interrogation by others.

[126] To assist his story, another participant, Pat, had one page of his 'points' listed on paper for our first interview.

Accepting Mason's (2002a) advice, I gave "…maximum opportunity for the construction of contextual knowledge by focusing on relevant specifics in each interview" (p. 64). These specifics were actually kept broad, but following the first free-style interview, the latter part of subsequent interviews involved me asking some questions about their present, their now, or to seek clarification about some point made earlier. Narrative writers can accept inconsistencies as part of life. Some scholars or theorists work hard to seek a definitive coherent account or narrative, but this could involve checking up on participants many times with a view to getting them to perhaps change their story, which I deem as unethical. What people chose to say about certain topics was accepted, but has not necessarily been used in this thesis. Narrative also assumes that I would know the meaning of what people were talking about. This was so, aided by the fact that participants and I shared many cultural assumptions, somewhat similar age groupings, and tacit knowledge linked with involvement in the ABI world in Ireland.

As the place or location of interviews affects what is said, or what is allowed to be said in interviews or meetings, location also affected the data generated and co-constructed in this study (See Mason, 2002a; Mason 2002b). For these reasons, and from my experience after my second meeting with one participant (Elizabeth) in September 2004, most participants were met at least once outside their usual location. People are unlikely to tell stories if they are uncomfortable in the telling setting and if a top-down approach is used in the process. The power gained through the symbolic appearance of 'a researcher' was reduced throughout this process by ensuring that I always looked like any caller to the home or workplace of the participants. My hand-held dictaphone and notebook were not allowed to be observed by others. Much power was still present, yes, but ethical dialogue as Freire (1972), Mason (2002a), Kronenberg, Algado and Pollard (2005) and many

others advocate, occurred in these interviews.[127] As all methodological considerations here tried to be as open and as participatory as possible, I waited until after one year of interaction and dialogue, which included five official meetings, numerous telephone calls, and many unofficial meetings with some participants, before deciding on which story to tell you in this text. The prioritization of themes and issues for this thesis was carried out in the fifth interview with the assistance of the participants. This will be discussed further below. (See also Appendices 17, 18 and 19).

Recording Fieldwork Data

An individual research notebook journal was maintained throughout the research for each participant. (See headings used in this notebook in Appendix 15). A Bio-Data Form was designed at the start to enable me to detail 'hard' data for each participant. (See Appendix 16). Most of this form was completed by the researcher after the first interview which focused on their general story linking their past to their present. Their told stories were audio-taped using a hand-dictaphone. Tapes were transcribed by me by hand first, and then, typed up on to computer files.[128] All this work allowed me to continue to almost 'be' with the participants for hours in my home. After the second round of interviews (twenty-four meetings usually of more than one hour duration each), the taped interviews were typed up straight from the recordings of the dictaphone. Three large hard-backed research journals were also used to aid my thinking, planning, and working through the layers of interpretation. Ongoing reports were written up for all meetings with my research supervisors and two college presentations were made about this study. A presentation on this research was also made at the annual conference of the British Association of Occupational Therapists in the summer of 2005.

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[127] Participants stories were not sought in order to fit into the categories of concepts of one particular professional discipline, or to recommend the need for employment only of the professional discipline that I belong to.

[128] The replay button was so much used on this, that ir wore out and broke down. Thus, a second dictaphone was purchased.

Data audit of data analyses

Much data generation and initial data analysis developed simultaneously in a dialectical process as associated with the interpretative tradition, and four long interviews took place with each participant before any in-depth official formal analyses commenced. I aimed to keep the data 'whole' (Hollway and Jefferson, 2000) and held on to their ongoing 'whole story' for as long as possible without fragmenting their experiences and accounts of same. Their told stories were finally interpreted in time and within the methodological framework of this study. Many of the minutiae of the workings at the abstract level over the past years may not, or indeed need not, be described here. I report more on major tasks involved when working with the data co-constructed with the research participants.

Analysis of data included much data management as Round 1 alone provided me with one-hundred and forty eight pages of typed transcript (57,280 words). I did not need or seek five rounds with this amount of data (Kvale, 1996), but by Round 3 less new data was emerging. After the fourth interview, broad coding was carried out on individual transcripts, noting the many themes that were repeated, along with noting critical unique events, patterns, links, triggers, along with intended and unintended consequences. Although transcripts were read and studied line-by-line, broad coding was carried out on large chunks of data rather than on individual sentences. I knew certain transcripts so well that I felt that I could almost recite them '*off by heart'*. Basic administration (colour coding, filing, and paper work) also assisted this analysis, for example, physically filing them in various ways assisted conceptualisation. Transcripts and associated notes linked with each of the participants were first filed in their own personal envelope file, then later re-filed with their 'partner' in a joint file for some time, before I physically re-filled them again individually. The unit of analysis[129] was predominantly the individual with ABI, but often my focus was more on 'the couple' or 'the family'. Following my mid-term review to an invited college

[129] The 'unit of analysis' is the category of data used to make comparison and/or aggregation in analysis. This unit could be about individuals or about settings. (See Mason, 2002a, pp. 34-35).

audience on 18 May, 2005, my supervisors asked that I prepare a case story, using narrative analysis, for each focus person or couple to underpin my analysis of narratives. Therefore, from August 2005 to January 2006, along with other readings and research analysis work, six case stories, based on the narrative analysis of the stories of the six 'couples', were constructed and presented. The following data and strategies were used for this individual case story, if and as appropriate, to develop my narrative of their 'whole story' as told to me at that time by the six focus persons. These included:

1. Transcripts from the four interviews per person;
2. Use of field notes per person (notebook and/or copy per person);
3. Researcher's research journal (Three A4 hard covered journals used);
4. Bio-data sheet completed for each disabled person (See Appendix 16);
5. Time-line of major life events per person for major events or issues since the time of injury (See sample Appendix 17);
6. Use of A3 notebook, to document main changes throughout the study period, and other data broadly coded and chunked per major event or theme;
7. Index or code words about rehabilitation services as this was one social practice that all participants had some degree of contact with;
8. Social Network Diagram showing main social relations today, e.g. daily/ almost daily substantial relations and irregular meetings; and
9. If required, a sketch of their main living space.

Making a link or links between the emerging themes, and between the specific and general, or unique and significant events amongst the data enabled me to develop a narrative for each person based on Hollway and Jefferson (2000). This involved using the 'factual' information provided by the participants, reading through and beyond their 'free' talk to search for other links, using our shared cultural assumptions, and using my academic knowledge and theories from various

disciplines. Searching for and making links highlighted many issues that may not have emerged had I focused only on particular or individual themes. This data analysis leading to the six 'case-stories' provided me with the opportunity to try to understand each focused disabled participant as a unique individual within his/her own network, and about their situation today. This work involved using abductive reasoning which starts from the particular and moves back and forth, across and between the data, our experiences, lay accounts, and social science explanations or concepts. As Coffey and Atkinson (1996) state, there is a "repeated interaction among existing ideas, former findings and observations, new observations and new ideas" (p.156). Writing up about their particular in context situations revealed that the "bedrock of the really real remains. Its name is often pain" (Frank (1995, p.72). Although individual case stories or narratives may be necessary, they are not sufficient when the aim is to search more for the social in the data or narratives (See Reissman, 2000a). The case stories are not included in this thesis, but they did provide the basis of the one page pen portraits of the disabled participants presented in the next Chapter. This work also provided some of the basis for my next stage of analysis, analysis across the data, their narratives, which is discussed below and linked also with Chapter 4.

Simultaneously, while writing the case stories, deeper analysis and interpretation work were also being carried out with the data and with further reading. Based on the seven most common constructed concepts, categories or themes discussed by participants in parts of their stories, a summary page was developed. This summary page included seven statements in written text, easy for all to read, or have read to them. A second page in diagrammatic form was also prepared. (See Appendices 18 and 19). This page was used for discussion and (optional) prioritization or ranking during our fifth interview, held between December 2005 and January 2006. Details on the construction of the statements, their use, and comments made by participants were analyzed and written up in a twenty-page report for my supervisors in January 2006. (See Contents page of this report in Appendix 20).

Here is one important sentence from this report to my supervisors:

> Totally unique contingent situations were not used at this stage because of confidentiality, and because of the aims of my research…and because of my search for what may be of some or more (applied) use in the future. (Report January, 2006, p.3).

In addition, the seven statements were edited by me before presenting them to the participants in order "to make this list suitable for all, without being too insensitive to all possible interpretations" (Report p.7). This prioritization was made through reading words and by use of a number, a ranked number offering me limited illusory precision (Danemak et al., 2002, p.174) and limited analytical value. These numbers were used mainly for focusing their views and our discussion. Time was given to each participant for discussing these statements and their meanings and implications, etc., after which they 'ranked' them, if they chose to do so. All did give a ranking number, and they were then asked if they wanted to change their ranking. No one chose to do this. While all seven issues were considered important, three statements emerged as 'most important'. These were better public awareness about ABI, access to/participation in community events (being allowed to fit in), and access to ABI support groups. Rehabilitation, and to be allowed some risk and time alone 'tied' next. As all issues or 'findings' were interlinked, this prioritization helped focus my study, but this exercise did not determine that only those three priority areas were named as findings in this thesis.

Analysis of their narratives

Once 'narrative analysis' was completed, I commenced official analysis of their narratives with the focus on the content rather than the form of their told stories. Reading across their transcripts and their narratives thematically and comparatively provided me with multiple significant sites for analyses on possible ways of being in the world with ABI in Cork and Kerry today. I now detail how I analysed *across their narratives* for the final interpretation of this study, showing the major empirical procedures used in my chain of interpretative reasoning. This

process moved from literature, to data co-constructed during interviews, to data management, through initial analysis, thinking, back to the transcripts, back to the participants, to the literature and on to my final interpretations. The main strategies used in the analysis of their narratives working across their stories included:

1. identifying and mapping or broad coding of the parts of many transcripts across the four domains as used by Fraser (2004), namely the interpersonal, intra-personal, social and cultural domains. (See Appendix 20 for more details on how I did this analysis in October 2004 on a small sample of first transcripts as a learning experience for my supervisors);

2. as the actions and behaviour of people are not carried out at random, but have patterns, I searched for patterns and tendencies across all the broadly coded data (Stones, 1996);

3. a search for, and with, recurring themes linked with practices and tendencies on ABI issues were also used. Themes were categorized according to those linked with post–injury, non-ABI pre-injury, historic issues, contradictions, cultural issues, as well as what was allowed to be said or not, or what was glossed over. Recurring themes of ABI issues post–injury highlighted for me certain components of the social construction of disability.

Learning from Chouliaraki and Fairclough (1999), I focused on social practices that cut across different institutions and that sustained and transformed rearticulating practices across a series of events and not just one event (p.22).
Analysis here included mapping their narratives on to five of the six social practices as named by Chouliaraki and Fairclough (1999), namely material practices, social relations, discourse, power and desire (p.6).

Thus, my categorization and mapping included:

material practices	coping with ABI/non-ABI services, accessing resources;
social relations	participation in local events; issues of stigma or acceptance and for five participants, difficulties in meeting other people like themselves;
discourse	words used for example, or their assumed meaning of the label *ABI* and their perception of the public meaning of this;
power	power of professionals, family and the media; and
desire	feelings about loss and resistance; their everyday everynight living.

The participants' ways of coping with these various issues highlighted their *unique story*, yet their embodiment of ABI embedded in their local area illuminated a pattern of response. This pattern may have been impacted by similarity in age-range and religion. All participants were around forty to sixty years of age, all Roman Catholics, and all shared aspects of Irish culture and coping with the local health care system.

4. Non-ABI pre-injury issues: Time was spent on identifying problematic or non-problematic issues which were not directly related to their ABI impairment. Pre-injury issues are noted as being of importance in neuro-rehabilitation;

5. I also spent time reviewing each person's story as re-interpreted by me on what brought them to this now, their present situation. A search for some form of general or weak explanation highlighted particular and general issues or underlying mechanisms which appeared to trigger events or transitions and decisions made in his/her life. This involved identifying and naming any social structures, social practices, and the social media, and specialist ABI discourse involved in this process;

6. Major triggering factors were also noted. These included the following: unintended consequences of various events or policies emerged also from studying the data along with noting wanted and/or intended consequences. Some of these consequences were obvious and named by people, while other points emerged only by making links in their told stories, or following in-depth reflection and questioning the data. Sometimes my initial assumptions or interpretations were checked out with the appropriate participant(s);

7. Macro issues (structural) and historic issues which impacted on all their stories, details of which are documented in various parts of this thesis; and

8. ABI specialist discourse: Another pattern appeared to emerge in most individual narratives from the use of the specialist ABI discourse which participants have 'learned' at rehabilitation or in counseling. The very limited and quite negative general public ABI discourse or narrative was also considered when interpretating their stories.

Then, under the stages suggested in Danermark et al., (2002), I moved from the concrete aspect of the research to the abstract phase where I worked with identifying concepts that distinguished underlying mechanisms that make something happen among the social relations, events and/or processes in question. Also, identifying issues at the different phases when living with ABI involved studying the disabled person as an actor and as an agent, at different times, while also considering macro, mezzo and micro issues. As Layder (1998) states, the "ligatures and interpenetrations between agency and structure is an absolutely pivotal issue" (p.148). Much time was spent therefore on linking and working between the individual/self and the social, the life-world and the system, in my search for the mechanisms causing or triggering the positive or negative social situations.

Critical realists search for mechanisms or tendencies in their analysis of events remembering that it is these mechanisms that are differentiated and not the people or the events themselves. I wanted to go beyond the self-individual and also beyond social determinism-social construction of disability which could disregard the power or agency of individuals. Structure and agency were separated often during my analysis because personal time, properties, and emotions are considered differently from organisational time, properties and conditions. Working through formal substantive relations, as noted by Danermak et al. (2002) included working out the necessary relations, symmetrical and asymmetrical[130], of the internal relations where the objects condition one another. Thus, at certain times, the person with ABI needs the professional person almost as much as the professional needs a client. But post-rehabilitation, the person with ABI may not need the health professional worker, yet still they are often held on to by the health professionals rather than be allowed to assimilate into the social world. Danemak et al. (ibid) identify generative mechanisms also by abductive reasoning and theoretical interpretations, because for them "theories…serve as an interpretative framework…and [help] conceptualize causal mechanisms" (p.121). Various writings from the following helped inform me more about 'social theory' and various mechanisms impacting on everyday life experiences. These writers included Best (2003), Collins, (1997), Edgar (2006), Fay (1996), Gergen (2001), Hollis (1994), Skeggs (1997), Smith (1999) and Rorty (1991), along with writers and theorists from many other disciplines. See also Appendix 22 for flowchart of main phases of this study.

The varied sad, fun, unexpected and everyday stories of the participants in this study are the point of departure in my inquiry. Going beyond the data, my deeper interpretations of this study are the basis of what is written in this text. Details on how I actually planned the final organisation of this actual thesis, especially my

[130] Symmetrical necessary substantial relations are those that hold real connections between the people involved, where one need not or does not exist without the other, for example, between a landlord and a tenant. Asymmetrical relations mean one relation can exist without the other, but not vica versa. For example, disabled persons can exist without neuro-rehabilitation clinicians, but such clinicians cannot exist without clients.

‘findings Chapters’ are noted in Section 4 of the next Chapter, Chapter 4. The final move back to the more concrete issues is discussed in the conclusion. In summary, this study was based on an analysis of participants’ narratives which included, but also went beyond, thematic or comparative analysis. “The generation of technical concepts from lay concepts is a hermeneutic process” (Blaikie, 1993, p.140), hard to describe and manage, but a limit is needed to manage the hermeneutic circle. While the participants’ lives have changed even within recent months, I write in the next and final section of this Chapter on the claims about this study.

3.4 CLAIMS MADE ABOUT THIS DATA.

“All knowledge is socially produced but all knowledge is not therefore equally valuable” (Crossley, 2005, p.202). As I accept this statement about epistemic relativism, I sought quality in this study so that it is not considered ‘fancy journalism’ which is how much research, especially qualitative research, is considered. This new empirical data co-constructed in this inquiry are the people’s ambiguous representations of their experiences as they chose to share with me. Therefore, criteria for quality other than those used in structured studies are required. The criteria of validity and reliability are treated differently in social research, while some theorists would argue that these concepts are not appropriate for this type of study at all. Ballinger (2006) seeks four considerations when evaluating research. These are: coherence between methods and researcher’s role; evidence of systematic research conduct; relevant and convincing interpretations; and being sensitive to the researcher’s role. These considerations were important also when planning, conducting and writing up this research.

Ethical issues, respect and confidentiality

Much consideration has been given to the ethical issues involved in my re-interpreting other people’s stories of vulnerability or otherwise. After the first

round of interviews, transcripts were forwarded to all participants who were asked to inform me if they wanted any parts removed or changed. Although the participants were forewarned that the spoken word is different when written out, all comments received, from four people only, were about grammatical or technical corrections only. Such worries arose because of reading incomplete sentences as used in everyday speech when written in an uncleaned format. Only two participants wanted transcripts after Round 2, and they had no changes to make. Lack of time and interest may be some of the reasons why so few wanted to review their transcripts, with trust in me, I hope, that I would hold onto their stories. I did not give my ongoing interpretations to participants because this assumes that they possess knowledge and understanding about both the concepts used and the requirements of an academic research project. Skeggs (1997) gives a good example of the most common response received from her research subjects, "Can't understand a bloody word it says" (as cited in Mason, 2002a, p.193).

While respect and no interrogation characterised my fieldwork, issues linked with 'going public' were considered when planning what precise specifics to include in this text. Confidentiality was managed as much as is possible by using their own chosen research names on all documents and files and in this text, although this may not be enough for such a small population in southern Ireland. Going public with their stories was one of the ethical dilemmas and many contradictions which I had to work through, especially at the early stages of this research. Going public with an illness story is part of life today in many cultures, especially in America. Witness how fast many private troubles in America are aired on global TV screens. This is now becoming more popular and on the increase on Irish newspapers, television and radio[131]. As Wright-Mills (1978) stated, "many personal troubles cannot be solved merely as private troubles but must be understood in terms of public issues…[and] the human meaning of public issues must be revealed by relating them to personal troubles" (p. 248).

[131]The daily radio programme *Liveline* is one of the most popular on RTE week-day radio, when people ring in for almost two hours about any personal or social issue(s) or events.

I have tried to be as ethical as possible while co-constructing data for this study, yet realize the conflicts and contradictions in which I was involved. Many wanted their situation to be made more public and this was one reason for joining this study while some participants themselves are going more public themselves now with their lived stories and knowledge. Some are also involved in ABI advocacy. Pope, Mays and Popay (2007) detail the numerous factors involved in appraising evidence today when qualitative research is more acceptable. Validity and relevance are the two broad criteria considered most acceptable and often used to evaluate qualitative research, especially in medical health care, claimed Mays and Pope in 2000. My conclusions are offered not as valid or certain, but rather "well grounded and supportable" (Polkinghorne, 1988, p.175), using the ordinary meaning of the term valid. Data was accepted as partial, ambiguous and temporal and thus not 'true' in the traditional sense of the meaning of that word. The data in this study does not claim to be true in the positivist meaning, but rather data which is accountable and may be critiqued (Fay, 1996).

ABI is now a very 'hot topic'[132] in Ireland, which was not the case when I started thinking about this study in 2003. Developments in this sector are noted in my Introduction and Conclusion Chapters. Relevance is claimed, therefore, as this thesis offers new insights because of the theoretical framework used, willingness to discuss uncomfortable issues, and by the challenges made to many of the assumptions used in positivist research. As meanings cannot be controlled and can not be expected to remain static, dependability or plausibility is offered here rather than reliability. This is achieved through the detailed linking of theory with supporting or challenging evidence. Although my summary interpretations and thesis planning was shared with the participants, this is not now offered as respondent validation or member checking, as meanings and memories of events change, especially with certain participants in this study. Authority for my theorizing is taken here, even if and when different from the views of the participants (Chase, 1996). Parts of the findings in this thesis, in Chapters 5 to 7,

[132] Hot topic here means reference to a contemporary media or political policy agenda item.

have been said and continue to be said in local BRI, Peter Bradley Foundation, Headway Ireland and Health Services Executive (HSE–ABI Project) documents and/or meetings. Health and social care professionals are now accepting the importance of including service-users in developing their knowledge base and their theorising, although this sometimes appears more like co-opting the comfortable aspects of disabled people's knowledge and challenges. Uncomfortable aspects, such as challenges to the underlying assumptions of many professional practices and assessments, are often left aside.

Generalisation

For research to move beyond art, it is important as Malcolm Williams (2002) states, that this research is "…able to say something authoritative about instances beyond the specific ones of the research" (p.126). In many ways, the six disabled people in this research could not be more different if I had tried for full variance. Yet, many aspects of their stories, especially the problematic issues, have similarities with or are linked with many public stories and issues on ABI available through the public media, ABI literature and internet sites and associated community groups. This allows me to claim moderatum empirical generalisations which are based on those aspects of the study which "can be seen to be instances of a broader recognisable set of features" (Williams, 2002, p.131). Based on the many consistencies in everyday life and thus in the lives of people with ABI also, moderatum generalisations are those "…means by which we are able to be social" (ibid, p.138). Even if such generalisations are more limiting than total or statistical generalisations, they are necessary and sufficient for this study.

Researcher Reflexivity

Feminist writers sought for greater inclusion of the researcher in the research text to show the impact of his/her presence or position on the research process or product, and to provide a space for personal and interpersonal issues or dynamics with the participants (Finlay, 2002). While there are cultural influences and cultural capital involved in being reflexive, I accept Silverman's (2000) view that

the benefits of social science are realised more when we learn more about the participants or the topic rather than the researcher. As the participants in this inquiry had the right to withhold and/or withdraw certain information and words given, I, too, claim authorship over how much I locate myself and how much of me I present. As Haney (2002) did, I turned the study out more to the structural contexts and conceptual debates within which the participants live, rather than constantly locating the 'me' in the study. And as Skeggs (2002) and Mason (2002a) claim, reflexivity on how research issues and inequality influenced the research process is more useful than writing about 'me my-self'. I noted often, however, during this research process that the participants, especially those with ABI, have carried out essential and/or urgent philosophical reflexivity on their own lives. They did not need me to develop their understandings, although I have learned much from their philosophy on and of life. Balancing the facts and stories about their suffering of the actual brain injury with the social causation of many of their additional, unnecessary disabilities, was often an emotional experience.

I was working on improving my education and career yet there may be little change in the lives of the participants, especially those who seek change. Initially during this research, I was a self-funded PhD student, returning to academia and occupational therapy after a six-year break of being a full-time parent[133], and later a very part-time volunteer with BRÍ, and not a worker with any or much influence. But while we developed our own research relationship, I passed on the names and/or telephone numbers of agencies to some participants, if appropriate, so they could follow through certain issues themselves. I also made some phone calls on their behalf. But, for most participants, they knew I could not bring about much social change, but they did want me to highlight certain issues. It must be remembered that even if we had/have our own (research and social) experiences, I took away words, raw material and not experiences (Letherby, 2003). And while realizing the limitations of a lone research project, I also wanted to hold onto the importance of learning from the experiences of a small number of participants. As

[133] Tight home budgeting and financial management occurred for three years.

Skeggs (1997) highlighted, it is important to hold "a place for experience in [disability or occupational] theory which does not write off experience as inconsequential" (p.27).

Meeting two couples not living with their wife or ex-husband created for me a certain sense of intrusion, even if temporary and superficial. I was asking these participants in particular to revisit past issues that they have moved on from and may not have wished to re-visit. These non-disabled participants shared a very close past with their partner (who then acquired ABI), they still communicate, visit and/or have particular ongoing care 'duties'. Although they have moved on 'apart', holding a different more distant relationship with their partners, they were keen to assist me, mainly to help other people who may some day be living with or working with people with ABI.

Meeting the other two couples who did live in the one house also had its own worries. Was I creating difficulties for them in meeting with them individually, if the non-disabled partner thought I was evaluating, judging or 'spying' on them. But time was spent with both participants together as much as possible, either before or after our 'formal interview' so that much information could be shared if appropriate. This also gave me the opportunity to let them know that I realised the joint situation they were in and to acknowledge together the difficulties and positive moments they encountered in living with ABI in Ireland today. By keeping the focus more on cultural and social issues impacting on their lives, enabled me to accept that I was not "digging into" very private emotional relationships (Wengraf, 2001, p.105), unless they themselves brought up very personal intimate issues. With the passage of time, most of the participants have settled into their present life and/or are enjoying living as best they can.

The merging of my knowledge with theirs was another important aspect in the process and the product of this study, yet I held onto my epistemological privileges and authority (Chase, 1996). Not accepting pure relativism challenged me to

reflect critically throughout all of this study process, including interpreting participants' stories, but this does not nor need not impact on the moral equality between us (Skeggs, 2002, p.363). Throughout this study, balancing and working with the agency-structure, macro and micro debate gave me cause for much critical reflection, as did my role in any aspect of 'othering' the participants. Power issues and relations remain, but were managed as ethically and fair as possible. Difficulties often emerged, though, as I negotiated how I positioned 'these others', yet not abuse or theoretically play with their suffering. Yet, it is important to link their voices, experiences and critical discourse into our evidence base today, even if their experiences or stories are mediated through me. While acknowledging the benefit of a "collective dialogue" (Haney, 2002, p. 297) in order to discuss power issues involved in this inquiry, such a collective dialogue was not feasible between the twelve participants and I. Apart from their time, busyness, and the fact that, for many, this research was quite peripheral to their lives, these participants are from ten locations spread throughout Cork and Kerry, with some living approximately one hundred miles apart.

As stated above, one reason why certain participants joined this study was to make their situation more public and to help others new to ABI. At times of fatigue or saddened because of little change in Irish health and social care services and/or academia, it was this stated desire of some participants that kept me writing up. And as Stoppard and McMullan (2003) state, one way to ensure that research participants' stories "can have an impact in the world is to make their work available beyond other researchers" (p.11). Thus, challenging and alternative issues and findings will be rewritten in plain English for local brain injury newsletters or local conferences. The relationship between the process of this research and this product which involved 'emotion, power…[and] constant adaptation, re-evaluation and negotiation" (Letherby, 2003. p.120) has not actually ended. Linked with this is the fact that changing the material or other numerous issues or needs involved for people with ABI is a larger ongoing process. To this end my volunteer participation in BRI, an advocacy support group

for people with ABI, continues. Some of the participants in this study are also involved in such groups, so I regularly continue to meet with three of these participants socially. Thus, the interconnections and the relationships built up with many of the participants, which were a very important part of the whole research process (McDowell, 1999), remain an important part of my life.

Disability groups are a public forum where many of the personal, emotional and collective issues discussed or told by the research participants here are repeated. Some experiences made public at these meetings could provide certain validity to the claims made in this study, if I had sought them, but I did not. The participants' own 'voices' are "sufficient evidence of the personal burdens [of shame and fear]" (Corker, 1999, p. 208) that they have had to live with, and for some, they must continue to live with. I was/am happy also to try and seek at least a change in professional and public discourse about ABI itself, but also about researching with people with ABI. While accepting the limitations of this study, and indeed of much research, it also seemed as if "…my mobility [is/was] based on them remaining in place" (Skeggs, 2002, p. 367). My career improved during this study, yet, little change occurred within the lives of those participants who would like or desire change, although they too are sometimes content enough. The contradictions, ambiguities and paradoxes within certain processes involved in this study and within professional and disability issues are ever present. The following Chapters 5 to 7 illuminate also some of the social paradoxes, ambiguities and contradictions that were co-constructed through the lived and told stories of twelve participants.

CONCLUSION

I have considered in this Chapter many of the theoretical and practical strategies used in this study from within the range of "knowledge problematics" (Stanley and Wise, 1990, p.46), to practise and present good quality qualitative research. I have tried to include what was most relevant in this research study and which may be

required reading for a related study. While it is important to be methodologically strict in social, clinical and disability research, it is important not to forget the purpose of this study and the real brute fact of the participants' original suffering[134]. According to Stones (1996), "the adequacy of an ontology is not the method by which it is arrived at but, rather its explanatory effectiveness, the range of questions it allows one to address with relative success, however measured" (p. 28). By using non-naïve critical realism within a broad multiple methodological perspective, I was forced and/or allowed to ask many varied and deep questions of myself and the data used in this study. Although most of the deeper analysis and interpretation occurred at one particular phase of this inquiry, interpretation continues today. The various and complex links between "biographical narratives, experience and emotions are ragged" (Gunaratnam, 2004, p. 216). This placed particular responsibilities on what 'findings' and interpretations I include or exclude in this analytic process, while it is accepted that all precise interpretations, actions or events from this extended study cannot be provided in one text.

Readers, too, are interpreters of what they read and like the researcher and the participants, they, too, bring their own interpretations to this research project (Seymour, 1998, p. 30). Thus, my interpretations of the findings are stated in the following Chapters 5, 6, and 7 which illuminate some of the many factual and social issues and theoretical conceptualisations that were co-constructed with only twelve participants. But first, in the next Chapter 4, following a brief introduction to the disabled participants and a little more about narrative, I discuss how I decided which particular story to tell about this study.

[134] Five of the six participants were injured because of car crashes, a crash not of their doing. The financial compensation for three participants helped only a little in their living with ABI.

CHAPTER 4 NARRATIVE THEORY, THE PARTICIPANTS AND THIS THESIS

> if we want to find out how people make identities, make sense of the world and their place within it – if we want to find out how they interpret the world and themselves, we will have to attend to the stories they tell (Lawler, 2002, p. 255).

The narrative genre or the biographical turn has become very popular in social and health care research in recent decades. This recent revival "seems, in part, to be a product of transitional, uncertain post-modern times and its associated politics of identity" (West 2001, p.30). Yet, this perspective was always popular in anthropological studies and in psychology and psychotherapy practice (Lieblich and Josselson, 1997; Polkinghorne, 1988). But which story will I tell you about 'narratives'? Will I tell you about their role in the structuring of experience (Mattingly, 1998), or in the search for identity (Teichert, 2004) or occupational identity (Forsyth and Kielhofner, 2006), for meaning (Becker, 1999; Ryan and McKay, 1999), or the truer narrative of history (Hall, 1999) or, the fictional narrative of storytellers and novelists (Ricoeur, 1981a, 1981b)? Or should I focus on 'told stories' about lived lives (Fay, 1996;Wengraf, 2001), or life-stories (Viney, 1993), illness narratives (Frank, 1995), pathographies (Hawkins, 1999), cultural narratives (Lawler, 2002), or on dominant narratives (Thomas, 1999b)? Narrative seems to be everywhere. Polkinghorne (1988) states that "narrative is the primary form by which human experience is made meaningful …it organises human experiences into temporally meaningful episodes" (p.14). Yes, certain stories are shared, they are international and universal; many are "retold almost daily in debates at the United Nations" (Bruner, 1986, p.149). That is why we have ontological narratives, meta-narratives, and public narratives (Thomas, 1999b), focusing on respectively, personal self stories, grand theoretical narratives, and cultural narratives.

In this Chapter, some generic methodological notes are made in Section 1 about narrative, and why narrative can be an important tool when doing research with people about living with ABI. The research participants are then introduced via a one page pen portrait in Section 2, while in Section 3, I note briefly how all of my analysis of their narratives and literature along with my interpretations was constructed into three 'Findings' Chapters (Chapters 5 to 7 inclusive).

Working with Narratives

Narratives are inherently interdisciplinary and are being used more in the social, medical and health disciplines, as well as in anthropology, history and education. For those focusing on the literary and/or oral aspect of knowledge, it is the oral performance itself used in the narrative that is the object of study. The focus for me, however, is more on the content of narrative as used in social research regarding a disability experience. From the narrator's point of view, any narrative combines two dimensions held in varying proportions, the chronological dimension and the non-chronological dimension (Ricoeur, 1981b). The chronological episodic dimension gives us, and so, and then, and what happened next, the dimension of structuring people's experiences in or with time. The non-chronological dimension seeks to configure and construct meaningful totalities out of scattered events. Thus, narratives are about something in time and generally have a beginning, middle and an end. The end may not, or need not, always be known, the end is only the end for now. Time is a major component in narratives. Time is often conceptualised and studied by occupational therapists and other disciplines under the concepts of tempo (the pace of life), temporality (a meaning of one's past, present and future), and use of time (Farnworth and Fossey, 2003). Anthropologists meanwhile have studied 'physical, typological and intersubjective Time' for decades (Fabian, 1983, p. 25).

Narrative blends many of these concepts of time as there are six features[135] of narrative time according to Mattingly (1998, p. 84-85):

1. narrative shows how things (and people) change over time;
2. action and motive are key structuring devices among multiple actors with multiple motives;
3. narrative time is organised within a gap, in that place of desire, while movement toward endings dominates;
4. narrative time is configured and unfolding;
5. narrative time is dramatic. Stories about difficult, even frightening situations present conflicts, while risks must be taken where enemies must be faced; and
6. endings are uncertain and suspense is present.

In structural analysis of the narrative, the plot and much of *time* are eliminated as the theorist works on the linguistics, semantics and language rules, indifferent to extra-linguistic reality. As Ricoeur (1981a) states, temporal aspects are reduced "to underlying formal properties" (p.281). Thus, the focus in formal narrative analysis is generally on the form of the content, the structure of what was spoken, as opposed to for me, the content of what was said. Personal narratives are not transparent carriers of people's experiences, but they are one way of connecting people's past and ongoing happenings with their own reasoning as narrative involves both telling and knowing. Narratives based on people's own 'told stories' along with the facts in their 'lived lives' highlight their tactical or strategic adaptation and experiences as they cope(d) with some transition in life. Narrative as reflective judgement reflects upon events from a point of view with narrative distance, thus in this way narratives are considered helpful as a form of sense-making (Fay 1996; Reissman, 2002a, 2002b).

[135] All of these features were relevant in places and at various stages of the narratives co-constructed in this present study.

In research, the strength of the biographical method is its ability to explore latent and many levels of personal meaning (Creswell, 1988; Lawler, 2002; Reissman, 2002a, 2002b). This is based on the ontological assumption in biographical studies that individuals are not completely determined or made by society, but that they generally have some agency. Many social researchers use narrative studies as a means of constructing personal identity, or as a means of re-framing past events, master motifs or `epiphanies'.[136] People may also narrate their experiences or life events as a chronicle, starting with "how it all happened" or "how I came to be where I am today" (Coffey and Atkinson, 1996, p.68). This makes use of the concept of a 'career', a concept that has been used for understanding ageing with an impairment. In addition to focusing on what was/is said, narrative analysts may focus their interpretations on what is/was not said or what is silenced (Lieblich and Josselson, 1997). Various cultural, ideological, financial, fear and/or power issues, along with the physical location of the narrator and others present or nearby, may impact on what a person says or what they are allowed to say.

The collection of past facts and placing them in chronological order is necessary, but not sufficient for narrative explanation. The clarification of the significance of particular facts, events and decisions that have occurred on the basis of, and their role in, the outcome that has followed is also required (Polkinghorne, 1988). Thus, both 'intentional understanding' towards a preconceived end, and singular causal imputation such as 'what if', may be used.

Illness Narratives

Three particular features of narrative form allow narratives to be very appropriate for addressing illness and healing experiences (Mattingly, 1998). According to this anthropologist, narratives are event-centred, experienced-centred, and do not refer only to past experience, they actually create experiences for their audience. For performative narrative theorists, the focus is on "what becomes experience in the

[136] Epiphanies are those "interactional moments and experiences which leave marks on people's lives" (Denzin, 1989, p. 70).

telling and its reception" (Frank, 1995, p.22). This may be the main reason why illness narratives are important and popular. The telling allows the person to "integrate their symptoms in a new sense of self, a new personhood" (Thomas, 2007, p.26-27). Narrative allows for the past, present and future within the one sentence. Mattingly, however, claims that the link between experience and narrative is different. For her and other non-naïve realists, "narrative imitates experience [but does not copy it] because experience already has in it the seeds of narrative" (p. 45). It is accepted that narratives about events, epiphanies and/or disruptions in life which are "experienced as part of a group, will be experienced differently from those experienced individually" (Becker, 1999, p.224).

According to Frank (1995), there are three major types of illness narratives, namely, the Restitution Narrative, the Quest Narrative and the Chaos Narrative. This typology may be useful for scholars and counsellors, and this student, but they should not be and are not reified here. In the Restitution Narrative**,** the person aims to be, hopes to be, and/or may feel, that because of their personality, 'guts', spirituality, past experiences and/or social and financial supports they will be better soon. The Quest Narrative holds three facets, the *memoir*, the *manifesto and automythology*. The *memoir* focuses on reminiscences, while the *manifesto* involves people who decide to use their suffering for social action and *automythology* includes or implies self-reinvention. The Chaos Narrative is that which occurs when people are temporarily unable to rise or cope with the telling of their story as they are in chaos. Crises may often feed the important drive or need to tell your story, but a crisis story seldom has a beginning, middle or end, as the person is in the middle of living it out. They are deep in the sub-plot, and even at this stage they may be silenced by powerful people. With illness narratives, it is expected that people will or "may move between these various types during their illness journey" (Thomas, 2007, p.27).

While enabling all people to tell their story is a very popular or common event in our world today, yet in our fast reflexive world, many are asked to do so while also

expected to move on in a very short time. There is little "tolerance for chaos as a part of a life story" (Frank, 1995, p.111). Nine years later, Frank (2004b) still sought a need for 'an enhanced tolerance' in this area. At a conference on *Talking Death: Narratives of Illness and Bereavement,*[137] Frank stated that chaos narratives need to be allowed in our world today, and to be told without offering a fantasy of either fixing all people or having a need to be in therapy forever.

Illness and healing narratives are much used by clinical therapists, psychologists, counsellors and medical anthropologists, although more general medical practitioners now realise how absorbing the patients' narrative can be.[138] This narrative, even if developed in short ongoing segments, illustrates aspects of the person's experiences, meaning, meaning-frame, their sense of time and their tacit knowledge. All of this enables the general medical practitioner, for example, in four main areas of their work, the diagnostic encounter, the therapeutic process, in research, and in educating other patients and professionals (Greenhalgh and Hurwitz, 1998, p.7). This text also illustrates how individual narratives can complement and often challenge the bio-medical model of medicine. The dominant narrative in medicine is generally told or (re-)presented by statistics, based on the gold standard of evidence, the double-blinded, randomised controlled trial. The recommendations are then expected to be followed with full compliance by the patient and family without reference or sensitivity to the personal self. Expert knowledge dominates the neuro-rehabilitation sector, while the call for more 'high impact' research and publication in 'high impact' journals is sought within the occupational therapy profession (see Walker, 2005). Simultaneously, but in a different manner, voice and the knowledge of 'expert patients' are slowly being included into parts of evidence-based rehabilitation practices. For example, in the United Kingdom formalised 'expert patient programmes' and the Database of Individual Patient Experiences (DIPEX) are well established within the

[137] Conference held in University College Cork, Cork, 29-30 October 2004.
[138] See Greenhalgh and Hurwitz (1998), *Narrative Based Medicine.*

National Health Service and the Cochrane Centre, respectively (Greenhalgh and Hurwitz, 1998, p.213).

Personal - Public Narratives

Stories provided by individuals would actually make no sense if they did not accord in some way with broader social narratives. Using Ricoeur's concepts, Lawler (2002) claims that social life is itself storied, and people make sense by using "the linked repertoire of available social, public and cultural narratives" (p. 254). Personal narratives, whether representing or imitating experiences, are affected by what is allowed to be said Yet, many people are blocked or not allowed to tell their story, silenced often by others with more status, power or knowledge. Bruner (1986) stated that narratives "are not only structures of meaning but structures of power as well" (p.144). Two decades later, his words are still relevant. As 'cultural scripts', stories also act as a means to pass on cultural knowledge (Mattingly, 1998), although many individuals and groups resist and challenge such cultural script-lines or public narratives (Silverman, 2000). Reflexive cultures today allow or actively seek all people to be constantly self-reflexive (Giddens, 1990; Skeggs, 2002), while the "ethic of our times affords each a right to speak her own truth, in her own words" (Frank 1995, p. xiii). This is linked with mainstream narrative theory which claims that discovering self comes about largely from our constant explaining of ourselves to others (Polkinghorne, 1988). Yet, even in 2008, many people are never given the opportunity to tell their account, and never asked for their story, and often if or when they are told, no-one listens, unless perhaps in a helping therapeutic private place. The Russian scholar Bakhtin sought to include more on the dialogic aspect of narrative identity rather than the monologic view. Bakhtin sought and allowed more interdependency, consistency, and inconsistency in narratives. Drawing on the work of the Russian social theorist Bakhtin[139], de Peuter (2002) claims that by "re-conceiving narratives as active dialogues, relationships privileged over authorship, identity and difference is celebrated rather than silenced" (p.40).

[139] See Gardiner, 2000a; Mayerfeld Bells and Gardiner (Eds.). (2002).

This enables the dialogical self to be ongoing and changing. Dialogue also assumes that there is an 'other' listening to each narrator, although this may still be an unrealistic assumption for many disabled people today. Many writers using a post-modern or post-structuralist perspective assume that all people are 'choosing subjects', and that all people can easily reframe their meaning frame, their words, their discourse, and then that change will follow.[140] But few people have pure agency, while people deeply hurt, in suffering, or with little status cannot '*just pick a discourse'*. In addition, some people often need support to tell their own story, because, on their own, they may not have the capacity. Thus social theorists Kittay (1999) has written an emotional and theoretical narrative about her daughter Sasha, while Berbure (2000) has written in a similar manner about his son Jamie. Both are disabled children. There are also other people who, need to have things happen in their lives, to have a life with some meaningful activities in order to have something to talk about. Otherwise they are considered to have a life without meaning, they have only brute chronology or brute sequence (Mattingly, 1998). Mattingly claims that the "essence of meaninglessness [in life] is when lived experience seems to be driven by no form other than brute sequence" (p.47). But what happens when you are dependent on others to enable or help create that future desire, that activity or happening? Are you left suffering in its (sufferings') own uselessness (Frank, 1995, p.179), but not of your own choosing? Without interdependence or solidarity, few narrative events are likely to happen for many people, especially for people with serious ABI, at those early stages post injury.

The concept of the 'narrative self' is/was often based on Erikson's (1963; 1968) view of a congruent self, with (full) self-understanding and the continuity of the self required and sought. Many researchers, health workers and the public seem to assume that people with ABI do not have or are unable to have a narrative self, generally because of their memory and/or insight or awareness difficulties.

[140] See Davies (1998).

People with ABI have no narrative self stated Zahavi (2004)[141] early on in my research. They live in a "*time bubble because of amnesia and because of their short attention span*", he added. But my study is based largely on the narrative selves of people with ABI and their partners. There is a small number of people with very severe brain injury who may never be able to configure a meaningful totality, a story out of scattered events. However, I believe that the participants in this study do have 'a narrative self'. During this research they had good insights into their lives, even if not perfect insight. Their narrative selves may be broken in places, but over many meetings, they have shared with me much of their remembered past, present experiences and desires. They may not fit into the criteria of a pure philosophical category of narrative self, but full coherence was not sought in their stories. I believe that we all live with certain contradictions and incoherence and, as Frank claims, chaos narratives should be allowed to be told without offering a fantasy of fixing or the need to be forever in therapy (Frank, 2004b). Plus, I was not testing their narrative self. (See Chapters 5 and 8).

Narrative research need not and indeed should not only reflect the real told and lived stories of the participants, but such research can also challenge taken-for granted beliefs (Fraser, 2004). Thus, personal narratives can be and have often been the basis for challenging social reality, if interpersonal and social issues are sought as much as the personal issues in told stories. As with the women's movement**,** stories and experiences of individual disabled people helped form the disability social movement which has brought much change to disability discourse and disability theorizing today. And as mentioned in Chapter 2 above, the social model of disability which emerged mainly from and through this movement, has been a powerful tool in challenging disabling social practices, including rehabilitation practice. All of this has offered a process of positive collective identification for many, and a choice of counter-narratives to the traditional disablist scripts circulating in society. Counter-narratives are those self-narratives

[141] Prof. Zahavi, Department of Philosophy, University of Copenhagen, answering my question during discussion time at his lecture, '*Philosophy and Science: Can and Should they Learn from One Another*?', in University College Cork on 11 November, 2004.

that resist dominant narratives and challenge the local social norms (Thomas, 2004b).

Disability narratives have, however, been criticized in disability studies as fuel for the true confessions brigade stories focusing too much on individual experiences (Corker, 1999). Some writers argue that such research only helps the narrator get something 'off his/her chest', and for the researcher to feel good about her/him self as they aim to `tell it like it is', evoking empathy in the process. Yet, as noted above, disability studies owe much and are often developed from collective stories or narratives based on personal experiences, and, as with interdependence, empathy is required in life. French and Swain (2006) highlight the continuing importance of individual experience in disability studies, and if linked with political analysis, stories and oral history may bring about further change (p. 395). These writers highlight the importance of listening to "voices excluded from the past …[for the purpose of] 'telling stories for a politics of hope' (ibid p.383). But another difficult unintended consequence of counter disability narratives is the rise of hero or 'super-cripple' stories, which can be problematic at times. Heroic stories about, for example, a person with quadriplegia sailing around the ocean single-handed (Spinal Injuries Ireland, 2007) or who completed marathon X or climbed mountain Y, may make life difficult for many 'ordinary' disabled people. These super-narratives, not personal tragedy stories, are part of a new dominant discourse on the need to be super-fit or that "one should fight heroically to overcome adversity" (Thomas, 1999b, p.53). But at least disabled people's rewriting of their own identity today, even if limited and/or about high-risk or extreme behaviour, does "strengthen the counter-narrative" (ibid, p. 55).

As Fay (1996) claims, "narratives are continually and infinitely revisable" (p.195). There is no correct story, no definitive ending, with new meanings being made available with hindsight and in new contexts. Stories are lived and told:

> stories are lived because human activity is inherently narratival in character and form: in acting we "knit the past and the future together". But stories are also told in that with hindsight we can appreciate narrative patterns which we could not appreciate at the time of acting…our lives are enstoried and our stories are enlived (Fay, 1996, p.197).

Negotiating the different aspects of identity in self-dialogue is more difficult if others think you do not have full understanding or capacity, or that you will not or may not remember. But you do, you remember more, there is always more.

By listening to the participants' stories over the past three years, I have heard their own chaos, hero, quest, and counter-narratives. I am not placing their narrative in a typology in this thesis, although I could have constructed a tragedy, a quest narrative, a legal detective story, and even a comedy. I was and am more interested in the 'content of the form' rather than the 'form of the content'. The participants' 'whole' narrative co-constructed in this inquiry was not seen as a direct representation of their life or their authentic identities, but rather stories co-constructed for the purposes of our meeting (Lawler, 2002). I moved then between the "middle course between narrative realism and narrative constructivism" (Fay 1996, p.195), that was, between the lived and told stories of the participants. I do not seek to make the participants the sum of their accounts or seek to homogenise them in a stable-order. Mindful of Gardiner's implied question, "do we use pre-scripted narratives too much in social research" (2000b, p.21), I sought and had many exciting discoveries throughout my research fieldwork, some of which are noted in Chapters 5 to 7.

4.2 INTRODUCING THE PARTICIPANTS

Twelve research participants were asked to participate in this study as knowers, to varying degrees, about many aspects of living with ABI in Cork and Kerry today and for recent years. General details about the relationship between the six 'couples' are documented in the following table. The participants could be presented by gender, marital status, or years post injury, but in the end, simple common alphabetical ordering was chosen. (See also Appendix 12).

Table 4.1 Data on the twelve research participants: marital status, relationship to person with ABI, number of children.

DISABLED PARTICIPANT	PARTNER / FRIEND
ANNIE Single	Mary Friend (since before her injury)
CLAIRE Married	Pat husband (three children)
JOE Married	Elizabeth wife (six children)
JOHN Separated. Infrequent contact with Brid, regular contact with their two children	Brid separated wife (two children)
SINEAD married, living apart from family in independent living unit	Paddy husband living in family home (five children)
VIVIENNE Married some time after her car crash. Separated after a few years. Given her diagnosis of ABI at a later date.	Helena friend, (since before her injury)

For the past three years the participants have enabled me to discover some of their different ways of living with ABI. Yet, living with many losses and desires, as well as fun, everyday mini-battles with themselves, families and bureaucracies, along with travels, both real and metaphorical, illustrated how much I had in common with them. Sharing stories about parenting, busy family life, relationships, enjoying moments of 'craic', an everyday Irish word for having fun, along with sad times because of death, were also held in common. The fragility of

our bodies and our lives were ever present in our meetings[142] as were stories about recovery, resilience, annoyance, and becoming a person with agency, an actor or a self-advocate again. A one page pen portrait on each disabled person is presented after the table, below where some of the facts about their lives, aims to bring them a little more alive. Their 'told story' about a 'lived life' cannot be written with justice in one page, but this is only a summary introduction for the purposes of this research. In November 2007, five of the disabled participants read these profiles, and only minor amendments were required. The sixth participant does not read but accepted my verbal summary. Hearing one participant say that they liked being in this research and that it was 'non-evasive' meant much to me.

Table 4. 2 Additional data about the participants with ABI: residence, number of years since injury and since diagnosis, receipt of compensation, nature of care supports.

RESEARCH NAME	HOME LOCATION	YEARS SINCE INJURY	YEARS SINCE DIAGNOSIS	COMPEN - SATION	SUPPORT/ CARE
ANNIE single	Town suburb Co. Kerry	11	11	No	Self. Financial management with brother
CLAIRE married	Outside rural village near suburbs of Cork city	10	5	Seeking same	Self Family, Hospital and Agency
JOE married	Rural Co. Cork	7	7	Yes	Self, wife and family
JOHN separated	Cork City	25	25	Yes small	Self
SINEAD living apart from family - in ILU	Town Co. Kerry.	16	16	Yes	Independent Living Unit
VIVIENNE Single separated	Cork City	38	15	No	Supported living unit

[142] In 2004, during fieldwork, my mother died (twenty-four months after my brother, and thirty-four months after my father). For three weeks in September 2005, my brother-in-law was nearing death, but has recovered somewhat.

ABOUT ANNIE *and Mary*

Annie, a keep-fit enthusiast, a single woman in her forties from County Cork, has lived for over twenty years in County Kerry where she has a good network of friends, her own home and her little car. 'About' ten years ago, she had an accident resulting in a coma for about four days and a subsequent brain injury. Exact times or dates are not important now to Annie. Her sibling in Dublin and friends in Kerry helped her to manage her self-chosen desires and to take risks following discharge from the National Rehabilitation Hospital in Dublin. This enabled her to return home to Kerry. When I met with Annie, she was back walking long walks, cycling and playing golf, although unable to return to her pre injury occupation as a health worker assistant. Between Annie and her friend Mary, also a participant in this study, they had some dramatic moments and stories to tell starting with how, between them, Annie relearned how to ride her bicycle again without any further injuries to herself or anyone else. Pre injury, she was outspoken, an independent thinker, an out-going fun person and a keen driver. She still holds all of these traits. Driving was and is still the one skill or interest she would really find hard to do without. She can still drive to her golfing, her shopping and socialising, as well as to do her voluntary and advocacy work, and attend the various adult education classes that she participates in for continuing personal development. She was and is financially independent, yet was never keen on 'money management' even before her accident. Although Annie describes herself as the "*crème de la crème of people with ABI*", she has faced many problems in her recovery to date and is still working through other continuing cognitive difficulties and coping with fatigue. Annie has also felt excluded and stigmatised because of her ABI. She is a political activist, interested in enabling other people with ABI to develop their 'voice' as they also learn to live with themselves, their ABI and others in the 'now'. Between the joys and heartaches, Annie has learned much not only about her own ABI, but also about the lack of ABI pathways of care in Ireland. She is a member of BRÍ and, along with this researcher, she has given some thought-provoking presentations to a sample of UCC students.

ABOUT CLAIRE *and Pat*

Claire, Pat and their three adult sons, in their twenties, have been living with ABI for about nine years, although Claire was not officially diagnosed with ABI until 2003. This was more than five years after her car crash a few hundred yards from her home, one October afternoon in 1998. This personal and family disruption was caused mainly by negligence of a car manufacturing company and a local garage for fitting a wrong car component, compounded greatly by limited acute medical care following her car crash. The focus was on other body injuries such as injuries to her jaw, shoulder and breast. Claire now lives with memory and attention difficulties, uncontrolled seizures, noise intolerance and much fatigue. She has also known much pain, loss and loneliness and the additional problems involved in gaining a diagnosis in the first place, and in gaining relevant services for her diagnosis. Private medical insurance[143], Headway Cork, and her sister have helped this family cope somewhat through these past years, while their sons gave up studies and work at various stages to stay at home and provide standby assistance when needed. Claire taught oral communications prior to her crash, but is not working now while Pat had often to forego over-time work opportunities which also impacted on family income. For many years, the only respite for either Claire or her family, were long in-patient visits to hospital for tests and treatments.

When I met with Claire and Pat, they were living with ongoing difficulties in accessing individualised rehabilitation services, personal assistance, transport, along with welfare issues because of the cost of disability in Ireland. Integrated team work in their required services has been limited and fragmented, with poor full-team communication. Financial difficulties and living in a rural area with no easy links or transport to shops, social services and/or ABI services makes everyday living difficult for Claire. While being very aware of her abilities and limitations, and the politics of disability, she continues to strive for ongoing re-learning to try and enjoy personal and family life more. Poetry, having time with family and friends, discussing politics, smoking, and watching television add to

[143] Limited private medical insurance is available through her husband's employment scheme.

her life, while creative writing enables her to articulate her pain, dreams and struggles. Deep suffering is intermingled at times with humour in everyday living for Claire and her family as they continue to live in troubled times.

ABOUT JOE *and Elizabeth*

While walking one day in January 2001, Joe was knocked down by a car and acquired a serious brain injury. However, he and his family focus on life from the time he 'came back' to them nearly three months later. Today, with the benefit of acute rehabilitation, slow recovery, a close family, material wealth, and a large social network, Joe continues to enjoy life. This ABI was Joe's third major acquired impairment,[144] therefore resilience, interdependence, transcending embodied difficulties and adapting to ways of being physically independent, have been part of Joe's life journey, along with his wife and their six children. His main support, advocate and wife of more than twenty-five years, Elizabeth, accepted a caring role for years while still having to take care of their family home, business, and their schoolchildren's needs, especially their travel needs. Joe and Elizabeth both hold a strong sense of local 'place' and take an active part in local Gaelic Athletic Association (GAA) organisation and local church or charity events. However, their intertwined stories with me highlight the lack of access to transport and to follow-up individualised home-based services available at a time and a place that suits the family. Since his return from the National Rehabilitation Hospital in Dublin in October 2001, and often when I met with Joe throughout 2004, he found his days '*boring*'. Yet, he also wanted some real alone time. This has changed with time as he was given more opportunities to take risks to do more everyday tasks on his own.

Joe enjoys his mentoring role in the family and farm business. Retaining much of this role has given him a great sense of achievement. Foreign travel has provided him and his family with opportunities to enjoy a taste of the good life for

[144] Since the end of our formal interviews, Joe has had another major acquired impairment, a heart operation.

themselves. But participating in his local card-playing club in his local pub is his main interest of the week. As early as possible post-injury, Joe rejoined this group as he had done for over thirty-five years before and three nights a week he would play cards in their local town, three miles from their country home. Like many other disabled people, Joe seeks more opportunities for mainstream supports rather than special disability services or groups. Both Elizabeth and Joe have lived through many tough days and months, yet both strive to allow love to work through all of those hard moments.

ABOUT JOHN *and Brid*

On the Epiphany holy-day in 1983, (6 January), John had his 'epiphany' because of a car crash due to a burst tyre in a new car. He was given four days to live. Now, twenty-two years later, he continues to live content, but with certain reservations. Living as a separated father for fifteen of those years, a second unwanted disruption in his life, has also been very difficult for him. But neither John nor his ex-wife Brid, who also took part in this study, is sure if his brain injury was the main cause of their marriage break-up. Could it be linked with another disruption that occurred to John sixty years earlier, at birth? John never met his natural parents as he was adopted by elderly parents and never had any siblings. *"I am one of those only adopted"* he often told me poignantly. His adoptive father died when he was about seventeen years old and his adoptive mother died about ten years later. It was around this time that he learned that he was adopted, so he soon started on a journey of trying to find out about his natural parents, a journey that still continues today. His other journey that morning in 1983, which resulted in a car crash, and then his ABI, occurred when he and Brid were "*on the pig's back*", an Irish saying for being happy and healthy, when everything in life is going well. They were newly married, expecting their first child, and he had a company car with his new job which involved much driving which he really enjoyed. Living in Cork City allowed John to gain access to out-patient rehabilitation in the Regional Hospital (now Cork University Hospital) and

in the National Rehabilitation Hospital. But there was no family-centred approach used, thus no supports for Brid and their new born son, and their daughter born two years later. They separated a few years later, but John maintains limited, but good communication with his family. He works full-time in the civil service in a position gained under the three per cent quota policy for public agencies aiming to employ more people with disabilities. John is active in his church and in church group activities and a music appreciation group. He loves classical music, film, reading, cycling, and being out in nature. Having a sense of public responsibility, he is involved in numerous community groups and events, seeing the city as his 'community'. However, having moved from disability support services to the social welfare support services as a single parent, Brid realised that this Department also worked on the premise that service-users "must continuously prove their need."

ABOUT SINEAD *and Paddy*

Sinead and her husband Paddy were a young couple with five children, self-employed, working long hours in their two small shops that needed to be open seven days a week to make an income for their growing family. One morning in 1992, Sinead was hit by an older car driver, a driver whom local people state should not have been on that road because of his visual problems. After approximately four months in a coma, Sinead spent a year and a half away from her family in the National Rehabilitation Hospital. She returned to her country home still very dependent, because of residual ABI impairment effects, including memory and mobility difficulties. Sinead was not enabled to continue to be a mother to her six children, to be a wife, or a friend. Friends and family dropped away. Transport and access, or being welcomed to participate in community social events were not available then, making her live out the 'social death' model of disability. (See Chapter 1). Sinead wanted to, but could not, meet people like herself to help her to understand and cope with her ABI. The lack of individualised rehabilitation and/or disability services in their home or community during this family's time of transition added to their difficulties. Paddy went through '*hell*' for

five years after her accident as he tried to cope with '*losing her'*, yet still care for her and their children, and manage his own business, seven days a week. The local public discourse on ABI also offered little hope while financial compensation could not substitute for all their losses. Neither slow recovery from ABI nor her family love was enough to allow Sinead to continue to live at home. Local community services or resources were not available to her in her home. After two years at home, she moved to an independent living unit one hour away from her family. Having survived her long coma, intense long rehabilitation, to having to live a life with limited choice and control, Sinead is now enjoying autonomy and life in her own space and taking part in supported work training and social programmes. Meeting with people with ABI has given her a sense of belonging. With a very part-time personal assistant, Sinead has worked out some new social networks and enjoys accessing live music weekly. Although still part of the family, they have all moved on, apart, with their own separate lives. That morning car crash, which added many difficulties for this family, was compounded by numerous other issues, not least the lack of community disability services and a lack of public awareness about ABI.

ABOUT VIVIENNE *and Helena*

As a young holiday maker in South Africa in the late 1960s, Vivienne, then an Irish air-hostess, was involved in a car crash. She had been unconscious for ten days and had/has, she claims, post-traumatic amnesia for approximately three weeks. She "looked fine" and was "mobile", but she herself realised that something was "wrong" or "different". Neither she nor her medical practitioner back in Ireland named this difficulty. Her life-long friend, Helena, who is involved in this study, also knew something was 'different' about Vivienne on her return to Ireland. But in the 1960s, awareness about ABI was very limited here. No one named this 'difference' for Vivienne until twenty-five years later, in 1993, when she was diagnosed by a neuro-psychologist in Headway Ireland as having had a traumatic brain injury. Officially, she has now lived with this for twelve years, but in reality, she has lived with ABI for thirty-six years. Vivienne managed some

good times during those intervening years, unaware that she had an ABI, although she could not "*keep down many jobs*". Some work was boring rather than difficult, but she did often get lost on the streets, had attention difficulties and remembers often feeling depressed and emotionally flat. Following a move to work in England, she married, but soon sought a divorce for issues not linked with her unnamed ABI. Family and many friends gave her little support at that time. Back in Ireland, she pushed herself to study and qualified as a yoga teacher, and was employed as a part-time yoga teacher until recently, while also doing voluntary literacy teaching. Vivienne continues to enjoy music, church activities, reading, television, and taking part in some social groups and travel. Her local city is her neighbourhood, and fortunately she can access the buses now easily and freely having gained her bus-pass last year on reaching the age of sixty. Financial and housing problems were her main needs over the past decades, so eventually in 2006, she moved to her own comfortable space, a place she has been waiting for, for decades. Vivienne knows the historical reality of living in Ireland before and after specialised ABI services were available. Although professional supports may have been of additional help at certain earlier stages post-injury, Vivienne worked out her own 'rehabilitation' plans. She is aware, however, of the drawbacks of having to do everyday living with an ABI in a fast, noisy, busy world. Recently, her friend Helena has also had to learn more about ABI and Irish ABI support services, as her son had a bad car crash resulting in a traumatic brain injury.

4.3 DECIDING ON WHAT STORY TO TELL ABOUT MY FINDINGS

There are three *tellings* of fieldwork (Bruner, 1986). First, we tell the participants why we are there and other ethical and practical details. Second, we take all the words and visuals and tell it to ourselves 'in the field', in our research notebooks and in our transcripts. And now in this third telling, I tell it to others (ibid; p.147-148). There are various ways I could report my findings and my interpretations of all my data sets, paradoxes, tensions, and uncertainties. Unlike a grounded theory

study, the use of literature before and during this study also played an important part of moving on this study. In addition, the numerous theoretical and methodological discussions with my supervisors, along with the many challenges and supports, gained in appreciation from or with them, impacted on how this final thesis is presented. Thus, in this short section, I document those theories or concepts and strategies that enabled me to organize my findings and interpretations and decide on the actual design and content of the findings Chapters, i.e. Chapters 5, 6 and 7. As noted in Chapter 3, there are many problematics in the production of knowledge or 'evidence'. As stated above, there are three important considerations or pointers while telling and documenting qualitative research, namely systematic and careful research conduct, coherence, and convincing and relevant interpretation (Ballinger, 2006). This section is aimed to present some evidence of these criteria, although this work had to be constantly balanced with the impact of this telling on the lives of the participants.

I did not want to fall into "fragmenting people's lives into specialisms [and] jargonising their experience" as Rickard (2004, p.171) stated. Thus, being an interdisciplinary study, occupational therapy concepts or specialised categories (professional discourse or jargon) were used sparingly. I did inform the participants that I was moving beyond their told stories, and telling formally more about the social and/or the political across their narratives, even if the political is personal or the personal is political. This was not to dislocate the participants from their biographies as Rickard (2004) denounces, but in my attempt to be more ethical and more critical. Although ABI is only a part of their lives, this disruption continues to impact on many aspects of their lives. ABI, however, was the reason I was with them, to learn from their tacit knowledge and experiences and co-construct new knowledge about living with ABI. This remains the focus of my next three findings Chapters.

Dealing with the analytical dualisms such as structure-agency and/or macro-micro also helped map this text. Individual issues or events were separated from social

practices and from given structures. The given structures in this study included the expectation of all participants that rehabilitation services are available throughout Ireland, even if limited. The separation of personal-self, context, situated activity and setting, as used by Danermak et al. (2002), also helped me to manage many of the overlapping issues, events and experiences. The participants' stories covered a multitude of events, experiences and tales. Using Frank's (1995; 2004b) typology above, some of their stories could be linked with 'self-reinvention' and how they and their families and rehabilitation workers enable(d) them to 'become', to be and to belong today**.** Other narratives could be linked with the manifesto form of quest narrative. Most participants actively sought through their links with community groups, to make life better not only for themselves, but also for other people or families living with ABI.

At the initial drafting stage of this thesis, one Chapter was included about Remembering the Past, but later I decided to stay more with their 'now', the main focus of this study, with the past interwoven.[145] This does not neglect or demean the participants' past, which included much suffering, but they have 'moved on a lot', even if their past is still very much part of their present. The many findings about their present included many dualisms, such as recognition and redistribution, identity and inclusion, body/impairment and disablement, and sameness and difference. These concepts emerged as important issues and were therefore given space in this text, as were the concepts of occupation, time and citizenship. Issues linked with and/or between identity and inclusion were separated in these Chapters, although 'being hailed' or 'not being hailed' impacts on both aspects of everyday living. This separation of identity and inclusion is linked with my holding on to the social model of disability as mentioned in my Chapter 2. While many theoretical concepts and empirical issues overlap, certain concepts or themes were separated for academic or analytical reasons. Certain body issues were

[145] An interesting point was discovered when preparing for my formal mid-term presentation in 2005. I noted that Round 1 interviews were, in general, more about their past linking to their present, while Round 2 interviews seemed to be more about their present linked with their past. The research design here then allowed meetings in Rounds 3 and 4 to stay more 'in their now'.

separated from structural issues to link in, somewhat, with specialisation in practice in health and social care issues today. Critical realism also highlights the reality of the stratification of our society which is especially strong today, given our increasing professionalisation of society.

My data, my analysis and my interpretation enabled me to name four main themes or strands in this thesis, which are also mapped on to particular Chapters. These themes and links are:

1. identity and social becoming (Chapter 5);
2. opportunities and barriers to participation (Chapter 6);
3. beyond rehabilitation assumptions (Chapter 5 and Chapter 7).
4. living a slow life in a fast world (Chapter 7); and

See also my Introduction and Conclusion Chapters.

The three levels of analysis named by Honneth's Theory of Recognition (Honneth, 2001) provided a major mapping guide for me. This theory claims the need for recognition at the level of personal or emotional relationships, the desire for individual distinction and at the collective level for formal equality and social membership (cited in Crossley, 2005, p. 262). Some of the personal issues are discussed in Chapter 5, while barriers or supports enabling individual distinction are in both Chapters 6 and 7. But recognition at whatever level is not sufficient. As Fraser (2002) shows, the old battles for redistribution are still around, and we still need a "more just allocation of resources and goods" (p. 21). Issues dealing with redistribution of material goods and services for the participants, collective generic disability services are noted mainly within Chapter 6. Improved collective recognition and status, addressed in Chapter 7, may enable people living with ABI to access services quicker.

I hold on to the need for specific body work, yet not negating the holistic needs of the person. Chapter 5 is more on or about body issues linked with impairment and

identity, linking in with the public discourse on ABI. Theories of identity generally deal with self-social issues about 'being hailed' even when different or living with diversity. Sub-component elements of identity, while being very important for most people with ABI in the acute phases of neuro-rehabilitation, are usually dealt with and discussed separately from the public discourse on ABI in the local community. Yet, as disability theorists have well documented, especially about other acquired impairments, this public narrative has a major impact on their personal ontological narratives. Thus, Chapter 5 includes both personal and social identity issues included in about 'becoming' a person with an impairment, and being hailed or labelled. There is a interrelationship between the need for knowing and interacting with others in order to know one-self, especially when developing a sense of self and self-awareness following an ABI. This Chapter is titled *Knowing Me Knowing You*.[146]

Chapter 6 turns to disablement and inclusion or integration issues. This sixth Chapter focuses more on the material embedded reality that disabled people have to live with because disablement includes many of those pre-requisites for participation and social inclusion. Material and temporal issues when living with disability can impact also on not being included in social events. This sixth Chapter is titled *We Need Car Park Spaces Too,* words used by Annie, one of the participants. Post injury, certain events or experiences occur only or mainly because of the passing of time (chronicity), while time and recovery of varying degrees, whether physically, metaphysically, or emotionally, are interlinked. Rather than seeing a pattern of recovery linked to time, time issues often emerged in this study as a major creator of 'othering' in our disabling society, another form of collective disablement. Thus, the latter section of Chapter 6 is specifically about this problem with time.

[146] This title was created by making small changes to the title of the song *Knowing You, Knowing Me*, by the Swedish pop group Abba, which was playing while thinking about my thesis plan.

Chapter 7 includes much on what the participants have had to or have to go through, or what they are doing to gain collective recognition. This Chapter looks towards a counter-narrative about living with ABI, theirs and mine. This includes discussion about becoming and/or being a citizen, and about collective advocacy for recognition and working towards citizenship. I titled this Chapter *Living the Slow Life,* words that I have often used to describe my study in general, and/or the lives of people with ABI. Some participants have also talk about slowing down and the need to slow down, which is also a message recommended to all people today, slow down and enjoy living a slower life.

Although the ICFDH (WHO, 2001) tool is problematic in part, see section 1, Chapter 2, two major domains of this tool enabled some planning of this thesis, also. These domains were the activity limitation and participation in life activities. Social participation underpins most of this thesis, as respect and recognition are always sought, whether in the neuro-rehabilitation centre or in the local 'pub' (public house). For occupational therapists, the concept of occupation may mean all those tasks, activities and experiences involved in everyday living, including social participation in local society. Thus, an occupational focus could have been placed on most of the concepts or sections used in this thesis. But as noted above, this is an inter-disciplinary study even if written within the present (problematic) trend of vocationalising almost all education today. Particular focused occupational therapy links, beyond those in Chapter 2, are included specifically in Chapter 5, occupation and risk, Chapter 6 participation in everyday living, and Chapter 7 advocacy / volunteerism as occupation.

The above Chapter plan, headings and subsections were developed from, and are used with, a balanced amount of quotations from the participants and from the literature, with some discussion. My findings Chapters, therefore, are in general about the persons with the impaired body (Chapter 5), the disabled person (Chapter 6), and, finally, the citizen making more explicit links with citizenship (Chapter 7).

CONCLUSION

While narrative may be everywhere, and while narrative(s) may have many positive uses in clinical practice and in everyday living, cultural, ethical, methodological and philosophical issues remain when narrative is used in research. People with ABI do have a narrative self, where change is accepted and coherence is not fixed. Their narrative self is obviously affected by the specialised and the public narrative and discourse on ABI. To enable and access some of the narrative self and their lived and told stories of the participants in this study, the above person-centred flexible research design within a participatory ethos is recommended. This allows a challenge to some of the public prescripted narratives that Gardiner (200b) discusses (see p.134), as limited prescripted narratives appear to be used too often when working with and researching with people with ABI in Ireland today.

This Chapter along with Chapter 3, identifies many issues involved in the construction, interpretation and use of narrative in this particular study. The pen portraits above, present only a little about the six disabled participants in this study and, for some, their partner is also included. As the participants shared with me many exciting and many sad lived narratives, it was difficult at times to know what to include and what to exclude, both about them as individuals and about my interpretations across the told narratives. I have presented in the final section above some of the details on how I managed this important aspect of the research process, and structured my findings, and how or why certain decisions and interpretations were made. This section gives a hint about my three Findings Chapters 5 to7, respectively titled *Knowing Me, Knowing You* (Chapter 5), *We Need Car Park Spaces Too* (Chapter 6) and *Living the Slow Life* (Chapter 7). These Chapters now follow.

CHAPTER 5 KNOWING ME KNOWING YOU

Developing identity as a person with a brain injury

"[B]odies have brains, but persons have minds – or better, they are minds"
(Jennings, 2006, p. 30).

The disabled participants in this study were literally out of their minds for some time because of the physical trauma to their brain. And, for varying lengths of time, they were not aware that this was so because, as the neuroscientist Greenfield (2004) shows, the physical brain is the basis for the mind. While Sinead was in a coma for four months, her family and hospital staff held a holistic bio-medical gaze on her body. But now, she can say "*I was so bad the doctors thought I wouldn't come out of my coma. I was in a coma for four months, so they were even half thinking of, of* …[long pause]" (Sinead 1, p.1). While usually there may be no separation between body and mind, the links between brain, body, mind have to be considered separately at different points in time after an ABI. For this study, living with ABI years post injury, it is almost "impossible to distinguish *mind* from the concept of *Self*" (Greenfield, 2000, p.185).

In rich nations today, there is a fascination with self, identity, almost a do-it-yourself biography (Beck, 2002). It is as if we are all "choosing subjects", and that we are what we make ourselves across time and space (Miles, 2001, p.96). This excludes, however, or places additional work on people who are dependent, vulnerable, and in need of much care or support. The above dictum may, however, give freedom to people to be different. But, this is not a freedom sought by all (Kittay, 1999, 2002) and/or it may be sought only after certain prerequisites are available or confirmed. As Sarup (1996) stated, our identity is "not only influenced by events or actions and their consequences in the past, but also how these events/actions are interpreted retroactively" (p.14).

Identity work, identity formation or re-formation, for Annie, Claire, Joe, John, Sinead and Vivienne, are different strategies or processes from that generally involved in the post-modern discussion of identity. After their ABI, they had to begin from that 'nano level' of identity work, starting in the domain of becoming self-aware again, before moving to a search for personal and/or social recognition, and social participation if wanted. Throughout these processes, their 'relational self' matters very much I believe, as they are affected by how people with cognitive and functional impairments are valued in local society. In Honneth's Theory of Recognition, personal recognition is one component of social recognition. This involves a need or search for love or social esteem for individual achievements and abilities (Crossley, 2005).

This Chapter is based on some of the data that emerged over time with the research participants about or linked with the concept of 'identity'. (See also section 3, Chapter 2). I use four sections to develop my argument about their difficulties and successes in '*Knowing me (themselves), knowing you'*, highlighting the importance of intersubjectivity and interdependence in self-awareness and identity work. In the first section, I present an overview of certain aspects of ABI embodied, to include, but not over-essentialise, the real different bodies the participants talked 'through' or about. This includes some of the suffering they have had to go through which may get lost in over-socialised discussions of celebrating difference and impairments today. In the second section, I explore their self-identity repair work as the person adjusts practically and emotionally to their ABI. This work is the first step towards recognition and discussed here under the title Self-awareness...and accepting the 'new me? The personal adjustment of the participants in this study had to be carried out within both the local public discourse on disability in general, and the discourse on ABI in particular. So in my third section titled, *They think we are mad*...social becoming within a mainly negative discourse, I focus on aspects of discourse that enabled and/or disabled the participants in their early post-injury identity work. Most people with disabilities have sought ordinary everyday living for decades

now, and such living involves the need for some risk. For persons after an ABI, this need for risk is still important, although it may need to be offered and taken gradually. So, in the fourth and final section of this Chapter, titled Risk and occupation towards self-same-ness, the joy of being granted or taking risks with pre-injury occupational interests, or otherwise, is explored. Particular critical incidents and typical representations are described and explored here, along with the unintended consequences of certain events or processes. The main substantive relationships therefore underpinning this Chapter are those between the disabled person and their family, friends and rehabilitation staff, except for section 3, where the focus is more on public discourse, attitudes and awareness.

5.1 ABI EMBODIED AND EMBEDDED IN LOCAL CONTEXT

"Embodiment is an existential condition in which the body is the subjective source or intersubjective ground of experience..." (Csordas, 1999, p.143). Participants in my study do not speak about embodiment or their embodied selves, but they are very aware of living with the impairment effects (Thomas, 1999a) or being-in-the-world with ABI. This section focuses on the impact of particular or 'essential' differences to the disabled participant's body, personhood and to their functional limitations or 'impairment effects' (Thomas, 2004). I hold on to their strategic essential differences, without essentialising them. I am not disregarding their whole selves, their embodied and embedded living with ABI, as this thesis is all about this concept. Yet, I cannot be holistic at all times remembering that reductionism can be as useful and as problematic as holism. This section links in with my discussion on 'the body' in section 2, Chapter 2,

For varying lengths of time, five of the participants in this study were out of touch with their consciousness and with their minds/self while they were in a coma. Their time in coma ranged from four days for Annie up to four months for Sinead. And even with the passage of much time, rehabilitation, 'guts', family and generic

community supports, they may still, at times, experience their body as an object. Unlike life before their injury, but like many other adults who acquire or live with a serious impairment, they may now have to work with strange feelings in their head, lift one leg or arm out of the way, and/or accept brain 'shut-downs'. Their "pre-reflectively lived subjective body is disconnected" (Finlay, 2006, p.192). Like Ann who lives with multiple sclerosis in Finlay's study, they now live with a somewhat different subjective body. As Annie, Claire and Joe said:

> *turning around in bed, bending down to put on my shoes...I could feel inside my head move, hard…had to wait years to learn how to manage my shoes* (Annie 1, p.21).
> *my brain gets so heavy I'd love to have a wheelchair for it* (Claire 1, p. 3)
> *feel those bumps there…the doctor told me he made that* (Joe 1, p. 3.).

Many people with ABI have to live with impairment effects such as perceptual difficulties, balance and mobility problems, emotional lability, loss of tact, difficulties following conversation, as well as the more talked about behavioural, speech and memory difficulties. Participants in this study went through the phase of certain memory loss, attention and insight difficulties. As Claire said, "*it's like waking up in the morning and forgetting your past and not knowing what's going on around you*". She now remembers, from her self and through her family, much about her past life and about her accident. Joe's wife Elizabeth did not want to talk to me about his time of post-traumatic amnesia, but rather focused more from the day he woke up, three months after he was knocked down by a car. She told me:

> *he woke up 17 April* [2001, knocked down in January 2001]. [eldest] *son rang home to ask me to go down to a neighbour and ask him did he call that day to* [the Hospital] *and did he leave a bottle of drink. This was a huge moment.* (Elizabeth 1a, p.1).

That neighbour had indeed called. Her husband, their Dad or father had come back to them. They were happy, and still are, even if he has not perfect memory or perfect executive functioning. Vivienne states that she was in denial for years about having any impairment, although she remembers that she found it difficult during that time to follow television programmes, especially when they resumed after an advert break. She also remembers getting lost on certain streets in Dublin, and the difficulty in retaining some of the content of her studies in evening classes later on in University College Cork (UCC). But as her friend Helena told me, "*she did make that brain learn*" (Helena 1, p.6). Other participants told me about those difficult early days managing in the kitchen, out shopping, or at work. Annie used to forget children's names attending the surgery when she tried to return to work, while Claire forgot on occasions where she parked her car. John would forget to bring money with him to work, and was unable therefore to buy even milk on the way home.

Today, participants may not have perfect source memories about time and place of particular events, but they have adopted ways of living with this loss. They have varying degrees of memory capacities, they have remote memory, and by now, years post-injury, they have regained various degrees of recent memory or various means of enabling same. Only on one occasion did Sinead forget, or remembered not to take her epilepsy tablet. Because her father was continuously encouraging her to '*get off the tablets*', she did not take them one day, but she had an epileptic fit on that day. She has never forgotten that tablet since then. Joe does not need good memory for his favourite interest, card-playing sessions, saying "*…you don't need great memory for poker, only tactics and lying"* (Joe 1, p.3). The participants remember much and almost all about what they need to remember in their life today. They use coping strategies or routines that we all use to help us remember our daily events or activities. They also use memory aids such as notebooks, diaries, or simple colour 'memo-sticky notes' around the house. Like Annie and her diary, John's diary and his glasses are now part of him. Plus they can also say openly *'I have forgotten'*. As Greenfield (1997) stated, memory "is multi-faceted

and multi-staged, more than a mere function of the brain...[it is] a cornerstone of the mind (Greenfield, 1997, p.187). And, perhaps more important for rehabilitation workers to remember, "there is no single region for a memory [in the brain] but rather it is distributed over many regions" (ibid, p.171). Personal resources for interpreting the world are also involved. Personal memory is linked with life habits, time and 'social memory', yet many rehabilitation workers use the old map of the brain, often disregarding the potential for new learning and all the social issues involved in memory work.

People with ABI are often portrayed as not having a past or future, and living only in the now. They are positioned as if they have permanently "lost their connection with the human order, the ability to project [themselves] into the past or future using abstract thought" (Butt, 2004, p.130). All the participants talked with me, however, about past, present, and many future events, even if they do not always have great clarity regarding precise dates of all events. They plan about and for future events within their control, sometimes with the assistance of a diary, as all executive people do. As Fabian (1983) wrote about the Hopi people, a fact also known about people in various cultures, especially in the past, their movement through life was measured more by events than by clock or calendar time. At times Annie may say "y*esterday, I've no idea, it's gone* [but] *I'm here now you know"* (Annie 2, p.1). Today is very important to Annie and she does enjoy living 'in the moment'. She is not removed from reality as she is very much part of it. She remembers much about her past, has plans for future days, both for herself, e.g. events with friends, family, or golfing colleagues, along with plans for/with others, including social life, voluntary work and advocacy. Annie has learned practical time management, from listening to her body, sorting out priority tasks and using her personal organiser. Time for Sinead came in the opening sentences of her narrative with me. She said that at the start of her rehabilitation "*I asked the specialist after, why was I so convinced that I was only sixteen. They said to me 'cos when you injure your brain, it puts you back in time. Look how far back it put me…*" (Sinead 1, p.1).

Coping with ‘real’ time and ‘felt’ time can sometimes create difficulties for many people with impairments without occupational engagement. Sinead, for example, lives in her now, yet the hurt of lost past time can be heard in her words. *“I’d love to be able to read again. What annoys me is that when I didn’t have time to read, I could read and now I have loads of time and I can’t. It drives me crazy”* (Sinead 2, p. 5). She is aware of past losses and limited future scenarios, yet knows she must put up with ‘her now’. John also remembers well the pain and loss of having to move into a flat on his own

> *…when we separated, I found I had an awful lot of time on my hands …I was anxious to use up some of that time and to take myself out of myself* …[now] *time doesn’t drag on my hands* (John 1, p. 6).

Like many other people who separate, he, too, knew the pain involved in the loss of his past and his hoped-for future, and the need to do something about it. Vivienne also knows the pain of past love and a lost marriage. Even before she was officially diagnosed with ABI, she wanted her then husband to go for counselling and/or some week-ends away together. He would not and did not. They separated.

The difficulties of communicating in time, without ‘*now speech’*, were shared with me by Sinead, Annie, Claire and John. ‘Now speech’ is what some disabled people have called everyday speech, but difficulties arise when other people will not wait for those with ‘slow’ speech (Robillard, 1997). Some people have told Sinead that they cannot understand her, yet I was able to transcribe our taped meetings. Yes, I played the repeat button on the audio-recorder often while transcribing, as with all of the participants, but with Sinead, I also had to try and understand her local accent. With fatigue and with impairment effects, Annie and Claire both know their speech may *s l u r* if they get tired. The concepts appearance and gaze are also often used by disability theorists when discussing disability in society. Yet,

major differences can impact on a person's emotions and social interaction even without appearance or the gaze of others being involved. Hidden impairment effects were one of the most difficult aspects of their ABI for Annie, Claire and Vivienne who spoke about the lack of any accommodation from the public "*because we look so normal*". Both Sinead and Joe have visible impairments which may prompt others to make some allowances for them while shopping, talking, or crossing the road, for example. This dialectical situation continues where disabled people seek valorisation along with compensation and/or support services, and/or seeking inclusion with accommodations. Coping with noise is another of those hidden difficulties. Living with their bodies in today's urban world with shopping malls and crowded urban buses and trains, create difficulties for some people with particular brain injuries.

> The self-consciousness and alienation caused by proximity to strangers, together with the bright colours, constant movement and novelty, are designed to induce a heightened level of automatic arousal, which may be experienced as either excitement or anxiety (Yardley, 1999, p.43).

Claire told me she could spend hours out in a quiet garden or park, but only wants twenty minutes in Cork city. Joe, the only other participant living with his family today, is not affected by noise, and he does not need to enter city spaces often. He prefers walking his country roads and visiting his nearby country town with his wife for shopping, business, or visiting relations and friends. The quiet noise from card-playing in his local pub in this town attracts him two or three nights a week. Annie and Sinead live alone in their homes or flat in small towns, and John and Vivienne, who also now live alone, can manage city spaces and small groups. Living alone with ABI was suggested to me as a benefit for people living with ABI in our fast world. Perhaps it is to the advantage of local people with ABI, that counties Cork and Kerry are not metropolitan centres. These counties have few of those "perpetually disorienting spatial layouts or motions, produced by mirrors and

split levels, escalators and lifts, rapid movements and flashing lights...or underground railway systems and motorways" (Yardley, 1999, p. 43). Vivienne and John love moving around Cork city either by bus or by bicycle respectively. Their community is the city, but why they want to and do stay out of their flats a lot is linked to other issues in or linked with this thesis, e.g. marriage break up and having few friends who call in to them.

To give an overall view of how ABI can impact typically on a person, John told me how his ABI affects him now, years later after having been given only a few days to live some years ago:

> [my] *speech, eh, my balance left an awful lot to be desired. I still have that problem today. My balance is fine on the left side, but on the right hand side of me, it's anything but fine. I'm not rooted to the ground on my right hand-side eh, I'm quite normal on the left hand-side...So, of course my memory eh, is certainly not one hundred per cent. Ah, maybe it's, I don't know, maybe seventy-five per cent but eh, a lot of details now I'm, I would be incapable of recalling. I'm fine for general things, but if I homed in on a specific area I could give maybe two or three sentences to cover it. Someone else might give a page and a half…*
>
> (John 1, p. 2).

> *I wouldn't be as quick on the uptake em as I was. I mean I was never one hundred per cent quick on the uptake but I was sharper than I am now. But now, you'd need to, kinda map things out on a blackboard for me. I wouldn't be so, get the brain to put two and two together but, I'd be a little bit behind the times on, on, on spotting things…* (John 1, p.3).

People with brain injury often have other impairment effects that are not generally realised by the public. For example, Joe has no sense of taste today. Sinead has visual processing problems along with hemiplegia,[147] which add to her memory and mobility impairments. Fatigue is still a major issue for Annie, Claire and Sinead, but like Vivienne, they pace themselves and plan their days and life around their energy levels, always aiming to prevent tiredness. For Claire, living with her 'brain shut-downs' was one of the more difficult issues for herself and for her family. The uncertainty of their arrival, however, is as difficult for her as the 'turn' itself, which has included some falls.

For example, on the arranged date and time of our third meeting at her house, I noted the following in my research journal 3 December, 2004, as noted in my progress report to my supervisors:

> *Claire answered the door, she looked dazed, empty faraway eyes and looked at me. I said "it's Phil here". She opened the door back some more saying "can't talk". I said "that's okay". She guided me in, as I asked is it okay to come in for a minute and we walked with the dog back to the kitchen. Her son was talking on the phone outside the kitchen door. Claire was mouthing and gesturing with her hands around her head whispering "pressure, tired, can't talk". I said "it's okay, have a rest". She had a few mini tremors in her hands, and she put her hands out in front of her. We had a peaceful silence for about five to seven minutes, more repeat of those same words and then more silence. Her son came into the room about fifteen minutes later and Claire was then going to lie down and rest…*

Back home I wrote in my research diary:

[147] Hemiplegia means that either the right side or the left side of the body is partially or totally paralysed. This often occurs after a cerebro-vascular accident (CVA), often called a stroke.

> *I will always remember the distant look in her eyes, that faraway gaze and the small tremor in her hands, and her apparent searching for an end to the pressure around her brain. The loneliness for her at times must be very hard. I understand more now about her fear of going out.*

Claire experiences fewer black-outs since she was made to stop driving in November 2004, and since accessing support with Headway Ireland. But they are not fully controlled. However, the loss of driving created new problems for her, a transport problem experienced by many of the research participants. This will be discussed further in Chapter 6.

Given that persons are their bodies, for many, embodiment is linked with body-image. But I did not ask participants about their 'body image', although references to this arose at times. Claire spoke about the difficulties with her mouth-piece,[148] while Joe talked about his artificial arm and using his wheelchair, and Sinead told many stories involving being outdoors using her wheelchair. Joe, with an upper limb amputation, never wanted his artificial arm, preferring to manage more efficiently without it. He has left it unused upstairs in his bedroom. He will use a wheelchair, however, when he thinks it may help him or his family get around or socialise more easily, saying "*I don't mind, I'm not one of those*" (Joe 2, p. 3). He did not finish this sentence, but he includes practical issues into his strategic decision-making. Sinead uses her wheelchair for practical reasons, when going shopping, to the training centre or to certain public events, but she dislikes it on most occasions. For these participants, strategic decision-making is combined with aesthetic or comfort issues.

I have highlighted in this first section of this Chapter some of the impairment effects that the participants have to live with, their ABI embodied. As the body

[148] Following the damages to her jaw in that car crash, Claire uses a custom made orthodontic product.

provides a route to the person (Edwards, 2005, p.127), embodiment is perhaps a changing fluid concept like identity. Throughout all this time, naturally, various coping strategies were used. Deep reflections on past emotional states whether feeling down, depressed, annoyed or feeling wanted, valued and content were not delved into. I did not engage in any therapy with the participants, nor study particular feelings or meanings at various times of their past, often sad, memories. Their present was of more interest to me, yet this now does include their past and future hopes. Their embodiment is interlinked with where they live and with whom they live. Other factors include the number in the home, their family form of social living, geographical space, occupations, along with aspects of local rehabilitation processes and time.

For most people living with ABI embodied involves "[e]xperiencing self, which is felt by the person, while the observing self is that part of ourselves which allows us to 'step outside' of ourselves and look at our behaviour" (O'Loughlin, 2002, p.10). Developing this awareness about 'self' with ABI, as discussed in Chapter 2, is explored via the participants stories in the next section. As always, I start from the relational self rather than a lone self, or an isolated individual.

5.2 SELF-AWARENESS FINDING AND/OR ACCEPTING THE '*NEW ME*'

Most adult people do not need to work on identity or '*who am I*?' after sports or work injuries for example, nor relearn how to do tasks and activities that they first learned as a young child. Unsworth (1999, p.3) stated that "[t]hinking, remembering, reasoning, and making sense of the world around us are fundamental to carrying out everyday living activities" (as cited in Golisz and Toglia, 2003, p. 395). But the participants in this study all talked about the loss of all or most functioning, and developing insight into these limitations over time, and the gradual recovery of some or most of this functioning. As in section 3 of

Chapter 2, assessing and relearning for partial or full self-awareness is a major part of neuro-rehabilitation work. In the past, self-awareness work in neuro-rehabilitation focused more on the patient's lack of insight as a denial of disability. Today, it is still linked also with this, along with differentiating unawareness secondary to impaired cognition. There are academic debates and ongoing practice developments regarding the precise classification of levels and types of self-awareness and the existence of a hierarchy or not. To map Sinead's situation, for example, with the three main levels of awareness as recommended by The British Society of Cognitive Rehabilitation (2005, p. 39) discussed in Chapter 3, would mean:

Intellectual awareness:	if and when Sinead says, *I keep forgetting things people say to me and this is because I have a brain injury*;
Emergent awareness:	if and when Sinead *knows that a problem is happening as it is occurring without requiring any prompts or cues;* and
Anticipatory awareness:	if and when Sinead *can predict or anticipate the events or situations in which her problems are likely to occur.*

Occupational therapists Fleming, Lucas and Lightbody (2005) map these levels of self-awareness on to occupational performance respectively as i) understanding impairments, ii) recognising when impairments are affecting performance, and iii) anticipating when impairments will affect performance. As noted earlier, self-awareness of competency in most areas of function tends to develop over the first year post-injury (Dirette, Plaiser and Jones, 2008; Fleming and Strong, 1999; Gray, 2000). Yet most rehabilitation assessments and training seem to be carried out in Ireland in the early months or first year, if at all, with little follow-up. In this study, John's ex-wife Brid told me "*it was a year at least I think before he was aware of it at all, you know*" (Brid 1, p.3). And in theory, "individuals who are considered unsuitable for intensive rehabilitation because of poor insight could be reassessed over time and given the opportunity to receive services at a later stage if

appropriate" (Fleming and Strong, 1999, p.15). This seldom happens in Ireland given the shortage of rehabilitation staff. Three of the participants, though, in this study each had a three month period in the National Rehabilitation Hospital, soon after injury. Sinead had a much longer time there, while Clare and Vivienne were never there, and may not need such specialised resources. Follow-up community-based rehabilitation is not or very scantily available in counties Cork and Kerry. There are no drop-in centres in which any of the participants can feel free to call into for general enquiries. Vivienne and Annie were in denial about certain inabilities for some time after their injury. Yet, by delving more into life on their own, with some friends and some family support, they did learn much about their abilities and limits. But Claire pushed herself without realising the need for rest. Having certain supports may have reduced difficult moments for these three people and their families. The need for access to informed expertise, at the right time, was repeated at every Health Service Executive ABI Planning Project Group meeting and at every BRI meeting in which I participated.[149] Yet, some awareness of deficits returns irrespective of professional interventions (Gray, 2000). This leads me to question, as mentioned in my literature review, the need to work towards almost full insight at a very early stage following such a traumatic life-event rather than a phased individualised approach over the long-term.

I focus on Sinead now briefly, as she had the most serious injuries, and now has more serious continuing impairment effects, with visual-perceptual, hand functioning, mobility and cognitive difficulties. She is now living in her independent living unit which highlights the importance of a supportive enabling environment. On returning home, Sinead remembered her lack of abilities. She had insight about her mobility and cognitive deficits, yet she remembers being really annoyed seeing her home "all messy", and not being able or enabled to do any housework.

[149]As Secretary of the BRÍ advocacy- support group for people with ABI and their families, throughout 2006 and early 2007, I attended monthly meetings with the local HSE Planning Project Group towards planning future ABI services for counties Cork and Kerry.

Sinead: *and to see her* [the home-help, an old friend] *now and running around doing the work that I cannot do, drives me insane*

Phil: *Oh*

Sinead: *and my youngest fellow especially, he was only two, when this happened me. Now he is thirteen, and to see, to see him with the mother he has, who can't do nothing and…you see,…my Home Help's son is* [weaker voice] *in the same class as my son and to see his, his mother running around and doing what his mother can't do drives me* ***insane*** [she stressed this word]

Phil: *that must be hard*

Sinead: *it is depressing cos I was always very fussy about housework and the way things are done and things being clean and my goodness now, to be there and to see all the work that I could do before I came to nought now drives me mad* [long pause]… (Sinead 1, p. 6).

It appears that Sinead had insight into her limitations when she returned home, nearly two years after her car crash. She was also self-aware of the expectations of her expected social/occupational role as mother of six children. She was not denying her impairment, she faced it daily. But she was left with no public-service supports to enable her and her family to continue with adjusting and learning for their new situation. Her words above highlight many of the social causes of her disability. She experienced additional oppression, loneliness and discrimination because of the lack of environmental adaptations to her home, very poor or non-existent community or home-based professional supports. She also had a lack of transport to go anywhere, along with few opportunities of places to go. Her husband was busy working seven long-days a week to earn for their young family at that time, although they were granted a Home Help to help with their children.

Negative attitudes or fears regarding impairments caused her friends and siblings to stay away, adding to her difficulties of living with her impairment.

Eriksson, Tham and Fugl-Meyer (2005, p. 40) claim that participation in leisure, social life *and ability to wash clothes* impact on couples' happiness. I found their claim about the effect of an inability to washing clothes as strange, until I remembered some of Sinead's words about her time living in her home.

> *and em, there's more in the house rather than steps, and then again with dirty clothes or anything I couldn't turn on the machine, the washing machine even, because I couldn't see them right to turn them on.* [Pause]*…and it drives me cracked not being able to see that...* (Sinead 1, p. 6).

Mothering roles, gendered occupations in the home, community/home-based rehabilitation and social care are all interlinked with how the person with ABI sees her/himself, and what routines are allowed or not. Sinead also told me

> *I used head off to bed not to bed to go to sleep, but more or less to get away on my own for a while. I'd head off on my own down to the room in the evening about half-past six and the kids would all say, 'Oh, Mum is gone to bed'* [she used a different almost cynical tone of voice] *and then when they would come down I couldn't say go away. I used be lying down on the bed pretending …they didn't think I wasn't asleep. I used be down there to be on my own more than anything else, so much stuff, I used have to put up with television blasting* (Sinead 2, p. 20).

I often wonder if her family and public health nurse at the time took her actions to mean that she was tired and had no awareness of or insight into events in her environment. But she had. In addition, the lack of follow-up professional services, lack of social visitors, along with poor attitudes to people with cognitive

impairments all impacted on how she saw herself. Today, Sinead is also very aware of her own abilities, limitations, and what she does not like about herself. A counsellor recently asked her what she does not like about herself, to which she replied "*my temper, impatience, I can't wait…*" (Sinead 3, p.2). Yet, this author feels that this could be said by many people without ABI. The new counsellor *also "told me* [Sinead] *off telling me to stop thinking about the past"* saying, *"can't live like that and that I have to think more about now* (Sinead 3, p. 2). Yet, Sinead's 'now' is not very appealing to her, having limited adult contact, limited contact with people with ABI, with family or local community events. Sinead also said, this new counsellor '*made me cry'* while the last one '*made me laugh'*. The earlier counsellor also enabled Sinead to meet with a small group of people with ABI where they learned from each other and had some fun. As can be noted from her words, not only is Sinead aware of her own limitations, she is also aware of the social barriers in her life. Claire, the other mother in my study, also knows her limitations. She told me "*I know my limits. I pushed myself for ages. Is it 'cos I'm a woman or a mother? I kept going, going, not realizing that I was making myself worse"* (Claire 1, p. 1).[150] A mothering role impacted greatly on Sinead and Claire as this form of mothering role[151] is very much part of the ongoing construction of femininity in Ireland, especially in rural Ireland. The ongoing gendered division of labour in their homes is tied up with their views of themselves as women and/or mothers and/and how others see and accept them. The parenting roles of the two fathers in this study were also affected by their car crash and will be mentioned briefly in the next Chapter under ABI, a family affair.

A lack of self-awareness or denial of impairments may be organic or may be partly linked with the person trying to preserve self-esteem while aiming to cope with the reality of her changed situation. "Denial of disability is linked with a struggle to cope, resistance, often angry reactions as the person makes sense of their impairment in relation to past experiences, personality factors within the social

[150] Claire was not diagnosed with ABI until nearly five years after her car crash.
[151] For more on gender and occupation within occupational therapy practice, see Wicks and Whiteford, 2005.

environment" (Katz et al., 2002, p. 282). Yet, these reactions could also be about the lack of social reactions and responses to the exclusion of people with impairments in society. The focus of treatment is still largely on individual or person-centred rehabilitation: implying that the person must change; you must accept; you will adjust. To regain and be granted recognition and respect in their community is then expected to happen automatically. In the literature, the development of awareness is now linked with an 'acceptance' of personal impairment, as noted in section 3, Chapter 2 above**,** yet supports to enable acceptance are limited in Ireland. There is also scant public awareness on ABI, few resources for supporting the family, or collective advocacy for people with ABI, although these mechanisms are slowly emerging or developing.[152]

There are also fewer opportunities for enabling greater social inclusion in mainstream society for those who want this. Klinger (2005) claims that "in brain injury medical rehabilitation…little emphasis is given to reframing self-identity beyond the need to develop insight into physical, cognitive and affective deficits in order to compensate for functional changes" (p.14). The disability movement, however, has sought opportunities for identity, recognition and community inclusion since the 1960s, and have identified many of the societal barriers impacting on their development. All the participants in this study are now very 'self-aware' and have adjusted or have accepted with some resistance their situation. But, as Sinead often said, she has '*no other choice'*, while Joe is glad to be so good and still able to smile. They are aware of their own functional limitations and of the many disabling issues in their local society. One of these issues is the state of public discourse about disability in general and ABI in particular in counties Cork and Kerry. In the next section, my lens switches to the emergent social tendencies linked with psycho-social emotional aspects of public discourse.

[152] In 2008 for example, BRÍ, Peter Bradley Foundation, Headway Ireland and the Neurological Alliance of Ireland (NAI) co-ordinated in ABI public awareness events.

5. 3 *THEY THINK WE ARE MAD*…SOCIAL BECOMING WITHIN A MAINLY NEGATIVE DISCOURSE

I agree with Crossley (2005, p.176), in saying that "we experience our world as a shared world", yet this intersubjectivity is in constant flux, and does not start or end with an isolated individual. Using 'social becoming' rather than 'becoming' allows for the ongoing work people with ABI and their families must do after that unwanted disruption in their lives. Their social becoming takes place mainly or initially within local rehabilitation practices and the local disability-ABI discourse.[153] Disability discourse is a major determinant of the material-policy dimensions of living with impairment and disability. Not all of our social practices are discursive, but discourse is broad and deep, and impacts greatly on our everyday social relations and relationships. Although the disability discourse will not determine the person's response to impairment, this section looks at aspects of another enfolding layer involved in becoming a person with ABI. This layer is in addition to and sometimes simultaneous with the more personal psycho-emotional aspects of living with ABI mentioned above. And, as most rehabilitation workers and disabled people know, some discourses are more valued than others. Scant attention is given to the long-term, community-based retraining and social inclusion in the local community.

This section of the Chapter deals with particular issues with social relations and relationships involved with this social becoming. This search for personal recognition in the home, or in the local community, is often difficult in a knowledge society where cognitive impairments are viewed as a stigma. The nature of the cultural space and the social narrative within which they must learn to live with their brain injury, accept and adjust, all impact on this work. And others, as noted above, are not asked to change much. A recent study of public awareness and misconceptions concerning ABI in England showed that the public

[153] "Discourse is the structure of statements, terms, categories and beliefs that are expressed through organisations and institutions" (Dominelli, 2002, p. 33).

do not know the possible long–term diverse effects of ABI or the recovery potential after an ABI (Swift and Wilson, 2001). ABI was also confused with madness and learning disabilities. Negative public attitudes were identified by the female participants as one of the most disabling issues affecting them, especially in the early years. The public or cultural narrative on ABI is still 'quiet' in Ireland: it is almost silent. Annie told me that she had "*never heard of anything about it except now. It's a forgotten race, now that's very sad since 10,000 every year have a brain injury in this country"* (Annie 1, p.2).

Coping with relational aspects of disability which "operates along emotional pathways is highly influenced by cultural representations and disabling images" (Reeves, 2006, p. 96). Much of what does appear in our local media or public texts today focuses on the negative aspects of a person's life with ABI, what people cannot do, or disclosure of large compensation monies granted to them, or about carers' need for respite. Without lessening the personal loss and suffering, I believe a more balanced perspective is required, for example, by including the recovery model more in the media and the need for societal changes. Annie, Claire and Sinead also talked about those times when other people thought they are weird or retarded.

> "*We may be a little off centre for a while...but we are not retarded*"
> (Annie 1, p.16).
> "J*ust cos I have ABI doesn't mean I shouldn't be treated properly*"
> (Claire 1, p .6) and
> "*people think if your balance is not great, you're drunk*"
> (Claire 1, p.5).

And Pat, Claire's husband, also talked about the difficulties coping with balance, etc. outside the home "*…especially now that people are less tolerant of each other than before*" (Pat 1, p. 9).

Being an adult with an acquired impairment is difficult for Sinead because some people do not accept her words or her story of events. She claims that "*to be brain injured now, you're treated like an alien"* (Sinead 2, p.15). In our fourth meeting Sinead talked about inter-communication difficulties. She stated that people

> *think I'm talking crap like…*[and] *what I've copped on long ago was that if you're brain injured you're talking crap* (Sinead 4, p.3),
> *you're treated like a grown-up child* (Sinead 1, p.7), and
> *treated as though you know nothing 'cos you've memory loss, as if you don't know, but you do, just forget it at times* (Sinead 4, p.10).

Social practices bear out this child-like status often imposed on her and other adults with other impairments. The juxtapositioning of childish behaviours or 'rules' for example, by a voluntary group having their Christmas dinner at three-thirty in the afternoon, gave Sinead further annoyance. She and her colleagues had to be home by six-thirty, making her state "*they must think we are all children*" (Sinead 3, p. 2004). Sinead now has a personal assistant who is young enough to be her daughter, while during her typical week Sinead seldom meets people her own age. The people in the independent living unit and in the training centre she attends are all younger than her. Her husband also claims that she is childish and selfish in ways. This could be expected if Sinead has been excluded from adult company, adult events, decision-making, etc. Not only is Sinead treated like a child, at times she is treated as though she does not exist, while the public patronize her. For example, the person who helped her across the road to weekly Mass "*used go on about me being a load of work, while everyone praising her for bringing me* (Sinead 4, p. 9). This arrangement had just stopped prior to the start of this study.

Yet, Brid talked about her ex-husband John almost wanting to be treated like a child. As she was talking about coping with their new baby and with John shortly after his car crash, Brid said "…*he had to be treated almost like, looked after, treated like a child. He was comfortable with that, there was part of him that wanted it for some reason. That became a difficulty, a big difficulty* (Brid 1, p. 4). John's earlier disruption in life, being adopted as a baby by an elderly couple who had no other children, returned as a major issue in his life. He was told this news only a few years prior to his car crash and he had started searching for his natural parents. And now, after this crash, he was searching again, and at a deeper level, for himself.

The hidden aspects of ABI discussed by all the participants also complicated even further, their recovery and social interaction in those early days with ABI. Being doubted by friends, family or employers added to the problems, especially of the disabled participants. In those early days, many people thought Vivienne was faking her problems. She was often told by her own family to "*pull yourself together*" (Vivienne 2, p.18). Her sisters joked with her if she complained about particular problems or feelings. For example, if Vivienne said she was tired, and she does continue to tire easily, one sister would say

> *sure I'm tired too, I'm older than you...They don't seem to realise. They forget that I had a head injury and that's why I haven't certain brain cells and whenever I say it, of course they just laugh at me. They say, oh yeah, I've brain cells missing too, sure* (Vivienne 2, p.12).

And if Vivienne said she had a headache, one reply could be "*oh, I have that*" (Vivienne 2, p.18). This form of under-protection or not accommodating for any difference can cause difficulties as much as overprotection. Jokes and teasing are enjoyed by Annie, but not by Vivienne. Annie can take the comments made in jest

about people like her with ABI, looking ‘normal’ but not working, being “*the idle rich*”. Annie claims these people are “*only jealous*”.

The attitudes and practices of others, for example, being stared at or patronised by strangers, and social and structural barriers impact on the psycho-emotional well-being of people. Claire has had problems being rushed in a bank, in shop queues, and in dealing with certain taxi-drivers. She was always assertive pre-injury, and she is now regaining those skills while aiming not to be allowed to be rushed by others. Rushing still adds additional stress to her and she knows she would feel much happier if she was allowed to go slow. Pat her husband states that “*people don’t know enough about it [ABI] ...they can’t see it so therefore it’s not in the public eye*” (Pat 1. p. 21). Pat and all the participants claimed that many of their problems arise because of a lack of pubic awareness about ABI. Yet some of their own families also treated their disabled partner as less able than they are and/or withhold opportunities. For example, in the summer of 2005, Sinead had her first family holiday abroad since her accident in 1993. On one occasion abroad, her husband, Paddy told me that he and their daughters slipped out to the bar without asking Sinead if she would like to join them. Then he wondered why she was awake and annoyed when they returned. Yet this was her annual family holiday, and her first time in their family holiday home abroad. Sinead is also displeased when her husband tells their youngest son that “*Mammy is like*….” [and names their nephew who has a learning disability]. Neither did she like the attitude of some of the Mass going public as they were always “*be praising her helper for bringing me to Mass*” (Sinead 4, p.7). Paddy claimed that Sinead was abrupt with this helper and that is why she left, but few seemed to have looked at this issue from Sinead’s perspective. I did not do further investigations into this issue, but, how to give and/or receive assistance is an ongoing issue for many disability awareness trainers where respect on both sides rather than patronizing behaviour is sought.

Social becoming requires a social network. As many other people with impairments have articulated for years, old friends left them. This happened with most of the participants here, also, but not all. Some have a close family or some 'special form of network'. Managing old friends can be difficult for the disabled participants and perhaps even these friends themselves are not sure what to do. Claire is glad in ways that old friends ring her up at times to ask her to go here or there, but on the other hand, she is saddened they do not seem to understand her fatigue. Later, she told me that *"I find it easier to talk to you or strangers than old friends. You just have to take me as I am...old friends want me like before. They hold on to a lot of old baggage"* (Claire 1, p.3). Sinead has limited access to social opportunities in the town where she lives and is dependent on paid care mainly for a social life, although her family still visits her occasionally. Her mother and own siblings seldom call to see her, citing 'distance' as the problem for not visiting. They live one hour away from her. On first arriving home from the national Rehabilitation Hospital in Dublin, even though she had speech and memory difficulties, few called. Now in time, with recovery of much speech and memory, she said, "*I thought I had friends*" (Sinead 2, p.24) but now she knows.

Meanwhile, Vivienne's social network is based in her church group and those in one Centre in Cork city, while John networks with church groups, a disability group, and charity organisations. Joe's social network focuses on his extended family, neighbours and card-playing colleagues. Annie jokes about those who have stopped trying to remain friends with her saying, "*if people drop off, well the way I look at it is, it's their loss"* (Annie, 2. p. 16). Her friend Mary told me that it was hard at the start holding onto their friendship as Annie would forget their meeting times, but this changed. (Even over the span of this research project, their meetings reduced again, for non-ABI reasons). The importance of having one close friend whether in a large or limited social network also came through in this study. Vivienne had one close friend who helped her throughout the years, even if this person also caused certain difficulties for Vivienne. Claire in Cork and Annie in Kerry both told me about the joy of having one person who will tell you on the

phone, *"oh you're tired now, put down the phone and I will ring again"*. Interestingly, the female participants narrated to me the joy of having one close friend more than John and Joe. Is this because John has a full-time job with many group activities in the city, and maintains regular open contact with his two children and with his ex-wife, at least until recently? Joe has a close extended family network beginning with his wife, Elizabeth, who perhaps cared too much in the eyes of some feminist discourses,[154] but she wanted to.

Another important "element of identity construction is the process of labelling" (Sarup, 1996, p.14). The process of classifying and sub-classifying ABI could be a separate study in itself. Yet, the label itself however does not cause the social reaction, and doctors are not responsible for the social attitudes. Without the right diagnosis, people can end up having other difficulties as encountered by Claire and Vivienne here. They told me the difficulties they encountered because of not getting the correct label at the correct time, and wandering around other services, etc. Both had to wait years to access correct information about head injuries, even though one had her accident in the 1980's, the other in 1998. So, being 'hailed' in Althusser's terminology may create particular problems, but the problem of 'not being hailed' can also cause difficulties.

Claire was happy to get a correct label. She told me in our first meeting in 2004

> *I think Headway is great. I only found them last year. They found me actually. I was thrilled to get the diagnosis of ABI in one way. I thought I was going mad. Am I normal? I said to her* [to the person from Headway].
> *Yes, you are normal for someone with ABI, she said.*

[154] Some women see family caring as oppression and a gender issue that must be managed by public policy. Feminists in 1960's and 1970's articulated these conflicts - the pleasures and frustrations of motherhood, personal and family lives and public policies. See Fink (2004). *Feminist Approaches to Care*.

> *I was thrilled to hear in one way that I had ABI. At least I knew what was wrong with me. Like an alcoholic, you don't want the label, but you know it'll help cope with it. Once you know the problem you can do something about it* (Claire 1, p. 2).

Vivienne too was happy to gain a correct label for her problems. This process started one night in Cork in 1993, when she and her friend were watching a television programme about the opening of Headway Ireland in Dublin. Her friend suddenly said "*that's you*", interpellation, that moment whereby "people recognise themselves in a particular identity and think that's me" (Woodward, 2000, p.19).

But then there may be the situation that some people may identify too much with a label. The role of unintended consequences of social policies is also an important area of inquiry. Take John for example. To access a protected employment scheme John had to identify as disabled and proceed through an assessment and interview scheme. He was happy to gain this position and he is still employed under this civil service three per cent quota scheme. But did he take this identification process too much to heart, as it appears this may have created unintended consequences for his family? During our first meeting, Brid, his ex-wife, told me that a time came where "*he decided to stop recovering ...and look on himself as disabled*" (Brid, 1, p. 6). In our second meeting I asked her did she have any idea when or why this stoppage may have occurred**,** and she replied "no"

> *…but definitely he stopped trying. I think, he just seemed to settle back into, and he started referring to himself differently as disabled, as if he had made up his mind he wasn't going to make a complete recovery and that it wasn't worth trying anymore. He didn't actually verbalise it like that, but what started to happen was that he started to refer to himself as disabled and refer to himself as just, having a handicap you know, which he hadn't before…* (Brid 2, p.2 - 3).

I then asked Brid whether John was going anywhere or getting those words or discourse from somewhere else or from reading books. She replied

> *maybe, because he got the position with the, the sheltered position with the civil services, which is one for life and he would then have to, em, it is a protected employment situation, so, cos the Civil Service give a percentage of their places to people with disabilities, perhaps that reinforced the fact he was disabled and this is where he slotted in and this is where he was going to function and this is how his life was going to be, you know*
>
> [pause…]
>
> Phil: *a huge issue*
>
> Brid: *could be yeah, but it definitely stopped his progress I'd say, you know, but stopped his, him, being motivated and that...*
>
> (Brid 2, p.3)

Beyond neurological identity issues, many post-modernist writers claim that "[i]dentity can no longer be derived from our traditional place within society, from class, family, gender or locality" (Swain, 2003. p.100). Yet, in this study, based in a country in transition whether in urban or rural locations, I claim that identity is still derived from some of those markers as much as it is also 'given' to them. The traditional place in society of family and locality are important components in identity formation for all. Locality and gendered occupations in Sinead's household impacted greatly on her requiring care. The family is very important for all participants. This may be linked with their age group as they were not reared in an individualised self or body society. Four participants have children which bring them much joy. Joe not only identifies with his family, but especially with his card-playing colleagues and rural locality. Most also have close relationships with siblings living nearby. Claire gains much of her self, her narrative and occupational identity, her social network and her meaning in life from her family

and this is one reason why she gets up in the morning. She told me once that she often wonders what if she had no family.

This section has explored common and some particular patterns and trends which impacted on the social becoming of the participants. Goffman's (1963) well known theory of stigma was appropriate and still is for some of the participants. But this concept is one-dimensional and short-term. Gayla Frank (2000) claims Goffman "doesn't explore how people with disabilities deal with stigma over the course of a lifetime and how their families and communities come to deal with it" (p.187). Many people become proud of their selves and their unwanted body disruption. Courtesy stigma (MacRae, 2001),[155] that stigma felt by family members or a friend on behalf of the disabled person, was also felt or experienced by some of the non-disabled participants in this research. Elizabeth told me about the difficult times she and her sons had when first going out with Joe and trying to cope with what he would say to people. They felt stigma in the starting years, but again this experience was not fixed or permanent. Living now more on their terms is discussed in Chapter 7.

Some of the disabled participants talk about their "*me now*" or "*new me*". The next and final section of this Chapter is about the role of risk and occupation in self-awareness work, whether with the old or new self. Because of the unintended consequences which this 'new me' metaphor can, and did in my view, give rise to for these participants, I now prefer to consider 'working towards self-sameness (O'Connell, 1999; Teichert, 2004).

Occupation in this context and within occupational therapy discourse and literature includes all wanted tasks, required duties, and activities, those culturally valued and personally meaningful occupational experiences. Thus occupation is discussed next- with risk.

[155] Courtesy Stigma was also discussed by Goffman (1963) but received less attention than general stigma.

5. 4 OCCUPATION AND RISK TOWARDS SELF SAME-NESS

> There is nothing in, or behind, the face except for organic matter, and nothing to suggest that the biological material of the head, as organic matter, has a greater propensity for 'self-hood' than the material stuff of other regions of the body. There just *isn't*…
>
> (*italics* included Broks, 2003, p.112).

There is no self stuff to be located (only) in the brain. But injury to the physical brain has an impact not only on the structures and function of the body, but also on the mind, the self, because "the mind is the personalization of the brain" (Greenfield, RTÉ interview, August, 2004). Redeveloping a new sense of self long after an ABI, especially in those early years post-injury, involves ideally the family, the rehabilitation team with the person with the ABI working together to help build "collaboratively constructed identity maps" (Ylvisaker and Feeney, 2000, p.26). Years now post-injury, Annie, Claire, Joe, John, Sinead and Vivienne realise that "disablement is an identity-constituting feature" (Edwards, 2005, p.137). This is a stage linked to, but prior to, the identity politics discussed within disability studies. The concept of identity here for me includes "identity as sameness and identity as self-hood" (Teichert, 2004, p. 177). Identity as selfhood involves developing an answer to '*who am I*?' as I move through life changing with varying experiences. This involves how I manage not just being a product of my family or society, but also not being a pure self-made free-choosing autonomous self. For people with ABI this may take much time and be at a different pace than before their injury. Identity as sameness for example, involves me looking back at myself as a twenty-one year old, and wanting to claim that I am the same. In a sense and in many deep ways, this is so, but I am also different. This question is also in the following, is Annie for example now some years post injury the same person as she was before her ABI?

The participants in this study may want to be the same, and for a while they may have some risky moments thinking that they are the same, as pre-injury. Now, years post injury, all these participants know they are not functionally the same as before that crash or fall. For me as for many others, a person is far more than their function. Outside neuro-rehabilitation literature and "according to Ricoeur much of the difficulty that we have with the notion of personal identity results from a conflation of identity with sameness" (O'Connell, 1999, p.70). Here, there is often a fixed "rigid identification of the self" (ibid, p.70), diminishing changes we may make or create. In neuro-rehabilitation literature and in ABI discourse in Cork at least, most of the emphasis is on the self, the person as he/she presents in those early months post injury. Do we, health professionals and the general public allow for recovery and for change over the long-term?

The narrative approach used in the interviews over two years for this study, allowed me to note much sameness and self-hood in the participants' lives pre and post-injury. I also noted the difficulties that some had in trying to move on from the stereotype of the ABI population in much academic literature. Yet, others had no difficulty as in their area there was not really a local ABI discourse, although impairment effects and disability still made their impact. But as Broks (2003), a neuro-psychologist, suggests, "a person is more like a club-a football club, say - existing by consensus, capable of dissolution and reconstitution" (p. 203). Broks's favourite football club, *The Wolves,* went into liquidation twice, the stadium was rebuilt twice, and when he started attending matches the present players were not even born. He claims therefore "nothing tangible survives" in our restricted universe, yet they are still around, him and *The Wolves.* Therefore, rather than focusing on the person with ABI as being 'a new self' or not, we may benefit more, I claim, by considering the participants here to be self-same. The concept of self-sameness "arises by applying the narrative account of human time to personal identity" (O'Connell, 1999, p.70).[156] Habits and identifications are two essential aspects of character which is the important link between identity as sameness and

[156] See also Jennings (2006) and Teichert (2004) about self and self-sameness.

identity as self-hood (Tiechert, 2004). In this thesis, I claim that based on the lived and told stories and certain literature that participants hold on to much sameness in their habits, interests, and behaviours today in their narrative identity as a person with and without an ABI. This is also discussed further in Chapter 8.

Changed habits, including patterns of behaviour, may be a difficult aspect of adjusting to or living with ABI. But many behavioural difficulties may be linked with the rules, roles and social practices that the person is trying to live within. Ylvisaker and Feeney (2005; 2006) claim that we often seek perfect behaviour from people with ABI which is not sought from non-disabled people. People with ABI are seldom taught to learn about coping with the unexpected and/or for greater risk-taking, within their training in safe meaningful routines.

From this study I realise more fully that not all changes in behaviour may be linked with the person's ABI. For John, an earlier disruption in his life caused him much emotional difficulty, which may also have led to changed behaviour. As noted above on p. 19, John had found out he was adopted only a few years before his car crash and had started to search for his natural parents. His ex-wife told me:

> *There were some things that I understood apart from the accident that were separate issues from. There was stuff that was em, crossing into each other you know, the accident, because it had almost stripped him of his own coping mechanisms about himself and awareness about and any of that, and the capacity I suppose, to improve himself. Then, he started wanting to go down the road to find out about his natural parents. He felt isolated within the family...everybody else noticed…*
>
> (Brid 1, p. 4).

His search for his biological parents still continues today. As he states, "*it's just a little something in the back of your mind, it never quite goes away*" (John 1, p. 4).

But Brid also mentioned John's lack of spontaneity which may have been part of his behaviour before his brain injury.

> *That was one thing that was really strange like em, no spontaneity, something that was very missing in our relationship because the accident happened within a year of us getting married. Our pre-married life was spent apart. We corresponded an awful lot because I was in England. Do you know that we didn't spend a lot of physical time together but, em, it would be hard to know whether this was missing from the word go or no, do you know...* (Brid 1, p.5).

His lack of spontaneity may have more to do with his pre-injury personal situation, living with elderly parents and from some time living in a monastery. John told me he was always emotionally "*in the middle of the road, neither hot nor cold*" (John 1, p. 9) and he claims he still is.

Life habits, that other aspect of character, may require memory which the participants now have to varying degrees. Joe, a hard working farmer, lived for his family and for his card-playing sessions, and continues to do so. He has been using his card-playing tactics and habits for over thirty years. Card-playing is actually a family tradition as his father played in the same pub for years. Sinead was always "*tight with money*", and she still is, according to her husband. And when she was younger Sinead was often told that she was very like her late father who joked a lot. She still likes to make jokes and use puns. Being house-proud was also always a part of her and, as noted above, it was a major setback for her when she was not able or enabled to do housework. Mary, meanwhile, claims that before her accident her friend Annie was "*eccentric, good fun and outspoken, loving sports and driving*". Annie still lives up to this description even if doing less sports or gym work, although golf is still a big part of her life. Many of the pre-injury life

habits of the participants are still very much part of them, or at least, still part of their dreams.

Occupational identity within an occupational perspective is “the cumulative sense of who one is and wishes to become” (Spear and Blesedell Crepau, 2003, p.1031). All of the participants in my study used certain aspects of their pre-injury occupational interests or roles to enable them to gain an occupational identity. By returning to their pre-injury occupations the participants in my study regained some sense of self-recognition and self-respect. Joy, fun or meaning was added to their life. This participation in their chosen occupational engagement should be evaluated on its own terms, as sought for some decades by disability theorists, and now accepted by occupational therapists. (See also Petrella, McColl, Krupa and Johnston, 2007). This does not mean searching for one hundred per cent perfection. Annie was determined to get back driving and back to her own home; John was really keen to get into a work situation and back to his church choir; Joe was and is happy to be home with his family, helping with the family business, parenting as is possible, and return to his card-playing colleagues. For Sinead, although now glad to have her own living space, she was made happy recently when enabled by an occupational therapist to do more of her own cooking, although she still seeks more community inclusion and a job or meaningful day activity. Yet, for some participants, and like the women in Skeggs’ research (1997), many goals were not for their individual self. Claire, for example, wanted to keep doing mothering roles and tasks for the sake of her college-going children. John wanted to be in a position to continue contributing to his children’s support, and to local charity groups, while Vivienne was a volunteer in Africa before her accident, and today both John and Vivienne volunteer in different agencies in Cork city in order to help others. Vivienne was also happy to care for her mother three days a week for six years before her mother died in 2004.

Klinger’s study (2005) on the occupational adaptation of people with ABI also found that self-identity and engagement in occupation were closely related. The

participants here also appear to have developed a sense of self-identity with ABI through occupation by participating in pre-injury occupational interests. This is common in rehabilitation, using a person's pre-injury interests in therapy. As with O'Connell (1999), Teichert, (2004) and Jennings (2006), this could be developed more into self-sameness, an important concept I believe, especially for people with ABI. This self-sameness is more fluid de Peuter (2002) claims than Erikson's (1968) more fixed model which underpinned much theorising on the self (See also Chapter 8).

Need for Risk in social becoming

But what about risk as part of life? Zola (1982, p. 395), a leading sociologist/disability studies theorist, wrote that "if society does not let us [disabled people] have normal risk in our lives many of us will go to extreme lengths to re-establish it…there is human dignity in risk". But the balance of interdependence and autonomy with safety and risk is important, yet precarious for many people with ABI, their families and support workers. McCluskey (2004), an Australian occupational therapist, reviewed the process of care decision-making and risk-management for fourteen people with severe brain injury in Sydney. Persons with ABI were enabled to move forward by this team, which includes the person with ABI, by planning for gradual risk-taking, educating the disabled person and family about risk management, while also developing a shared mutual risk tolerance between all the team. An important part of all of this was actually allowing the person time-alone**.** Interesting that when I first met Joe in 2004, he was searching for more time alone although he was spending time alone 'bored' with the TV or walking a little around the house. Yet, he said *"I would like more time alone"*. I now take this to mean longer chunks of time where he would not feel over-protected. For the first three years post-injury, Elizabeth, his wife, told me she was afraid to leave him alone for more than twenty or thirty minutes in case he had a fall or would go hungry. This short time allowed her to drive three miles into the local shop or drop their children to school. But this impacted on both his and her freedom, independence, and the space and time for Joe to develop even

greater competencies. Some call this over-protection. Some call it love. With Joe's slow recovery and with the children getting older, and Elizabeth realising she needs time for herself, this situation has now changed. On my fifth visit to their home, they were both happy to tell me that he can now make a cup of coffee on his own even if he spills some of the drink, and he uses the micro-wave. He was also travelling abroad more often. Elizabeth was out more and he was happy, having 'slow recovery' and taking risks. The other participants took risks or wished to be "afforded the dignity of risk" (Conneelly, 2003, p.444).

Annie, a single person, developed her own different home resettlement plans. She and her family knew that she could not stay too long living with her sister in County Dublin. So Annie carried out her own graded risk activities with local friends in County Kerry until she was able to live full-time alone again. Initially she stayed with a friend at night-time, and in her own home during the day allowing her to return back full-time and slowly into her own home. She still had difficulty however getting up in the morning and walking around her bedroom, holding on to the wall. Annie was also lucky to have a friend who did gradual risk taking work or leisure activities with her.

> Annie: *a good friend of mine, we used go walking every day, nearly every day, before the accident, and when I came back and then ready to go walking a bit, I don't know why, I said, I think I'll go cycling. So anyway, she used meet me everyday and we'd go off cycling. She'd walk and I'd cycle. I was falling all over the place. It was terrible and she used do it, not a lot at the beginning, now it was only short routes. I'd be wavering around the place and I'd be coming up here and there, definitely falling all over the place, terrible, but she stayed with it. We used do it everyday and then, now,*

I can cycle up and down. I would be careful now, most certainly, but I would belt around, no problem.

Phil: *fabulous*

Annie: *I was kinda lucky that I had somebody who would stay with me, cos if she didn't, I probably wouldn't have. I'd have got too nervous you know, that was that.*

(Annie 1, p. 22).

She was fortunate to have someone to share with her this ordinary, yet risky activity. She also helped with driving practices in between formal driving classes. Yet, many health workers may not be allowed to carry out risky behaviour such as cycling on public roads today. Sinead meanwhile today is not allowed to take a risk in crossing a private lane from her sheltered unit to the hospital next door for Sunday Mass. Both Claire and John work within their limits, but realising also that minimal risks are still best for them. Both realise the limits on the amount of their walking they should do in public areas and what shops to avoid.

Balancing risk, with goals, routines, habits and needs are all important within their daily occupational performance. The participants in this study know the benefits and drawbacks of having to manage their energy, fatigue and stress levels. They know the "heightened sense of risk involved in failing to balance the tension between bodily input and output" (Seymour, 2001, p.242). Seymour claims that such "careful living and regular habits... serve to produce a well-contained body which will not threaten society by its anarchic activities" (p. 242). Yet, it is Annie's, Claire's, John's, Joe's, Sinead's and Vivienne's life which will be threatened if they do not do 'self-surveillance'. Like risk-taking, routines are also important for many people with ABI to varying degrees. Annie however has nothing regular in her life. Yet, she, like other participants, has an overall routine, aiming for lots of rest in the afternoon or evening as is possible, and spacing out her leisure pursuits in order to retire to bed early.

Risk and self

At times, Annie says, "*me now*" and "*the new me*", while Claire says "*I have to let my old self go, otherwise I'd go demented. I hate losing my old self...*"(Claire 1, p.1). But she also told me that "*people can't cope with you as you are now. They only want the old self back. I can't go back, this is me now*" (Claire 1, p.4). In her words, we can feel her pain in losing her 'old self', as well as the difficulty her friends must have had in not knowing which self to deal with. Participants learned about the 'new-me' discourse mainly in rehabilitation, and this was useful for some people. Generally, the official neuro-rehabilitation recommended goals and words are towards *a* new sense of self. Yet, no-one in this study mentioned these words to me. They said new self. An unintended consequence of this new self discourse is that it can become reified as if, a) another person really does exist, and b) this 'new' discourse allows others therefore to say strangers. For example, Paddy, Sinead's husband, said "*you're dealing with a complete stranger*" (Paddy 1, p.6), and "*you get back a stranger*" (Paddy 1, p.16). *A Stranger in the Family* is the title of a UK Television Channel 4 (1992) documentary on life post ABI. The phrase *stranger in the home* is often used in media and self-help literature. This focus is thus more on difference while families in need of much practical help are not enabled to work those tough years of early transition to search for some sameness. Should we be so definite using this old self-new self dualism? I suggest not.

I have shown that by involving risk over time with some recovery, pre-injury occupational activities, interests and/or everyday experiences as much as possible, enables greater self-awareness working towards self-sameness. This concept of self-sameness may help in creating a more positive public discourse on ABI. As Jennings (2006), stated, following an ABI, family and friends

> are challenged to respond, not really to a new person or self, but to the same self**,** the same human being, now becoming in new

> ways, a self that needs new accommodations and new modes of articulation and expression (p. 36).

Identity work as self-hood and as sameness after an ABI is hard work. Risk, routines, and personally meaningful occupational experiences for self-sameness are only part of the answer. In the conclusion to this Chapter that follows I will link them with other issues made in earlier sections that impacted on the participants knowing themselves by knowing 'us', friends, family, rehabilitation staff and/or the public.

CONCLUSION

This is the first of three Chapters about personal and social aspects of participating in the everyday-everynight living with an ABI. In this particular Chapter, I have re-interpreted the participants' stories to present many brute facts and social patterns involved in their embodiment and their identity formation with ABI. Links between self-awareness, risk-giving and risk-taking, involvement in individual meaningful activities in slow time and within the local ideological milieu, were particularly important for their personal identity, re-formation and their social becoming. The hidden aspect of their impairment and the limited usually negative public awareness about ABI combined to give additional suffering for Annie, Claire, Joe, John, Sinead and Vivienne and their families or friends. Much of this data highlights the fuzzy boundary between the personal and the social and why the relational self and social becoming are [my] important base lines. It is more difficult to repair or develop a narrative self with ABI amidst a negative public narrative on ABI.

I have presented above much evidence from the participants about finding out about ABI and managing and coping with their own lives with ABI and that of their family. The age of the participants and that of their children, if they had children, seems to have made an impact on how everyone managed this major disruption in their lives. Also, small but major issues such as words people used,

positive and/or negative, or being allowed time, to be content even if living with ABI, made an impact, as much perhaps as major professionalised cognitive-behavioural retraining in everyday living. Risky and personally purposeful meaningful participation in activity, everyday living, or occupation for occupational therapists, was also important. But in our growing risk-averse society will risk-giving be allowed to develop? With the passage of time, and much slow recovery, which is a pattern for many people with ABI, the participants have "*moved on*" to live with their differences to life pre-injury. Yet, there is much of their self sameness around.

The participants with ABI as with other people with ABI sought and still seek to be included more in social life and enabled to live with their strategic and sometimes essential differences, which themselves are not fixed. But differences and working with and across differences, are not the only feature in our society: a certain amount of assimilation is also required for social living. Some sense of, or search for, sameness is required in our shared reality, this one shared world that we live in. As mentioned in Chapter 3, I do not believe that there are multiple realities but rather multiple perspectives or forms or ways of living in our one reality. This search for sameness is part of managing and living with difference, the body or the self with ABI.

From particular personal identity issues linked with ABI in this Chapter, I move on in the next Chapter to write more about disability as social inclusion. Rather than focusing so much on ABI impairment-specific issues as above, Chapter 6 will focus on certain generic disability issues, because some things are more socially constructed than others.

CHAPTER 6 WE NEED CAR PARKING SPACES TOO

Developing identity as a disabled person

This Chapter focuses on particular socio-political disablement issues named by Annie, Claire, Joe, John, Sinead, and Vivienne and how these issues impacted on their lives and on their families. Structural mechanisms that impacted on the social participation issues of the participants are presented in the form of certain material, structural and environmental barriers. These range from family support services to transport or work supports. These issues are important requisites or pre-requisites in working towards opportunities for more participation in local life.

The title of this Chapter evolved from the numerous transport issues experienced by the participants, and because Claire, especially, was experiencing an acute transport issue at the time that I was structuring the writing plan of this thesis. Additional ideational material was gained from Tom Shakespeare's television documentary, *Who Stole My Parking Space* (Channel 4, March 17, 2006). Shakespeare, a sociologist/theorist writing also in disability studies, highlighted the difficulties experienced by disabled people as they tried to park their cars, book an air-flight, and access particular shops in Newcastle, England. This programme then presented action live research carried out by Shakespeare and other disabled colleagues, as they observed the use of disabled parking bays in the car park of a large local shopping centre. Within two hours of commencing their observation study, eight people who did not hold a disabled driver/passenger blue badge, parked in these reserved parking bays.[157] Although many gains have been made for certain disability populations today, the difficulties mentioned above are, for Shakespeare, *"indicative of our status"*. Driving is very important in everyday-every-night living in most countries today, therefore I use car parking spaces in the title as indicative of a real family material need. The title is also used as a

[157] In addition to parking wrongly, some of these able-bodied people did not welcome being informed of their action.

metaphor to symbolise the abilities of many people with ABI, and to link the specific often hidden needs of people with ABI with generic disability policies and services.

In discussing these social issues, I consider the impact of ABI on the family discussed in the first section: ABI as a family affair…and when love is not enough. This title is linked with a question in my original proposal for this study, do we set families up to fail and then, are we surprised when this occurs? Second, I present particular difficulties linked for participants with a hidden impairment in *You look okay…*services for people with hidden cognitive impairments. My third section entitled Opportunities and barriers for participation and community inclusion, describes certain issues that participants had in accessing generic disability services. The fourth and final section of this Chapter explores the importance of time in problems of living in different time frames.

6.1 ABI A FAMILY AFFAIR...AND WHEN LOVE IS NOT ENOUGH

> ...few individuals live alone as isolated atoms: most live in households, clusters of persons connected to each other and moving together through time
>
> (Bertaux and Delcroix, 2000, p.73).

People live in many forms of networks, households or families. In this section I focus on the family networks the disabled participants lived with after their ABI, even if Sinead and John are no longer living with their family. Four hetero-sexual couples had children of different ages at or around the time when those car crashes greatly disrupted their family. Sinead and Paddy and John with Brid[158] had very young children, while Joe and Elizabeth, and Claire and Pat had teenage children. The other two disabled participants were single at the time of their accident, and still live alone. The 'dyad' here is considered as 'one unit' because family stories

[158] John and Brid's first child was born two months after he, John, was discharged from hospital.

bring more information to the story. As mentioned in my Chapter on methodology, these stories can "illuminate and reflect upon each other like the gems of a necklace" (Bertaux and Delcroix, 2000, p.74).

ABI being part of family life today for these participants impacts on the parenting roles for both parents, while ongoing 'family life' itself also impacted on them.
These simultaneous events included enabling personal, social and emotional development, doing the school runs, shopping, and family meals, accessing college and nightclubs, disciplinary issues while also running the family business. Elizabeth claims that Joe's last accident affected especially two of their five children. In 2001, six months after Joe's major accident, their oldest son was doing his Leaving Certificate.[159] For many weeks, this son drove the one-hour journey into Cork at six o'clock in the morning to visit his father for a few minutes, and then drove back home again in time for school. He did go on to study an academic course in third level college that he enjoyed, but this was not his first university course of choice. Joe and Elizabeth also talked to me together and separately about their worries for one daughter who they claimed played on the loss of the father's disciplinary role. In 2004, she was doing little study for her Leaving Certificate although both parents repeated often '*she has the brains'*. Education is important additional social capital for this family, but this daughter is happy now working near her family home.

For Claire and Pat, her car crash "*…affected our whole family. People don't realise the whole impact of it, the financial impact and the impact on everyday life. Money problems affected our son's education*" (Claire 1). Their working life, social life, everyday living, financial situation and their son's education have all been affected by her car crash. As Claire has said about her mothering or wife role "*…I feel guilty or bad at times when I can't do what other mothers or wives do, I'm too tired often to go for a walk…*"(Claire 1). Being a mother though,

[159] The Leaving Certificate is the major public school-leaving examination for Irish second-level students.

contributed to giving her a sense of meaning, belonging and a future over the past few years, although she now wishes that she did not push herself so much in those first years post-injury. Because of Claire's need for standby assistance, Pat's career opportunities for promotion, further training, work overseas, as well the expected income from overtime, was lost throughout the past years. He stated also that he has lost out on the possibility for promotion in work, and work is very important to him. In addition, Pat claims his work-based medical insurance must have paid "*about maybe thirty to forty thousand euros or more at this stage*" for her assessments, treatments, travelling to and from Dublin and all the hospital accommodation (Pat 1, p.31). Without this financial help, Pat does "*not know how they could have coped over the past years*". They have continuous difficulties even today, accessing practical and financial support to cope with the additional costs of disability, especially transport costs. Their family income has reduced, and his employers are questioning whether to continue funding any further hospital and/or consultant visits and treatments. They were told by a civil servant that if they separated, temporarily, they would have a better chance of accessing financial support for their needs. Claire would then not be assessed on Pat's income, which in the past always included the need for overtime hours. Getting accepted for personal assistance in the home was "*another battle*" although their youngest son was recently granted a part-time Carer's Allowance. Over the past years, their three sons have carried out most of the 'caring' or supervision, by foregoing either their studies and/or part-time work.

Sinead's husband, Paddy, spoke about "*the dark side of ABI*" (Paddy 1, p. 2). He tried to have Sinead live at home for about two years while working full-time and parenting six young children. Their only support was the Home Help.

> *You get little support. It's up to yourself...you couldn't run a business, run the kids and mind her. You couldn't do that. Anyone with a brain injured person at home, like, would end up going psycho themselves. You would, you couldn't handle them…*
>
> (Paddy 1, p. 11).

He also said

I doubt you [anyone] *could live all the time with a person with ABI. The children well…they're good now, em, but at the time, we went through about I'd say, about three years of pure hell like... one or two of them went off the rope a bit* [and he made a small laugh] *and it was hard to keep them on track, but I did eventually get them on track again, and eh, they are all pretty good now, I must say, excellent…* (Paddy 1, p. 2).

A family approach was not adopted even in the process of making Sinead a Ward of Court, according to Paddy. The personnel involved never met with him, while her new solicitor is, according to Paddy, "*into her individual rights and focuses on her only*", and '*family needs'* are not taken into consideration. This family had three housekeepers over eleven years, paid for through Sinead's compensation. Their last housekeeper, who was with them for many years, stopped working with them when their youngest son started secondary schooling in September 2004.[160] This family gained no home or community-based rehabilitation for Sinead, wife and mother. And for Paddy, living with someone with ABI

…is like a living bereavement really in a lot of ways because you're dealing with somebody there who is actually gone, and she's gone, and she's still there in some ways you know…it's hard on her like, but she's trapped there inside, every little bits of her here and there, so, you're trying to keep it as good, as best you can to keep the show going you know... (Paddy 1, p.12).

For those two years when living at home, (early 1990s) Sinead had nowhere to go, nothing to do and almost no-one to talk with most days, apart from small noisy children. She could not carry out many of her mothering roles. She did go to

[160] By mid-2005, Paddy had not received payment from the Courts compensation services for the family housekeeper for the school year 2003/2004.

respite places for short breaks. It is understandable for Paddy to say "*the only alternative was to get her happy in someplace where she'd be happy herself*" (Paddy 1, p.5). He heard from the nurses and other people about the "*six year*" plateau of recovery after an ABI. He worked hard for months and months to get her somewhere "*where she would be happy*". With lots of work and help from three local politicians he got her into the centre, where she is now living, saying "*it was a hard task but we got there eventually*" (Paddy 1, p 14). Paddy is "*now over the fence*",[161] and at the time of our first interview, eleven years after that car crash, he is "*happy the way I am now and I've got the kids and good friends and going away on holidays and I run my business*" (Paddy 1, p.17). He is doing his "*own thing now"*. On a more personal emotional and sexual level in family life, Paddy introduced the term "limbo land" with regard to his relationship with Sinead. He implied he was living with or through a difficult transition...

> *You're in limbo land really 'cos you're married and you're now* [pause] *cos your married life is over, and eh, you're still married, eh as such , you can go out on dates and stuff like that, fine, that's no problem you can do that if you want to eh, if you don't do it you're gonna be, you're gonna be a disaster for yourself and the kids, you're not going to be happy sitting around all the time* (Paddy 1, p 17).

Family is still important for Sinead even though she no longer lives in the family home. Yet Sinead could also be described to be 'in limbo' at times regarding her family life or membership in her family. On the Christmas Days and Mother's Days during this research fieldwork, Sinead did not know until close to or on the day itself, if "*they*", her family, would come and take her "*out home*". She would wait and see if she was asked, and/or if her favourite daughter was there. This daughter is "unlike the others and really cares and wants to help me" and is the daughter that Paddy claims can handle and manage Sinead best. If this daughter is

[161] This is a local saying meaning over the worst part of a crisis or an unwanted disruption.

at home, Sinead generally goes home[162]. Family duties for both Sinead and Paddy are not restricted to caring under the one roof.

John and Brid, the other couple with small children, are now separated. Because they lived in Cork city, John was in a position to access ABI services and work training where he continues to work under the three per cent quota scheme in the civil service. But without a family approach for them, Brid and their newborn baby (and later a second child), life became more difficult, especially for Brid.

> *It was like minding three children…you got zilch support from the services* [you] *had to prove your need over and over and beg on each phone call and had to constantly retell your story…*
>
> (Brid 1, p. 6).

This point about the difficulties of dealing with the professionalized services was repeated in various forms many times on other meetings. Brid also found great difficulties in gaining support for Single Parents welfare issues when she moved from the disability sector into the welfare category of citizen needs.

Neither Brid nor Paddy felt that they gained any benefit from the counsellors they visited. They wanted more practical support, such as cash and a home help, and not 'talking therapy'. Brid, and her then husband John, worked with a mainstream marriage counselling service. But neither John nor Brid gave me any hint that showed this counsellor had knowledge about brain injury, or his ability to cope then with the home exercises given to them to work on their relationship. This is to be expected perhaps, as then around 1990 I would think, that few generic marriage counsellors knew details about ABI. I asked Brid, did the counsellor know about John's ABI? Her reply was "*yes*... [but does not mean the counsellor knew the

[162] At the end of our interview time, this daughter was leaving college and moving to work in Dublin.

impact of his then mainly hidden ABI. Brid added quickly] *but that is not why we went*..." (Brid 2). I did not ask (for) any more details.

Paddy seemed to have no time for counselling in those earlier years post ABI, saying "*it* [managing life] *is still left to yourself*". He does however like the key-worker[163] that Sinead meets now irregularly, saying "*this new one, she knows all about us* [the family]…*the last one never bothered*" (Paddy 3, p. 2). Relevant support for the partners or families is very important especially in the early years.

Care and caring in the family

Kittay (1999; 2002), writing from a personal and academic experience, claims that by caring for the 'carers' of dependent and vulnerable persons, 'care as labour' enables 'care as relationship' to develop. For Kittay, personhood is all to do with relationships and not rationality. Stein (1993) has developed a working model of 'felt obligation', which included negotiation of different domains of felt obligation with family influences, relationship and individual factors, along with cultural and social influences. The age of the caregiver and family adaptation strategies were found to be the most important variables in how the family coped when living with ABI according to Kosciulek and Lustig (1999). These variables were found to be more important than the financial situation of the family or the physical functioning of the person with ABI. Caring had a major impact on the life of carers and this is illustrated now by some of Elizabeth's story.

At the start of our meetings in April 2004, the constant rushing, worrying and chauffeuring of children appeared evident to me from Elizabeth's face and movements. She looked very pale and tired, constantly looked at her watch, and her words while very rushed spoke of these issues. She had had some difficult times coping with Joe's needs and family needs, while not having any time for herself, a common plight for many mothers, many carers. Her words were:

[163] A key-worker is the one named person in an agency or a team that acts as the link with the family and as liaison person for team-work and/or with new personnel or events occurring within case work on hand.

> *it's all on me, all I'd be afraid of, like, is, if I get sick, like you know, you're always thinking…*[pause] *sometimes you're not feeling, not great in yourself, you find it hard to keep going…*
>
> (Elizabeth 1, p. 6).

Elizabeth appeared to me as one of those traditional Irish mothers, selfless, always giving love, gaining much satisfaction through being with, and enabling the lives of others who she loves. But she knew what help she would have liked. She did "*not want an outsider coming into the house to help*" (Elizabeth 2, p.3) on a very regular or daily basis. She would however have welcomed assistance but only for certain times, with easy on-going access to those supports. She wanted practical information on managing in the home, risk management, transport to enable Joe to access vocational services and financial assistance. She did "*not want counselling*" (field notes when with Joe 2, p.2), but time to have a break, some rest, and a little more time to and for herself. Her choice of an outing or 'time out' is to get out to a GAA[164] match, and not to go to the shops as many may assume.

> *yeara no, I mean with the lads around now I'd go to football in the evening as a referee. And then, I'd be fine then again, do you know I would, I'd do that…* (Elizabeth 1, p. 6)

She did apply for The Carer's Allowance, but to no avail. This would have been welcomed, although they agree that money is not their main need. They viewed the carer's allowance more as a symbolic support from the State towards the cost of disability on this family, while also recognising their contributions as tax-payers and citizens. Up until very recently, Elizabeth carried out the traditional duties in the gendered division of labour in the home, and most of the chauffeuring of their younger children to/from school and to GAA training and matches. This caused

[164] GAA is the Gaelic Athletic Association, the organisation which organises and co-ordinates the traditional amateur All-Ireland sports of Gaelic football, hurling and camoige.

additional stress and hardship for her. During our meetings 2004-2006, with then, only two in secondary school,[165] she was sharing the house-work more. Supporting Elizabeth, especially for the first two years after the ABI, would be supporting Joe, and all involved, as Smith and Godfrey's (1995) stated. Families who received family support for the first two years post-injury had better emotional adjustment than control group relatives, and low distress at two year follow-up assessment.

Overall, Elizabeth feels now that *Joe* "i*s about as good as he'll get*" (Elizabeth 2, p. 4, field-notes) and "*the best he can be*" (Elizabeth 3, p.1). She is glad for all that he can do, what he still is, her loving husband, father to their children, and what he has become and is becoming, even with all his illnesses and injuries. Since this time, Joe has had another major heart operation. Like most human beings, Elizabeth does compare their situation to other people in somewhat similar situations saying:

> *He's good really, we've an awful lot to be thankful, thankful to the Lord for…* (Elizabeth 1, p. 5).
> *Thank God he doesn't suffer from any epileptic fits or anything like that which is good really* (Elizabeth 1, p.8).
> *Lucky he's mobile, some other people just there, I don't think we could have coped* (Elizabeth, 1 field book notes).

By the end of 2005, on my eighth visit between both of them, Joe was, with time, making slow recovery and involved in more 'personally meaningful occupations'. Family adjustment was continuing, and they also had the settlement of their compensation case. Joe was also developing some degree of participation in family property developments and going on short holiday breaks with Elizabeth and/or their family. She, too, was partaking more in her passion, namely volunteering in the running of their local junior GAA club and/or attending local GAA matches. Joe is 'content enough' now, largely because of her love and care, saying that it was Elizabeth and the family who were "*the biggest support*" in managing after

[165] Only their youngest son is now in secondary school.

his ABI, even if *"we have words at times"* (Joe 3, p. 2). Interdependence and love is lived out in this home. This very close and supportive family have, like all families, some hot moments. But, if there were no change in behaviour surely life would be boring (Ylvisaker and Feeney, BRI Conference 2005).

Yes, families have to cope with emotional, financial, practical, physical and transport issues, and stigma as mentioned in Chapter 5. The literature on rehabilitation and caring for a person with ABI documents these issues very well, often within a discourse of loss and grieving. For example, the booklet, *A Carer and Family Guide* (Headway Ireland, 2002), contains much useful factual ABI information but has little about interdependence or social issues. Perhaps the limited rather negative public discourse about ABI needs to be balanced with a recovery focus, caring solidarity, fun, along with naming the various collective social changes which are also required and could help living with ABI. As the second half of the title of this section states 'When love is not enough', for the family living with ABI, developing self "cannot be entirely divorced from the conditions which make it possible" (Skeggs, 2004, p.75). These conditions include, not only the biomedical status of the disabled person, but also the pre-injury personal and social factors of all involved, along with time post-injury. The material brain injury services and generic disability service practices are an important aspect of adjusting to, and living with, ABI. These are the focus of the next section.

6.2 *YOU LOOK OKAY…*SERVICES FOR PEOPLE WITH HIDDEN ABI AND COGNITIVE IMPAIRMENTS

Material practices are an important aspect of social processes (Chouliaraki and Fairclough, 1999; Swain, French and Cameron (2003); Thomas, 2002). I focus here on services ranging from work supports, technology, transport, housing, and professional practices especially with a focus on some of those hidden impairment effects of ABI. Although three participants in this study gained some financial

compensation following their car crashes, for most, the cost of disability includes the loss of employment, paying for care or assistance, transport costs, and the opportunity costs which impacted on all involved.

No work supports were available for Annie, Joe or Vivienne to help them return to work, even on a part-time basis. They had no occupational therapists or vocational support workers, no information guides for their employers, and no formal flexi-time. Annie tried to go back to work many times, but she was unable to manage the difficulties. As she said, "*I went back to work I don't know four or five times. I seemed to lose the plot completely so...*"(Annie 3, p. 6). She knows now that perhaps she may have returned too early and without any supports. Always being a perfectionist, she did not want to make any mistakes and she had no empowering support to enable her in this time of transition, even though she was employed in the health services at the time of her fall. In fact, when back at work, her work colleagues wondered why she rested so much, which made Annie's friend, Mary, also a participant in this study, state that those work colleagues "*doubted her needs*".

Joe was not offered any support to move into any computer training, the one area he was particularly interested in, while Vivienne was left to her own devices and her own perseverance for years. She moved between the services and courses for 'the underemployed', 'the unemployed' and tried out different study courses in her search for an interesting job. She completed yoga training.

Sinead remembers the long boring days when she could not access community vocational or other occupational rehabilitation. Now she is accessing sheltered training:

> *doing what's called a course in [names the agency]*[166] *in…*[names the town]". *The Health Board wrote and told me that part of my course is to go to Headway.*
> (Sinead 1, p. 5).

For nearly two years now she has spent four days a week "*doing things*" or attending classes that she is not really interested in, in a "*school with people much younger*" than her. At times, Sinead feels that the process of, or the end goals of this course, appear limited in their usefulness or meaningfulness to her. But this '*outing*' is better than staying alone in her bed-sit or in the common lounge room. This course has offered her the benefit of meeting other disabled people, especially some people with ABI. She is now more informed on ABI and about advocacy, someone has read to her about ABI, with further opportunities expected to emerge. The trainers in this workshop cope well with Sinead's need for suitable physical access and assistance needs in pushing her wheelchair downtown, but it appears difficult for them to accept her need for a rest during her training day. Meanwhile, John gained much positive vocational support twenty years ago, which could be linked with the location of his city home and his recovery post-injury. John gained a permanent and pensionable position in a civil service department in the city even though there appears to have been an unintended consequence of this job, as mentioned in Chapter 5.

Paid work is not 'the' main or the only requirement of these participants. For those with good compensation, or for those unable to, or not interested in working the hours required for inflexible employers in Ireland, work is no longer required either to give them their main source of identity, as so often in the past, or their income. Work is not the guarantee for social inclusion, as many governments think it might. As Abberley (2002) claims,

[166]This agency is a non-government partnership agency providing many educational, rehabilitation and vocational services throughout Ireland to people with physical disabilities.

> an inclusion which is dependent upon employment is by no means advantageous to all disabled people, since it is not likely in modern labour markets that all disabled people could find or reliably retain employment (p.134).

Abberley (2002) cautions "against the over-enthusiastic espousal of work-based programmes for overcoming the exclusion of disabled people which leave welfare systems unchanged or worse still depleted" (p. 136). See also Terzi (2004). Along with work or occupation needs, people with ABI often require other technologies beyond those used in/for any work-occupation place. In everyday living, from dawn to dusk there are numerous products, mainstream and/or assistive technologies that can benefit those living with ABI from mobile phones and dictaphones to alarm watches and memory aids. Byatt (2004) states that

> we live in a social world of prostheses, things added on to the body – telephone television, cameras - which drastically change our human relations and perceptions of each other, and ourselves (p, 6).

We can also add on breast and lip enhancements, 365banking, mobile phone with internet, camera and games, and global blogging using any identity. These are linked with either the aesthetic self or the 'prosthetic self'[167] (Skeggs, 2004**,** p. 79). The former is self-explanatory, while the prosthetic self, experiments and plays with objects, knowledge, technology, and culture to make "self-extension" possible (ibid, p.79). Appliances, aids and equipment, which are very common for certain disabled people, could come under this 'prosthetic self', enabling many disabled people to say "*I can therefore I am*" (ibid, p.79). This is generally one of the aims of rehabilitation, which may assist in their self-identity work. But many disabled workers "are not allowed access to the resources and technologies required for self-production" (Skeggs, 2004, p. 91). Sinead has received limited

[167] This term was coined by Lury in 1998 as cited in Skeggs, 2004.

information about what is available to enable her to 'extend' her self, her capacities. She tried to use a Dictaphone but the problems linked with replacing the batteries caused her to discontinue this.[168] She was also recently given simple, but useful kitchen equipment, a simple vegetable board around the time of my third visit following a rare visit from an occupational therapist. Sinead was happy that this occupational therapist enabled her "*to do my own cooking with fresh vegetables, that cheers me up…fed up with frozen foods. Nice to have fresh vegetables…*" (Sinead 3, p.3). Accessing simple technology meant so much to Sinead, yet it took her years to obtain this.

Transport needs and/or issues

Joe, Claire and Sinead had numerous additional problems because of the lack of transport to enable them access to specialised services in Cork city mainly. As Elizabeth said, '*if only there was transport',* this would allow Joe to be brought into specialised services, one hour away. For those in a position to drive after their ABI, parking your car could be an additional issue. Annie and Claire claim that some of the public doubt why an ambulant person with ABI needs or should get a, the European blue card disabled parking sticker. Many non-disabled people are not aware of the fatigue that people with ABI can experience and /or the difficulty in getting lost. When Annie was talking about coping with public attitudes, shopping and downtown parking, I asked Annie if she found that people ever misuse the disabled people's car park spaces. She replied:

> *Oh they do…no problem for me. Well, I'm disabled. Not that I'm as good as gold, but that's one thing I never did, when there was nothing ever wrong with me. I feel that's there* [parking space] *for disabled people but I can park anywhere…I can leave the disabled person's space for people who need it more*…[Once] *some lady did pull beside me, she was an elderly lady and*

[168] Following recommendation from a professional Sinead bought a Dictaphone and enjoyed using it for a while. But she stopped using it when she found it difficult to get assistance to buy and physically replace the batteries, at or around the time they were needed, rather than weeks later.

> *she looked at the car and said to me 'excuse me, do you know where you are parked?'*
> *yes, I do, I do* (Annie whispered), *"ell it's for disabled" she* [the lady] *said. I said thank you very much Mam, if you got out of your car and walked around, you'd see my card is up*
>
> (Annie 3, p.14).

At least both of the people in this little story live out the code that Shakespeare, mentioned above at the start of this Chapter, would like all people to hold. If people with ABI could park in designated disabled parking spaces, the signs could act as a memory cue for them, less energy wasted, thereby creating less frustration within the overall shopping or parking experience. Yet, there is a local debate even among disability activists, if ambulant disabled people should use these designated spaces.[169] In addition, Annie, Claire, along with others at ABI support group meetings, claim that 'some of the public' think that because of their imbalance when walking, they are drunk. Some of the Irish Gardai (Police force) have also asked this, especially if they were seen off balance near their car.

Housing and having a home while a major issue for all people, was also an issue for some of the participants. Sinead was sent home to a rural house with steps, an inaccessible kitchen, with her husband working away from home sevens day a week. John went home too early to a house with steps and stairs, said Brid, as he still had many balance problems. Joe and his family got a bathroom-bedroom extension downstairs using the Disabled Person's Housing Grant soon after his ABI, but no longer needed to sleep downstairs after the first year. Meanwhile, Vivienne lived in a small charity bed-sit living situation until very recently, and when we first met in 2004, housing was the one main issue she would have liked to change. Now, after many years waiting for a better place from the local

[169] A full-time local disability advocate/worker told me that some wheelchair drivers in Cork question, or are unhappy, that ambulant drivers are allowed use the designated parking spaces.

authority, Vivienne, with the help of her brother, was re-housed in the summer of 2006. She is now enjoying living in a more spacious supported living apartment.

Accessing information

Accessing information in an appropriate format was difficult for Sinead, Joe and Elizabeth and for John and Brid. Sinead was offered *Books on Tapes* to compensate for her inability to read books with her visual difficulties, but she was not happy when given books on tapes from the children's library. Elizabeth would like to have had access to information when she needed it, rather than when the professionals thought that she needed it. Joe wanted large font print in literature while Brid would have liked 'a package of information similar to what new mothers get when they leave hospitals with their new babies'. Access to local generic disability services is also important for Brid as she was not aware that she could have sought talking tapes or books with large print for John, although they were available but targeted only for blind people. Meanwhile, Annie has learned to use her personal computer, and links into European issues dealing with ABI, while Claire uses her telephone and local paper to try and keep in touch with her entitlements and following up with her required needs.

Accessing personal assistants

Accessing personal assistants or an appropriate Home Help was another major problem especially for Sinead and Claire. Claire's family had major difficulties organising standby assistance over recent years. Eventually she was informed that she was sanctioned defined hours for a personal assistant (PA), but it took a long time to work through the administrative maze involved. This caused unnecessary worries and frustrations for the family and yet no personal assistant was found one year later. The discretionary powers of public health nurses are also part of Claire's story. She falls into the area where it is harder to gain the discretionary agreement of the local community nurse and subsequent services. More discretion is used by the neighbouring public health nurse.

The Home Help on Sinead's return from hospital was a friend of hers pre-injury, which made resettlement harder and not easier as perhaps the organisers expected. As Sinead said, "*…I was friendly with her, and to see her now and running around doing the work that I cannot do, drives me insane"* (Sinead I, p. 6). Additional problems were linked because the sons of both women were in the same class at the local primary school. This disturbed Sinead. Again, this may be another example of an unintended negative consequence of what seemed like a useful service, although planning this service did not include the service-users perspective and dignity.

Professional Practices

As stated in my Chapter 2, rehabilitation is a social and political act, thus, the relationships in this process can be another source of tension and/or empowerment. Smith and Godfrey (1995, p.150 citing Godfrey and Knight (1988)), found that the "very pessimistic expectations of service providers… represented [one of] the main barriers to the integration of TBI individuals into the community".[170] The negative attitudes of professional health care workers are seldom written about in the literature. An occupational therapist[171] informed me that she publicly asked an emminent Irish-based neuro-surgeon at a Headway conference in Dublin, 2003, to explain more after saying that *'people with brain injury cannot learn'*. In this study, Elizabeth and Joe, and John and Brid were the main people to share certain good experiences with therapists, although this was only for a short term, during the first months post injury. Vivienne meanwhile thought that some professionals live a blinkered life. She enjoyed telling me about her neurological assessment in Dublin in 1993, fifteen years after her accident. "*You know what it's like. Ask some numbers then say them back ways. Subtract something from one hundred…some of it went very well, some of it didn't…*"(Vivienne 1, p. 7). She smiled as she told me more about this assessment saying:

[170] Other barriers noted were the personality changes and emotional problems of people with ABI.
[171] Personal Communication: Name withheld of this occupational therapist.

Vivienne: m*y writing and everything was very bad after the head injury, so she* [the psychologist] *suggested somebody holding your hand when you're writing*

SILENCE… pause

Phil: *who'd do that?* [then we both laughed a little]

Vivienne: *yeah, and help me walk…my balance isn't great*

Phil: *yeah*

Vivienne: *but having someone help me walk again!*
I read all this, a joke, but then some parts of it were very accurate…She also suggested I should have another [test] *done in a couple of months time. I said well maybe she's looking for business, but what the point you know. I said to* [my friend]. *I'm as good as I'm going to be…* Pause

(Vivienne 1, p.10-11).

Vivienne knew the unlikelihood of experiencing any significant changes twenty-five years after the accident and was managing well, living alone.

The timing of and the use of appointment times with professionals were often discussed in this study.[172] Claire claims that many professionals treat her in a negative, dismissive way, or do not accommodate her need for short assessment or meetings with maximum length, one hour. She claims that some professionals use much of the appointment by asking questions that 'must be in her notes already'. While she knows that some repetition could be linked with the turnover of staff, or for developing rapport, Claire still wants to be on form for 'the test'. She believes that these professionals do not seem to realise that she can get very tired answering questions, and thus this impacts on her test results. Annie meanwhile is annoyed that professionals often claim to want to learn from 'us people with ABI', yet they

[172] These points are often discussed as problematic at BRÍ meetings.

seldom want to listen. And when ideas are offered to them, they, [the professionals] often take them as their own, to get all the kudos.

Although person-centred goal-setting is supposed to be part of rehabilitation practices today, other social factors such as the timing of rehabilitation, ethos, discourse, place and focus all impact on how a person manages their allocated rehabilitation service. The forty-five minute time slots that clients have individually with the various professionals often frustrate all involved, but especially the client. The fragmented rehabilitation services link in with the fragmented body in our age of specialisms, although some trandisciplinary work is also emerging. As mentioned in Chapter 2, Ylvisaker and Feeney (2005; 2006) ask therapists to rethink how they organise their timetables. This reconstruction of rehabilitation time impacts on the client's potential in developing an acceptable sense of self, but narrative, feminist and multicultural approaches are now informing rehabilitation practices more today. Swain, Griffiths and French (2006) claim these approaches, linked with the social model of disability, challenges and question power issues.[173]

I now turn towards other barriers or opportunities in the community, that impact on social participation and perhaps in that elusive search for integration and inclusion.

[173] These power issues can include inclusion of service-users voice and whose evidence counts in naming a problem and power relations from within disability services to the local communities.

6.3 OPPORTUNITIES AND BARRIERS FOR PARTICIPATION AND COMMUNITY INCLUSION

Participation, especially social participation is not as easy as it looks.

> *She* [Sinead] *goes out on a Saturday night, so, she seems to have no worries like. She likes the day-centre, no worries anywhere… If she was at home with us she'd have more stress with kids and work and stuff…* (Paddy 2, p.9).

Sinead is "*happy now*", Paddy claims, yet her own story is not in agreement. Participation generally means taking part in some way in a socially valued activity. Yes, Sinead does enjoy her weekly Saturday night outing, but she would also love more meaningful participation in local life on other days and occasions, with other people with or without ABI of her own age. I do not fear that we have no accepted measure of or for participation, unlike Madans (2004),[174] or Desrosiers (2005). In 1983 for example, The United Nations published the document *The World Programme of Action Concerning Disabled Persons*. The index of this document includes twenty-eight references to the term 'participate' or 'participation'.
These include for example:

> *Equalisation of opportunities: to achieve the goals of full participation* (p. 6);
> *The participation of disabled persons in decision-making* (p. 26);
> *Participation in religious activities, community action* (p.34 -35);
> and on (p. 20),
> *Full participation in the basic units of society - family, social groups, community.* (UNDP, 1983).

[174] Disability Statistics Office, United Nations Development Programme. New York.

Today, it appears that many rehabilitation professionals link in with the dominant discourse in our society aiming for independent participation although there are numerous forms of participation. In this study, Annie participates actively in her golf club, and for some time, shared the secretarial duties of this club with another colleague who would check any reports or notes that Annie typed. She also enjoys participating in a painting group with her local Adult Education Centre, and is also very active in her church.

> *I play golf. I don't play as good as I did but it doesn't matter. I'm there and I play. I have a keyboard now. I always wanted to play the piano so I'm learning that. I'm not very good at that either because trying to read the music and the numbers and the letters- sometimes they go a bit off-centre but I play away and have my lessons. I'm doing that and am happy enough. I haven't gone back to the reading. Reading, I liked very much but it's a bit slower you know.* (*Annie* 3, p. 9).

Annie would like to be more involved in disability politics. This is discussed more within the final Chapter, Chapter 7.

Vivienne and John, who are in the employment sector now for many years, also participate in their church and family duties. John told me that his

> *life is full really, that suits me too, 'cos I…*[pause] *there's a danger when anybody who is separated could become introverted* [could get] *cut-off, focus in on themselves, cos out of the house really is a tonic in its own way, to realize that the world is bigger than your concerns, you know* (John 2, p.1).

A hint of loneliness, though also came peeping through to me as he told me about his busy schedule but this 'busyness' does allow him not to be too alone in his

home. Large financial compensation is not enough if you are imprisoned at home, without any connections beyond your walls. Participants here were glad to be included in some ways in local community activities, church, cultural, adult education, sports or women's groups and events. But for Sinead, paid care in the form of a personal assistant, or else a volunteer is required to access social events and services. When I asked Sinead about her participation in local groups, she said

> Sinead: *No, I want to but not, you see my PA*[175]*, the PA I had, resigned. I have no PA now I haven't. I don't know how the outside world is now I don't*
>
> Phil: *is she gone long?*
>
> Sinead: *since before Christmas [now April]*
>
> Phil: *are you hoping to find someone else?*
>
> Sinead: *well they are finding it difficult enough cos of me wanting to go on a Saturday night, the only night, the only night I have to go is on a Saturday night…'cos television is the worst of all on a Saturday night like, so there it is. Difficult to get a PA 'cos they can't get nobody who would go out on a Saturday night but I never ask to go any other night, like. TV is good enough on a Friday night. I mean during the week then I'd have to rest a lot 'cos of having to get up for* [work training] *in the morning. Saturday night is a big no, no I'd say…* (Sinead 1, p. 8).

Sinead is aware of her own life planning needs and about 'pacing' herself with her ABI. Although she had six public or partnership agencies involved in her life for those six months when no paid assistant was available to her, no-one offered to bring her out on Saturday nights. One daughter called a few nights. Eventually, a young adult woman "*young enough to be my daughter*" was found.

[175] Personal Assistant. Sinead had five hours of a paid personal assistance per week.

Sinead would like additional participation in group decision-making about issues in her residential unit. Group meetings are held but, in Sinead's view, it is the fast-speaking, vocal, political, disabled residents dominate proceedings. Perhaps people with ABI are not considered reliable enough to participate in planning. Sinead would also welcome increased social community life. Sinead cannot go downtown on her own because of her visual perception problems, as she said

> *what scares me is that I could be quite near the edge of the footpath and I wouldn't know until I land down this way* [pointing towards ground] *the thoughts of being back to square one again, if I crack my head, oh my god, I'd rather be dead than go through that again* (Sinead 1, p.11).

'Time use' especially when living with disability is now a popular topic for occupational therapists to use as a framework in their studies. Winkler, Unsworth & Sloan (2004) carried out a study on 'Time Use following a severe TBI'. Yet, they disregarded the involvement of paid carer's in the occupational lives of their participants although many non-disabled people pay people to enable them to carry out particular activities. Paid care[176]is also more the norm now because of changes in society, in the family with working parents, a lack of volunteers, and the demand for greater autonomy in life. Sinead's story highlights the contradictions of individualism in our society. As one chooses and pays for your own services, no-one else need know or bother when this individualised service is not available. Or perhaps no one wants to cross work role boundaries.

Claire is now, however, enjoying writing, art work and balancing her family duties and energy as certain specialised services are being made available to her. Talking with others, chatting and networking are also important to Claire. This could be linked with her involvement in public speaking pre-injury. But, transport and

[176] Paid care usually means the presence of formal carers for both "nuture" and/or " treatment" while unpaid care generally involves informal carers, including family, lovers, volunteers or neighbours. (See Fink, 2004, p. 5).

personal assistance (PA) needs, along with the problems of noise, add to the difficulties in planning any events, placing spontaneous events in her local community almost off limits. Her brute irregular brain 'shut-downs' must also be taken into consideration. As noted above, spending fifteen minutes in silence with Claire in December 2004, taught me a lot about her personal situation.

Joe is now back participating in many aspects of family life, and with his regular card-playing sessions, he enjoys life. At first his wife supported him at the card-games because he used to say "*silly things*". She had to drive him in and home also late at night as he could no longer drive. Now Joe attends some nights on his own, as he has improved much in making and following conversation, while a friend, neighbour or taxi can take him home.

To participate more in social life, requires non-disabled people to meet disabled people at least half-way. John claims that the public are

> *I suppose, particular persons are a little cautious, not only are they protecting their own selves but they are, they are kinda treating the person who is handicapped as, I don't know, kind of a case apart. I'm not sure if it's possible to overcome that or, how to, how can that be tackled or if it's just part of the scene…*
>
> (John 2, p. 6).

John neatly describes the process of 'othering', being defined by ones impairment-disability, with boundaries set up and then treated as a case apart.

Participating with a virtual community is becoming quite the norm, but this requires certain computer skills. These networks may demand that all past discussions on the concept of social participation may need to be reviewed. Plus society has yet to study the long-term limitations and benefits of this form of social participation. As discussed in Chapter 2, the *Community Integration Measure*

designed by McColl et al. (1998, 2001), identified participation and belonging as two major components. These writers maintain a focus though on independent participation, but as mentioned above, Annie enjoyed co-sharing the role of Secretary in her local golf club. This measure focuses on the person with ABI doing something 'useful' and 'productive', but many non-disabled people are not asked to do something useful, productive (in the common meaning of this term) or be independent in their community. But for some occupational therapists the term 'productivity' is used to discuss work and leisure, the need for challenge, and identity, and almost all of life (Pierce, 2003, p. 10). For Pierce, "[p]roductivity is an inborn human trait" (p. 58). For others, thinking or reminiscing is productive 'being' (See Hammell, 2004b).

Social participation or using life habits was assessed by Pepin, Dumont and Hopps (2000) using the *Index of Well-Being*.[177] This scale includes four measures which focus on mobility, physical activity, social activity and a generic scale. Again, additional or full points may be gained on two scales in this index by being independently mobile, not being hospitalised, and by walking without restriction. These mobility scores raise the global score, but this may not mean that the person is involved in any social participation. Paraphrasing Oliver (1990), walking may be a goal for rehabilitation therapists, but unless there is meaning in having a place to go to or with someone, why bother.

Living in the community need not and often does not mean being integrated in the community or having a good quality of life and although having functional independence of varying degrees may help, it does not determine happiness. Butt (2004) claims we live in anticipation and it is this anticipatory stance, living in time that makes us human (p.132). I read this as having a good enough reason to get out of bed in the morning. Yet, anticipation is seldom mentioned as part of participation. Waiting, and waiting with personal and social meaning is accepted in many traditional cultural groupings, yet this is generally not accepted in our era and spaces of rapid sophisticated modern economies.

[177] Pepin et al. also used other measurement tools.

Participating in family life, social life whether getting to the pub and/or to the church, along with resting, and occupations or work, etc., were, and continue to be important for the participants in this study. The everyday difficulties linked with doing some of these activities cause much difficulty for some of the participants, not only because of access, transport, etc., but also because of the issue of 'time'. This study has made me realise more about the importance of time and how much coping with time add to their difficulties in everyday living. Time is thus the focus of the next and final section of this Chapter.

6.4 THE PROBLEMS OF LIVING IN DIFFERENT TIME FRAMES

Time. Time. Time. According to Edwards (2005), people exist in time, so time is one of the essential components of personhood, important in social living. Fabian (1983) claims that "time is a constitutive dimension of social reality…not just a measure of human activity" (p. 24). The difference between objective and subjective time, i.e. the differing perceptions of time which has elapsed during certain events, occurs between all people. But the impact of impairment effects in the temporal aspects of people's narratives is perhaps understood more by disabled people, their families and many of their service-providers. Many disabled people have little choice but to continue to live with "difficult ramifications for the timescale needed to engage in…typical, everyday tasks" (Edwards, 2005, p.133). Yet these temporal effects are often ignored by others. Technology and paid assistance may help, but this same technology may also negate what the person would like to do for him or her self, working towards one of their self-goals, which is another component of personhood.

Occupational therapists writing on time, use time-use, tempo and temporality (Farnworth and Fossey, 2003). This links in with the objective, phenomenological and social-constructionist concepts of time (Sandywell, 1998, p. 205). I am not concerned about the participants time use following a severe TBI, even if such

data provides “a window on lifestyle changes”, according to Winkler et al. (2004, p.69). This Australian study, though, highlights the methodological issues and difficulties in such studies, and the conceptual limitations in coding and naming activity A as A, and not B. Time use data may be a useful source of information regarding occupation and social support, two components in community integration according to Winkler et al. (2004). But as Hammell (2004b) claims, enjoyment of time, which she terms as “being”, comprises of “dimensions of time use that are not captured by classificatory systems devised by able-bodied, career-oriented academics...”(p. 21). Temporality, the subjective perception of a past, present and a future, can be relevant for people with ABI at particular stages post-injury, when people regain some self-awareness. As mentioned above, brain-injured people are often considered to have “lost their connection with the human order, the ability to project himself into the past or future using abstract thought” (Butt, 2004, p.130).

The participants in my study know much about their past, even if they have some lapsed moments of time. They have, I claim, refilled most of the gaps that they wanted to or that urgently required filling. Even Elizabeth, Joe’s wife, said, “*I’ve forgotten all that. I’ve wiped that out”*. People without ABI can also not remember, and remember to forget certain events. The participants here are also very aware of the present, and have a very good sense of what is happening tomorrow, next month or not. They are planning for their future if they can, and when dependent on others, including Government services, they await and see if there are any changes occurring.

Tempo concerns the pace of life, time pressure and may be divided into time felt and time understood (Farnworth and Fossey, 2003). Again, all the participants here understand time**.** Sinead knows the day and the hour now, assisted by a talking clock, a watch, and certain fixed routines, although memory lapses may still occur. She also knows how long waiting time can be, if there is no interaction or meaningful occupation. Vivienne and Claire also are aware of this. John found the

time long after his family left him three years post injury, while Joe also had some long boring days watching television. Most of these types of days are behind them all now.

Time felt, especially feeling rushed, impacts greatly on the everyday world of many disabled people, rehabilitation workers and planners, as well as on business people working in other 'slower' nation states. Coping with space in time, walking a certain distance, walking across the room, walking to the shop can cause irritability for some, if the other person has to go slow. Fabian (1983), claims that anthropologists generally made "use of Time for the purpose of distancing those who they observed from the Time of the observer" (p. 25). Is this what occurs for many people with ABI and other impairments? If others cannot cope with their slow sense of time, this can often lead to arguments and difficulties, especially in our busy fast world. In this study, certain stories about irritability, anger, or managing independence or not, appeared to me to be linked more with coping with time or the lack of it. Taking more time to dress or to walk created difficulties for some of the participants in this study, especially Sinead, John and Joe. For example, Sinead and Paddy appeared to hold opposing views about time, and time for independence. Sinead wanted to do as much as she can for herself, otherwise she "*would feel like a pensioner*".

Yet, for Paddy, coping with her sense of time is very difficult. He said

> *She likes everything now you know* (Phil mmm*) she doesn't want anything in a few days time, or maybe tomorrow, (*Phil mmm*)* now *it has to be done, everything now you know. Like for instance, if she was going to the shop and it was raining outside, she'd eh, she'd want to go in. It might take her ten minutes to walk into the shop and me with her and get drowned* [stressed this word] *wet like, where I'd hop in and get it like. She'd get annoyed that she couldn't get it herself. She might want to go*

> *back for...something silly like, so I'd say look, I'll pop in and get, get a receipt, you can pay me next month, simple operation like, but sure…* (Paddy 2, pp. 6-7).

Paddy also mentioned her aggression or abruptness. When I asked him a question about her aggression, he said,

> *who'd want to get out of the car and it raining hard and maybe walk fifty yards you know, and get drowned wet and come in just for a packet of tea or something like that when I could hop out and get it for her. It'd be quite simple like, do you know? The logic of it is, just, you know, straight forward enough, eh so she can be very that way alright you know, a bit...* (Paddy 2, p.7).

But Sinead wants to do as much as she can for herself. John in this study also wanted independence for himself.

> *This is something I would fight very hard for. I wouldn't want anything done for me which I was capable of doing for myself, even if it took me twice the length of time to do it, no matter how much difficulty, or no matter how much more easily anyone else could do it, or they can do it in a fraction of the time, but that's not the point…* (John 2, p. 5-6).

This shows some of living in the fast world, with Sinead and John getting on with, or trying to get along with the slow life Perhaps 'independence in activities in daily living' is also a generational issue. Older people have had a life-time of having had to work hard and do most things for themselves, for better or for worse, and have had to make do without many material supports. Fabian (1983) states that it is important to "meet the Other on the same ground, in the same Time" (p.165). He claims that for "human communication to occur, coevalness

has to be created" (p.31), i.e., a sharing of time, to develop 'we' relations. This sharing of time is often denied today with otherness and difference created instead. Robillard (1997) for example writes that because of his neuromuscular disease, he cannot "talk or communicate in anything approaching the social consensus of real time" (p.253). He communicates only in a very slow manner. While in an Intensive Care Unit, Robillard found that not having "a real time voice" was "equivalent to not having any defence to what was done to [his] body" (p.254). Because of being told continuously by the staff, "not now", and being cut off so often when he wanted to speak or communicate, he wrote about the experience calling it, 'the "not now" problem'.

Time emerged as a major concept in this study at various levels. These include the impact of time post-injury which impacted on the stories the participants told me, their recovery in time, adjustment in time, with the person, family and/or friends developing new routines. Time was also present when they told me about all the time they had to wait or live through, while waiting for the call to Dun Laoghaire (the NRH), or professional x to call, or waiting for a decision to be made about accessing benefit y or service z.

CONCLUSION

The four sections in this Chapter are interlinked in my claim for the need for greater access to generic services for people with ABI in their search for sameness. Specialised services may assist in working on particular differences, but devising very specialised services can bring about their own difficulties. The specialised-mainstream debate continues. The above data highlights how love, social relationships and social participation are affected greatly, but not totally, by the public services available, while living in different time frames and with hidden cognitive impairments effect opportunities offered for community inclusion**.** Some of these participants have developed their own content slow life without the input of specialised professionals as they had good family and social networks living in

time with them and not over-exaggerating differences. Accessing the right type of support at the right time in the right manner would have been more than appreciated by all. Participation in an event or activity on disabled persons' own terms, as much as possible, is becoming an important goal of person-centred social health care today. Following their systemic review of evidence about community integration (CI) when living with ABI, Reistetter and Abreu (2005) state that there is a need for "occupational therapists to continue designing (CI) support programmes many years after the onset of TBI" (p. 208). Positive stories about social participation are interwoven here to show that when living with a neurological disability, social exclusion need not be inevitable. Actually, as Bauman (1999) wrote, living together "…is the norm, not an exception...if understanding is a miracle, it is a daily miracle and one accomplished by ordinary people not professional miracle-makers" (p. iii). Too often, people with ABI are segregated because of stereotyping, over-generalisation of this identity marker, poor or no linkages between services or linkages with the wrong service as Clare and Vivienne experienced for a while.

Disability may be recognised more today as embodied, as well as being a socio-political construct. Impairment can also be accepted as beyond the body, as social, with boundaries blurring between the body and the social. Yet, for practical, analytical and policy reasons, separate action is required on both impairment and on disability issues at particular moments in times. Action on recognition and identity because of body issues was explored more in the previous Chapter. Gaining personal-social recognition impacts on the redistribution of services or public funding. Today, a justice of distribution or redistribution is required for many disabled people. Fraser's work on the integrative status model unites redistribution and recognition needs, and claims that only from this "can we meet the requirements of justice for all" (Fraser, 2002, p.38). The next Chapter links in with this. I tell how some of the participant's developed or tried to develop their own collective identity, at different times, to gain recognition, and services, and to gain a sense of belonging which enabled them enjoy life more on their own terms.

CHAPTER 7 LIVING THE SLOW LIFE

Being a citizen – being or becoming like everyone else

This Chapter entitled *Living the Slow Life* is not about rich people or ex-hippies who have gone '*back to nature'*, or about islanders living in Tahiti for example, and neither is it about people once labelled 'slow learners'. Even though Annie, Claire and Sinead claim that they and people with ABI in general, are often compared to slow learners, I am aiming to use the *slow* life in a positive manner. Following my involvement in and reflecting on the nuanced details of the lives of the participants, I conclude that slowness and time is a major issue and need in their lives. The positive aspects of slow or slowness are not incorporated sufficiently in disability or ABI rehabilitation practices and discourse. Continuously, people with ABI are assessed against local norms, thus a fast norm is used in industrialised countries, although 'pacing yourself' is used in rehabilitation or therapy programmes. The SLOW movement has much to say and add to social inclusion for all, especially I believe, for people with ABI. Living a slower pace of life including slow planning, slow talking, slow sex, slow cities, with more time for talking and sleeping, could change how people with ABI are assessed and how they can get on with living. They could perhaps then enjoy living a good enough slow life on their own terms like many other proud disabled people. The benefit of slower community living may also enable living with other difficulties, such as schizophrenia. A recent study claims that the recovery rate for people with schizophrenia in England is about thirty per cent, yet in Nairobi, there is a fifty per cent chance of recovery (Bentall,[178] 2006). Part of this reason is attributed to the importance of the sense of belonging and community, and having time to talk. "*In Praise of Slow Inclusion"* (Bates, 2005) is also included as one of the 'emerging 'themes papers' of the 'UK National Team working for social inclusion for people with learning difficulties'. As Hammell (2004c) stated, "the

[178] Professor Bentall is a Professor of psychological sciences at Manchester University, quoted in *The Guardian* (10 October, 2006, p. 10) on World Mental Health Day.

experience of quality of life is not dependent upon the quantifiable, material conditions of life but upon subjective, qualitative factors: the content of life" (p. 299). And while 'quality of life' is a hot topic in industrialised countries,[179] we are seldom allowed to go slow, be bored or to be goal-free. Indeed, there is a high correlation between selfish capitalism, materialism, and emotional distress (James, 2008).

Slowness is assumed, required and intertwined throughout this Chapter as I focus on the participants living as citizens, living life much on their own terms, searching and finding their own meaning as citizens in our complex society. This links in with and/or develops on from the last two Chapters where I focused on Annie, Claire, Joe, John, Sinead and Vivienne as persons with impairments in Chapter 5 and as disabled persons in Chapter 6. The personal impairment effects at body level were separated from the social disabling factors for analysis and policy purposes only. All of these identity markers, along with other "cross-cutting identities and relationships of...gender, race, age and class" (Williams, 2001, p.140), are naturally interlinked. The 'identity marker' focused on may depend more on which need is most salient at the time in question, although many also overlap even within that moment. But this is still not accepting fully the autonomous 'choosing subject' as in post-modern relativism, because capacity, choice of or for all involved, social supports, and costs of disability also need to be considered.

As our society becomes more professionalized, professionalized rehabilitation services which are encroaching more into the lives of disabled persons, involves generally working with the 'unique individual', a person different from all others. This is one of the two meanings of the term, the individual. The occupational therapist for example, works mainly with a unique, distinct person, "specified...uniqueness by its differentiation from an other" (Wallace-Scott, 1996,

[179] See also *Affluenza* (James, 2007), *Need or Greed* (Hoad, 1999), *In Praise of Slow (Honore, 2004), Small is Beautiful* (Schumacher, 1973).

p.5). However, the other meaning of individual, “the abstract prototype for the human”, where this unique person is the same as all others also must be considered, especially in a world with limited resources. This second meaning is what gave and continues to give the basis for claims to universal rights, freedoms, and the political rights of the citizen (Wallace-Scott, p. 5). Balancing both and ‘all other(s)’ is part of the daily tension for me, and no doubt for many health or social care workers, and for disabled people themselves. Oliver (1996, p.27) claims that under the *citizenship approach* of service provision, which includes economic, political and moral dimensions, disabled people are seen as “equal citizens with full rights and responsibilities” (p. 28). This is in contrast to the “humanitarian approach where services are controlled and provided by professionals who see disabled people as ‘less fortunate’ and ‘the problem’”(p.27). I agree fully only with the first half of this last sentence, as I believe naively perhaps, that by now more professionals and ‘public’ are changing their attitude to disabled persons. Under the compliance approach, Government policy and legislation drives service provision, typically doing only the minimum amount required. The question of whether citizenship is the best approach for our work with people with ABI will be discussed in the next and final Chapter. So these two meanings of ‘the individual’, the unique and the abstract universal person, are interwoven in this Chapter as in life.

In the first section below, *Play the Cards or Fold…*I present some aspects of the ‘meaning’ the participants give to their lives now. This included certain experiences and knowledge from years of living with ABI, periods of social discrimination and how they discussed adjustment or what helped this process. They all have ‘moved on’ with renewed self awareness and political awareness because of lived experiences with discrimination and/or respect in their life-world. The second section is titled ‘Developing collective recognition for gaining status’. Many have learned by now that certain problems are linked with social relations and social practices in our world today, and are not caused by their actual brain injury. This is the basis of the social model of disability, including recent

developments of this model, where personal experience is more explicitly formalised and discussed. Thus disability politics for collective recognition remains active even in inclusive societies. In the third section, I explore some issues discussed linked with 'Being different and being the same', thus use of the old paradox for the title. While most participants feel a little different from their pre-injury self, from other disabled people, and from the general public, they are and feel also the same as everyone else. In the fourth and final section I consider their stories on Advocacy and volunteerism as occupation. Their involvement in volunteerism and advocacy provides them with much joy, meaning, social networks, contributing to other people while also passing the time in life, all part of present occupation therapy discourse. As discussed for decades now, both recognition and improved redistribution of resources are still required to enable disabled people enjoy being part of either or both the disabled and the non-disabled community. Belonging to networks on their own terms, as Annie, Joe, John and Vivienne now are, enables them to live life slowly and with some fun. Claire and Sinead are working on this, having achieved this somewhat in their own personal but limiting space.

7.1 *PLAY THE CARDS OR FOLD...*

The words in the heading for this section come from Annie during our first interview when she was telling me about one of her discussions with three other people with ABI.

> *...this is the way I look at it now. Well, we're here and this is us, and we've been dealt, the cards we've been dealt are rather crappy so, we have choice still. You can either play the cards or FOLD* [stressed this word]. *The choice is ours and I said, it's not the greatest, em* [cough] *it would be great if we could say to God would you ever em, shuffle them again and throw us down a couple of more, but that's not just the way. But that's just why, I*

> *don't know why, it happens to us. For whatever reasons, I presume that, I've always assumed, I've always taken things happen in life for a reason, they mightn't be explainable, but they do. And I don't know what my reasons were, it was a pity that I wasn't able to do my work that I was doing. My life, I suppose (pause) I slowed down if you like…* (Annie 1, p.5).

Annie's metaphor for getting on and living with ABI, "*play the cards of fold*" comes from poker card games, and is used no doubt in living through or with many difficulties or transitions. Ricoeur (1981c) claims that the "function of metaphor is to transpose the meanings of ordinary language by way of unusual uses" (p.181). But we must remember that not everyone can *play the cards,* and neither will all *fold* if they do not. And although "[m]etaphor is central to embodied experience" (Becker,1999, p.52), metaphor like other "pattern of words figures of speech, concepts values and symbols…are embedded in historical, political and cultural settings" (Lupton, 1994, p.18).

Thus words are not politically neutral and Annie is as she describes herself, the "*crème de la crème"* of people with ABI. She knows her privileges, her wealth and functional abilities. Annie has regained much in her recovery, which has allowed her return to much of her old lifestyle. But she does live alone in her own home, has peace, space and time to herself when required, is financially independent, and has had a relatively good network of friends. She can drive her car again, the one domain of living that she did not want to live without, and seems to have been her main rehabilitation goal. Annie has adopted a number of other metaphors that she repeated to me on many occasions. They can invoke journey, battle, and about being part of the forgotten people. She also uses movie and song phrases, such as *'Goodnight Irene, Goodnight',* to describe the lack of action or follow-up of certain professionals who referred her on and on for various services. As Becker claims, metaphors "do not reorganise thinking, but they provide one way of locating new meanings, which in turn may facilitate efforts to reorganize

life" (1999, p.65). And while "cultural meanings cannot be reduced to metaphors", Becker claims, metaphors can act as a mediator in a disrupted life or can be selected and used to aid transformation when there is a form of existential loss. For example, Sinead's husband, Paddy, used the 'battle' metaphor regularly. He told me he thought he could

> *battle it you know, and maybe win that battle you know, but it's a battle you, you might win, but you never win the war as such, you know…* (Paddy 1, p.2).

I use *play the cards or fold* therefore only as one possible metaphor for people's search for meaning and/or for adjustment to living with an ABI. Participants have accepted or have had to accept their ABI at some level, in order to have a future, this present time, even if linked with resistance and resignation at times.[180] Elizabeth had much emotion in her few words when talking about her husband Joe adapting, accepting, saying "*...I suppose he's, he's accepted it, I suppose, in some sense of the word*" (Elizabeth 1, p. 2). Deeper pain was hinted at though in the words that followed immediately, when Joe complained of sore eyes in his sitting room when I was with them both. According to Elizabeth, Joe's sore eyes are the result of watching too much television or looking at the computer screen. But "*what else can I do*", Joe replied to her. Elizabeth then said, looking at me, "*he is lost, he is"* (Elizabeth 1, p.2). But that was my first visit with them in 2004, and in keeping with the human condition, other or new experiences, positive and/or negative, have been created by or placed upon this couple and their family[181]. Now, after four major impairments or disruptions to his body, they want mainly to celebrate life and celebrate being together, still. Most days, Joe seems to have accepted his situation, saying "*I'm grateful I've got as good as I can, didn't think I'd turn the corner*" (Joe 1, p. 6). He has his routines, some old ones such as meeting their postman almost every morning, being involved in the parenting of

[180] As discussed in Chapter 5, compared to people who acquire other impairments, people with ABI often have an additional stage of 'awareness- self-awareness' to work towards and through.
[181] Since our interviews, Joe has had another major body disruption.

his children, and playing cards with his old 'club' two or three nights a week. Two new daily routines are walking on their country road, and helping their youngest son with homework.

Adjusting was however a longer and different process for John. He talked about how he "*...went from being an organizer, definitely being out in front, to being definitely taking a back seat…and* [Brid], *had to, to, to carry me I suppose for a long time until eventually, I began to become independent" (John 1. p. 6).* But even when you have adjusted, accepted, and maybe told when assessed that you have reached this moment or day of adjustment, other new issues may emerge. As mentioned in John's pen portrait above, a few years after his crash, John had to adapt to being a separated husband and father, while only some years previously he had to adapt to the news that he was adopted. So when John says, "*it is possible to adapt. I try my best to adapt" (John, 1. p.3),* he has much practical experience of doing so, as had Annie.

Speaking to Annie near the end of our first meeting, I said,

> Phil: *you've gone through a lot. You seem to be coming through a lot too*
>
> Annie: *well, I suppose, I'm doing fine, I suppose, it's learning to accept. You mightn't understand so very much, but I mean, to have an acceptance of what's, what you've been dealt with, just live to the best of your ability...*
>
> (Annie 1, p.15).

This may seem that I was putting the 'journey' metaphor on Annie words using *gone through* or *coming through,*[182] but I did not intend to link Annie to a 'quest motif'. Quest motifs are those where, the hero "journeys into distant lands,

[182] I now realise I did use the words "*gone through a lot*" and "*moved on*" often during our research meetings or interviews.

undergoes various ordeals, and trials, and returns with some gift or trophy" (Hawkins, 1999, p.78). I know that Annie would always prefer never to have had her ABI. Plus, she is not willing just to accept things, however, in our very unequal society. Being like an organic leader, she wants more socio-political action on change in services and attitudes for people with ABI. Vivienne meanwhile knows that "*people say there's a purpose in everything or everything happens for a purpose* although *I am still looking for the purpose*...of my ABI" (Vivienne 2. p. 20). She is not sure if religion helped her at the time of her accident as she was "*only in her twenties and stopped going to Church then for a while*". But now she attends Mass daily (Vivienne 2, p.20), and she participates in a weekly meditation group. Clare also prays regularly at home, while religion and church were also important for Annie, Sinead, John and Joe for personal, spiritual and social reasons. Spirituality emerged as being of importance for most participants in this study, perhaps not surprising given that all participants are over forty years of age, and all seem to be from catholic families from older Ireland.

Perhaps also due to the age group and religion of the participants, stories about visits to Lourdes emerged in our meetings. Going on religious pilgrimage to Lourdes (Southern France), a holy site for members of the Roman Catholic Church, is an annual event for many Irish people, including many people with chronic illnesses or impairments. Many people believe this to be a place where Mary, mother of Jesus in the Christian religions, appeared and where miracles may occur. Irish regional diocesan church groups organise annual pilgrimages and helpers to visit Lourdes, including time for fun, as well as time for prayer, meditation, blessings, and visits to secular and sacred spaces. Three of the six disabled participants in this study have been to Lourdes, while Sinead, John, Joe and Elizabeth travelled there twice with their own groups during this research period. Many spoke of the sense of peace and sense of community there.

Sinead, for example, told me

Sinead: yeah, *that was my sixth time going now. I'll go there again next year, hopefully, a place I love going to*

Phil: *it's very peaceful*[183]

Sinead: *Oh, it's lovely, the feeling there is too good. When you go into the Grotto where Our Lady appeared, the feeling is so good. I couldn't describe it* [Pause]

Phil: *and, are you able to get to Church here whenever you want?*

Sinead: *Here, I can't get to Church, not here now. My PA takes me out on a Saturday night, that's all I have, five hours a week. Can't get to Church here at all...*

(Sinead 2, p.5).

Linking her appreciation of time for spirituality and meditation in Lourdes, I moved to her everyday or weekly living in Kerry. Meeting her spiritual needs is almost non-existent, even though participating in prayer and communion with your fellow faith members is expected within the Roman Catholic Church. As mentioned earlier in Chapter 5, Sinead did have a helper in the past who helped her get to the church nearby. Mass is available in her independent living unit, but only once a month.

Religion and membership of a faith community were very important features of life for John prior to his injury, for adapting to his ABI, and still in everyday living today. His faith and regular communion with his local church seem to be very important to him as he talks often about this, and much of his social life revolves around church activities. He seeks greater justice in life as informed by liberation theology.[184] It is because of their religion, that neither John nor Brid are seeking a full divorce following on from their separation. They have an annulment from

[183] I was in Lourdes twice with teenagers with disabilities many years ago, when I, too, was a teenager.

[184] Liberation Theology is one form of catholicism developed in South America in 1970s using the gospels and Freire's conscientization to reduce oppression and injustice in local societies. Used widely for Roman Catholicism search for justice, much in common with socialism and Marxism.

their church. John too told me about his earlier visits to Lourdes, although he had the added difficulty of remembering being there as a helper in earlier years and then returning after his ABI as a patient.

> *I went with the Order of Malta a couple of times out to Lourdes. I never thought there would come a day when I would go back to Lourdes as a patient, or as an* ex-patient *you know, a different ball game completely...* (John 2, p. 5).

Spirituality is still an important concept or issue for many people in Ireland, although it is in danger of being medicalised, trivialised or over-complicated. Now it appears that every daily action and event are expected to have deep Meaning, although managing with a small 'm' in meaning is good, is life (Svendson, 2005).

Conclusion

In this section I have noted some of the various factors involved for the participants as they '*played their cards'*. How they rebuild or piece together their narrative is linked with their pre-injury self, their age and education at injury, their recovery pattern, their social supports, and formal structures in society including local disability discourse. (See also Chapter 2). Like Ashkinen et al. (1998), Koshkinen (1998), Fleming and Strong (1999) who have studied long-term issues when living with ABI have noted, the actual time and place when you, the researcher, meets participants is also important. (See also Chapters 2 and 4). I met all participants years post injury, and years post rehabilitation apart from Claire. She has lived with ABI for some years and has gone through much 'adjustment' already.

The adjustment and *self work* of these participants occurred within a time and place of a lack of public awareness about ABI, a lack of brain injury community services and when narrow assumptions underpinned the very limited personal neuro-rehabilitation services. And, as noted in Chapter 6, a lack of generic

disability services such as transport or information compounded their situation. This added many difficulties for partners and children especially. Additional but time-bound suffering was experienced by participants and their families by not having individualised community or home-based services, for at least the first few years post-injury. While health and social care professionals may be at times, part of the problem, they are also often part of the solution. But by avoiding dependency on non-existent specialised professionals, the disabled participants in this study, have learned much themselves and balanced their limitations, with personal acceptance of ABI and did risk management themselves towards their own and/or family goals. Part of this adapting, change and relearning process seems to have included much personal reflection, faith, family adaptation, acceptance by friends and family, along with perhaps time-limited rehabilitation/disability services. But accessing and meeting other people with ABI like themselves were and are also very important for most participants. This is the focus of the next section in this Chapter.

7.2 DEVELOPING COLLECTIVE RECOGNITION FOR GAINING STATUS

> Personal identity gives meaning to the 'I'. Social identity guarantees that meaning, and in addition allows one to speak of the 'we', in which the other-wise precarious and insecure 'I' may be lodged, rest safely and even wash out its own anxieties
>
> (Bauman, 1999, p. xxxi).

In this section I move from 'I' to 'we', from the importance of developing a 'self-story' to the usefulness of meeting with your own reference group to confirm this personal meaning. As Rorty (1991) stated, most people do spend some time with like-minded people, as well as mixing in the bazaar of life. Honneth's theory of recognition includes the desire for individual and emotional recognition, and "at a

collective level, the need for social membership or rights based recognition" (Crossley, 2005, p.262). These three forms of recognition, love, legal order and solidarity, relate to gaining "self-confidence, self-respect and self-esteem" (Honneth, 2001, p. 50). Focusing on participants' stories about their past and ongoing involvement in a support group will show that this mechanism was/is important for most participants in order to learn how to cope with unwanted disruption in their daily living. Such groups enabled self-confidence and solidarity as they developed and learned with peers, perhaps literally and politically, about their individual and/or collective 'voice'. Necessary social relations at this stage need not include rehabilitation, clinical professionals working in their professional disciplinary role, unless working as a non-oppressive advocate and ally.

For Sinead, it was *"lovely to get together with people who are more or less like yourself, lovely comparing notes" (Sinead 1).* She would have liked, however, for this to have happened earlier on returning home from hospital to help her adjust, learn and adapt. Remembering those early days at home she told me:

> Sinead: *Em, I heard of Headway in Cork, but so-called husband wouldn't take me in there at all, no way in the world. And I wanted to know why he wouldn't take me in to see people like myself and what it was like and compare notes like. He said no. He said if I brought you in there he said, I would only think it would depress you. I said why depress me and then he went off like, but never took me once.*
>
> Phil: *Oh! He went in to visit like?*
>
> Sinead: *He used to go into Headway all the time, like, but never brought me once, until I came here to live* [here]. *I went to Headway in* [names town] *and it was very good…* (Sinead 2, p. 21).

Paddy did tell me that he did not want to upset her by going to such meetings. Yet no professional health worker offered to bring her to this ABI group, even if transport would have been required. This short quote highlights not only patriarchy in the home, perhaps more common in rural Ireland at that time, but this may also highlight a disablist attitude held by many still today. Many non-disabled people think that people with cognitive and speech difficulties may not be able to participate in or benefit from a verbal meeting. There exists still today a lack of supports to enable and allow those disabled people needing assistance to meet with peers, if they choose. For Annie, accessing a peer-group was useful, especially when dealing with a hidden cognitive impairment that others, the public knew little about.

> *we used have them* [small groups meetings] *in* [names her County]. *There were six or seven of us, well, some would come or some would move on to other places. Well in the beginning, I wasn't particularly pushed about going, but because like that, like everybody else, I didn't see my disability. It took me a long time to understand there was something wrong, I didn't understand what it was and everyone would be saying to you, you're fine, you're grand, perfect and all that…* (Annie 3, p. 6).

Even now years after their injuries, five out of six disabled people in my study want to, and continue to meet up with other people with ABI, whenever they can. Four participants meet in a support group whether through BRI or Headway on a monthly basis. Clare would like to attend such meetings, but is not in a position to do so now while Joe wants no involvement at all in such groups. He may have ABI, but his other markers and networks are sufficient for now. He lives in a rural area, away from the urban location of such meetings. He is a family man, husband, parent, a member of an extended family, card playing group member, a 'good neighbour, a farmer, a property owner, a Gaelic fan, both football or hurling. I could list many identity roles for all participants. "That people are constituted in

different ways when called upon… is not surprising or interesting" (Alvesson, 2002, p.151). Along with other sceptical post-modernists Alvesson claims this 'postmodern fragmentation of identity' where subjectivity is seen more a process linked with the various 'markers' a person holds, is neither new or critical. Joe's social network offers him all the contacts and recognition that he needs, although at the start his wife Elizabeth would have liked him to have something more to do and/or a group to attend, especially during winter days. But like Annie, Joe has favourable material resources, a social network and fewer impairment effects than Sinead or Clare. Some disability theorists claim that such support groups are a form of surveillance, maintaining and protecting order in society (See Tremain, 2002). They also claim that social role valorisation should not entail or involve having to join a group, as this can bring about loss of self identity. And, such "collective action depends on identification with the wider [disabled] group" (Shakespeare and Watson, 2001, p. 548). But this latter point can be the reason why some people may like to, want to, or need to join a 'wider group'. However, few people have the status that Shakespeare holds (Professor of Sociology in a British university) whether they are disabled or otherwise. Many people seek and work on collective action for some reason beyond their own individual 'self' need, while such group membership is not the basis or essence of their identity, and generally not their only valorisation of role. As it is almost impossible to be fully self-sufficient in our society, identification is generally required in some way, with other people in some form, even for basic survival needs. It is accepted that for some people with ABI, meeting other people with ABI is, or may be, as important as meeting with non-disabled people, while for other people with ABI, peer-meetings may need to be balanced with meeting non-disabled people.

Annie described some of the practical benefits of meeting with people with ABI.

> *We have learned a lot from each other, and because I met people who had brain injury that I relate to, because, you're still not, you've still things in your head, you've got this, you can throw*

it out to the floor, and you'll always get somebody who comes back and says "well, this is what you should do now, because I've been dealing with that and this is how I worked, try that out and see (Annie 3, p.15).

For Vivienne, it was "*good to go at times*" although there were also limits for her as to how long one can listen to other people's stories. She enjoyed the '*guest speakers'* best.

Vivienne: *people all telling their stories about their sons and their husbands. I'd heard it all about a dozen times before like. I found it doesn't help me really. Now, prior to her* [the counsellor] *being there, there used be guest speakers which were very helpful.*

Phil: *So it was good to have someone come in with some interest or focus?*

Vivienne: Y*es, maybe it was time for a change...I'm okay*

(Vivienne 1, p.11).

However, in a later meeting she said she felt abandoned because there was "*no Headway meetings lately. We're abandoned*" (Vivienne. 3, p.1). So, although she may not like to or want to attend often, she still would like to have the choice. She remembers particularly not liking "*the meeting which said you never ever recover from a head injury*". She was "*so fed up with it*" (the ABI), although "at least I got a pension out of it [ABI]". Now that Vivienne is not working so much she attends and participates actively in monthly advocacy-support meetings in her local area. While Clare would like to be involved in both political advocacy and in peer-support meetings with other people with ABI, she is still having much fatigue, and transport difficulties even to access her weekly psycho-social educational vocational rehabilitation.

Once a person acquires an ABI, power relations are important throughout all the processes involved, although as noted in Chapter 1, for many people power and social relations are involved in the actual (social) causation of their injuries. For those living with ABI, it is important that they can meet in a safe space, on equal footing, equal social relations as much as possible, to share emotions, queries, and discuss both body and social issues. Peer-support, one form of self-help, is being organised today by many disability groups themselves for themselves, including BRÍ, Irish Wheelchair Association, and People with Disabilities in Ireland while the service-agencies Headway Ireland and Peter Bradley Foundation also hold peer-support programmes. This should help a personal and, for some, a collective counter-narrative to develop. As participants develop(ed) further socio-political awareness, they have learned much about social relations and social practices at a national level. Thomas (1999b) claimed that "reconstructed ontological narratives are built up through accessing counter-narratives about disability and impairment" (p.53). Belonging to some form of support, peer-support or an advocacy group can thus help to manage the "emotional dynamics of power relations" (Burkitt, 2002, p.166), assuming leadership is managed well. Unless these peer or self-help type groups are supported as with or in proportion to professionalized services, the voiceless or those with little representation in public life, "[t]he subaltern[185] becomes spoken for" (Bernard-Donals, 1988, p.115). The mistakes of past years are repeated when professionals and carers always speak for 'patients', and when achieving voice, recognition and status are delayed.

Disabled people have been demanding their voice and participation for many decades now, and this lack of voice was the original cause of the split of disabled people from Rehabilitation International, the professional service-providers' global association in the 1970s.[186] Therefore, until this present decade, people with ABI

[185]In the 1980s, Spivak wrote about 'the subaltern', people or subjects who occupy a marginal position, with their voice very fragmented in relation to a dominant culture and language (Bernard-Donals, 1988, p. 112).

[186] Rehabilitation International (RI), founded in 1922, was an international organisation of rehabilitation professionals who "tended to view disabled people as sick and childlike" (Driedger, 1989, pp. 28-39). They had few disabled people participating in their Congresses until the 1970s,

in Ireland could be likened to "subjects which occupy a position so marginal and whose voice is so fragmented in relation to a dominant culture and language" (Bernard-Donals, 1988, p.112). This is changing, albeit very slowly. As noted above and in Chapter 8, there are many new ABI services, groups already established or being developed. (See above and Chapter 8).

Is gaining recognition required for being different or for being the same? Next in Section 3, I move on to issues involved in 'being different and being the same'.

7.3 BEING DIFFERENT AND BEING THE SAME

I want at times to dismiss the concept of normality and allow only for individualized differences. As Terzi (2004) states, "if there is no normal functioning, there is no non-normal functioning, and therefore impairment and disability do not exist" (p.155). This could bring the social model of disability to its knees, Terzi claims because the social model of disability is based on the concept of the non-existence of normal functioning. This philosophical debate, albeit interesting, is separate from that used and lived out by many living with and working on improving social policy informing social and disability services and practices. The social model of disability still has a part to play I believe within the fuzzy world of increasing equal opportunity to 'sameness' and reducing or celebrating 'differences'. Plus, if we focus too much on individual difference, where can we find a sense of shared humanity and sameness? There is still a need for the social model of disability today. As Young writes, "the social model of disability seems necessary for activists to maintain in their arguments with employers, educators, legislators and judges" (2002, p. xiv).

In this section I explore particular tensions or experiences mentioned by the participants linked with those important concepts, sameness and difference. The

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yet their participation not taken seriously. By June 1980 disabled people had formed their own coalition.

participants spoke about feeling different from other disabled people, yet they also have many similar needs as them. Transport, housing, welfare, information and accessing rehabilitation services were some of the generic disability needs and issues named in Chapter 6. The participants also spoke much the same as the general public in how they talked about other disabled people or people with impairments other than their own (ABI). What is fore-grounded, why and when, is part of the long debate on normality, diversity and rights, in which we are all involved to some degree with our ethnic, faith, gender and cultural divides, social movements or networks. The celebration of difference within the disability sector is often juxtapositioned with the rejection of normality. But this is contradicted by seeking special or extra resources by those with more or the most differences. This is one consequence of section 2 above, single impairment recognition.

The main issues I write about here can be clustered around the participants' experiences of a hierarchy of impairments within the disability population itself, and how some spoke about other people with impairments. This includes their views on the differences involved if one is born with an impairment compared to acquiring an impairment in life. Within the disability network in Cork and/or Kerry, for those who choose to try and be included in 'a disability community', the participants here often felt somewhat marginalised or excluded. Sinead, Annie and Claire, in particular, claim that there is a hierarchy of impairments in Irish society, and that they are near the bottom of the hierarchy.

Reading across their narratives, the reasons for being on this end of this hierarchy according to the participants could be

1. living long-term with serious ABI is historically, a more recent phenomena compared to other impairments. Other single-impairment agencies, who, because of their long history and presence are well established in Ireland (for example, the Society for people who are blind, or Society for people with Multiple Sclerosis);

2. the wheelchair symbol is the well-known international symbol used on public signs or notices to welcome, or allocate spaces for, disabled spaces – emphasizes physical issues or needs;
3. As ABI injury is often hidden, other people think that they are faking tiredness;
4. the current name of their impairment, *brain injury* and not head injury, may imply that they cannot remember much, cannot learn, and/or cannot do very much;
5. ABI is a silent epidemic here, as Annie repeated regularly, yet there are few public ABI awareness projects;
6. the focus on ABI services in Ireland to date is on individualised rehabilitation, with little social, political or community action or public education; and
7. in 2004, ABI was very low on the public agenda of our government, the HSE and/or Irish disability politics, although now in 2008, there are many ABI service projects already established and/or being prepared.

Thomas (1999a), quoting her colleague French (1994) named the four factors that play a key role in shaping a person's experience of impairment. These are, the relative visibility of an impairment, the point in life at which the impairment is acquired, the comprehensibility of the impairment to others, and finally, the presence or absence of illness (p.39). These factors are very salient to the situation for people living with ABI in Ireland today and are referred to next. The issue of visibility is often linked with gaze and written about as being problematic for disabled people. Excluding the specialist's gaze, the public are often said to stare and make judgements on others only on appearances. This should benefit those living with a hidden impairment such as ABI, as their injury is generally 'hidden'. Yet, accommodation or assistance is sometimes wanted or required and a public sign or symbol can help.

Clare, Annie and Sinead talked about the public signals that blind people give out and gain when using a white cane, or from other people using a wheelchair. These public symbols enable some form of public awareness about these particular impairments and in turn a form of accommodation is given they believe. Claire told me she enjoyed receiving some attention and offers of assistance when she had her arm in a sling at one point during this research, whereas no one ever realises that she often would love "*a wheelchair for her brain*". ABI implies acquiring the brain injury in life rather than before birth. John, Claire, Annie and Sinead claim that to be born with an impairment is very different to acquiring an impairment in childhood or adulthood, and that this difference needs to be considered more by all people, especially professionals. When speaking with Sinead, I asked her if it helps to meet other disabled people, excluding people with ABI,

> Sinead: *No help in* [agency x] *now, people are nearly all born with the way they are, like. If you're born the way they are, they see no difference at all. But people who were once okay and then, they get head-injured, a different life. It's nice to compare notes to people who are the same way, otherwise feel like a real weirdo...* (Sinead 2, p. 22).

It seems that for Sinead, and for some of the other participants, that people born with their impairment do not have any identity, emotional or material needs. For these participants above, if you are born with your impairment, you grow up with it, you do not know a different life, even though they too may have personal difficulties when they do realise their difference.

All participants felt also that much about ABI is incomprehensible to 'the public' as few people do understand the workings of the brain, and/or all that can follow once you have an injury to your brain or head. This was linked mainly to the lack of public education or public awareness programmes as discussed also in Chapter

6. Most participants have asked that front-line health care workers, e.g. public health nurses, community health workers, and welfare officers be more informed about the potential as well as the needs of people with ABI. Because most people with ABI look so well, they generally are not sick, and because the public do not know about ABI, Annie believes that people with ABI are the lost or hidden people in Ireland. As noted above, the relative visibility of one's impairment; acquiring ABI in adulthood, the lack of comprehensibility of the impairment to others, and in the main, an absence of illness, all make ABI an ongoing changing complex condition to live with. People with disabilities themselves are also informed by cultural narratives about other people with other impairments other than their own. For this reason, they too do not often want to mix with those other people with certain other impairments. As Fawcett (2000) stated, "[p]eople with disabilities can and do make each other become 'the other'"(p.27). Fawcett also claims that "wheelchair users react angrily when seen by others as having a mental as well as a physical impairment" (ibid, p.27). It may help that people with impairments compare themselves at times with each other, used much in society today. This is illustrated in John's story (John 2, p. 8) about his participation in a social event in a residential centre near his home for people with Alzheimer's disease.

> *Sunday afternoon I was over in* [names place] *with Cork Alzheimer's Society. There was a party for people with alzheimer's and…I was looking around too. A lot of them were in wheelchairs and em they some of them didn't seem to take much notice of what was going on. In fact, one chap there was definitely asleep so, they, there are headaches and on the other hand there are really serious problems too. So, Sunday afternoon, was I suppose, time spent getting in touch with reality you know. Many who have been through hell...it was a sobering experience but it was also a good experience* PAUSE.

This "*sobering experience*" enabled John to get in touch with reality because for him, impairment is "*I suppose, it's a question of scale too*". He also said he saw *people who are in wheelchairs or people who can't talk properly or people who can hardly speak at all. I kinda think, I, I've a lot to be thankful for too…"* (John 2, p.7).

Reading, writing, talking and participating in various functions and activities in everyday living are lived in a variable manner by the participants and their colleagues. This is generally expected of the non-disabled population. Belonging to the category of disabled persons does not homogenize that group, nor make them saints, or forever empathetic to other people with disabilities. Sinead gave me an example of this when she told me in partial whispers about having to dine at times with a fellow resident in the centre in which she lives.

Sinead: *we all eat in our own place* [here]…*and* [speaking softly] *anyway, between you and me I'd rather it like that because* [Mr. X] *there eats like…*[gestures with her hands] *and it's all gathering up there, cooked food and easy,* [putting her hand to mouth], *all over you, puts you off your food. If he coughs it goes all over the table and then, makes you feel dirty. I mean, he'd never put his hand to, or turn away, only cough all over again. When there's food with him, I could run away* [said in a whisper] *and then the staff say to me ah now…don't be like that, he can't help it. I say he can't help it?* [said with a raised voice]. *I can't help my stomach getting upset. If he'd turn away or put his hand to his mouth. How is he supposed to know these things unless he's taught like*

Phil: *you've a good point there*

Sinead: *so wherever he is, I do my best to get as far away as I can, cos I know the coughing will start. Even going into a bar and have a glass of anything* [she mimes throwing up]. *Oh my god, that kind of carry on, I can't bear.* (Sinead 1, p. 12).

Although disabled people are not a homogenous group, "...many share common conditions of exclusion, marginalization and disadvantage" (Williams, 2001, p.141). The minority-group analysis of disability is often adapted today for a universalistic perspective of disablement (Vrkljan, 2005, p.57). Under this latter perspective, as mentioned in Chapter 2 above, "universalism recognises disablement as a continuum…social policy should respect the range that exists along this ability-disability continuum" (Vrkljan, p.58). But social and disability policy seldom dictate hospital or clinic policies or screening tools as they are usually the domain of health and rehabilitation services, the first line of services required by people with ABI, spinal cord-injury or multiple sclerosis, etc.

In agreement with Low (2003), I claim that while it may be positive to accept that all people are temporary able-bodied (TAB's), this can demean the reality of the brute impairment or disruption that people with schizophrenia, or stroke, or MS are living with now. Many people may never move out of this TAB identity, trying their best to remain able bodied especially today, given the links between wealth, status and health. The wealthy can be life-long consumers of cosmetic surgery seeking elective surgery for replacing or upgrading various body parts, expanding the prosthetic self.[187] This universalism of disability concept may be of limited use to people with ABI. (See also Chapter 8). Also, under this perspective, the issues of the body, including suffering, pain and disruption can often be sidelined or nearly removed from this debate, yet in our corporeal society, the search and dominant discourse is about the active 'perfect body'.[188] Valuing people who are

[187] As mentioned in Chapter 6, Skeggs (2004) uses this concept as developed by Lury in 1998.
[188] More on 'mask of ageing' in Lupton, 1994; 2003 and Hyde, Lohan and McDonell, 2004, p.174.

different, perhaps less able needs to be included, otherwise contemporary eugenics develops. Universal design, an important aspect of this debate on the universalism of disability, does not automatically benefit everyone (Ashe, 2001). Thus as mentioned in Chapter 2, the concept of universalism of disability would create a very large minority group!

As mentioned above, people often need to work together in order to develop voice and status. Disability politics can be long hard work with lots of voices talking simultaneously, thus making it difficult for those 'neurologically different'. Plus, the question still remains, "how do you include people who may need the benefits of inclusion but cannot bear the physical and emotional presence of it?" (Singer, 1999, p. 67). Being different and being the same enabled some of the participants to do both advocacy and volunteerism. Therefore, the final section of this Chapter explores advocacy and volunteerism as occupation.

7.4 ADVOCACY AND VOLUNTEERISM AS OCCUPATION

The concept of 'occupation' for occupational therapists means, "engagement or participation in a recognizable life endeavour" (Christiansen and Townsend, 2004, p. 278). Occupation can be subdivided or reduced into activities or experiences for occupational determinants, form, (im)balance, identity, principles, performance, roles, rituals, all within occupational disruption, deprivation, alienation, and justice. Occupational therapists assume or seek occupation as a source of meaning, a source of choice and control, chunks of activities and as a determinant of health (Hammell, 2004b, p.21). Yet, 'occupation' for most service-users and their families generally means perhaps being able to do 'some form of a job or work' either at home or away, voluntary or paid. For other service-users, completing tasks or activities such as feeding, washing, or independent toileting may be their major need or job, and these tasks too are a major part of the work of occupational therapists. The personal meaning of the goals of and in rehabilitation is more

accepted today, although that is what the disability movement called for over four decades ago. Yet, routine aspects of personal care or medico-rehabilitation intervention, which may actually be the favoured goal, aim or occupational fit for that person, for that moment or day(s) are often devalued in today's professional discourse. A search for deeper meaning is often sought or implied in order to be more occupational. Beyond the meaning of a task, occupational therapists Larsson Lund and Nygard (2004) claim that many disabled people engage in fewer occupations than they did prior to the onset of their disability (p. 244). The number of tasks or occupations is considered important for them. While these writers are aiming to learn more about occupational engagement for disabled people in their own homes, they state that "people with disabilities devote less time to productive tasks" (p.244). They state that their participants devote "more time to personal care, resting/sleeping, and they have more time for leisure". Yet, personal care may be the most productive chosen 'occupation' for certain disabled people, while their actual impairment may demand that they spend more time on these tasks. As John and Sinead said above, this is one area that they want to spend time on, while leisure may be secondary.

In this section I write about how some of the participants spend time on tasks such as volunteerism and advocacy, which could be classified as within self-care, leisure or productivity. These are the three main categories used in occupational therapy typologies. For years, John worked as a volunteer in a literacy centre in Cork city. Today, one morning a week, using flexi-time at work, he continues with some short volunteer literacy training for disabled people in North Cork City. It is important for John to help others and to be involved in community groups. He also participates in a church group and an elderly club, as *"...there's give and take with most organisations. You contribute something you get something as well so"* (John 1, p.7). Certain people live more through other people, and their goals are not totally their own (Skeggs, 1997). Many parents worldwide[189], for example, place their children's needs and development before their own goals. Annie, too,

[189] I include my own late parents in this category.

often lives through others. She too likes to help out, to volunteer, saying that "*if someone wanted a hand or something I'd most certainly give a hand back"* (Annie 1, p.16). At the time of these interviews, she helped friends and colleagues often by chauffeuring then to visit friends or family in their local or their regional hospital. She also likes to meet with others and inform them on ABI. Vivienne has been working in a community literacy group for many years as a volunteer tutor, helping people to learn English. On another morning each week, she volunteers in a local charity shop, staying away from cash-till duties in case she either gets rushed by the customers or has any difficulties managing numbers.

In a study on the benefits of volunteering for people with mental health difficulties, occupational therapists Black and Living (2004) claim altruistic and egoistic motivations involved in volunteering combine to contribute to emotional well-being. This well-being was provided by "social contact, roles and a sense of community involvement" (p. 529). These authors conclude that volunteering as an occupation may hold some therapeutic value for mental health service-users. Some of these benefits were mentioned to me also by the above participants and were part of traditional Irish culture.[190] However, these benefits to self and social contacts also need to be considered today against the very real possibilities of additional stresses, frustrating demands linked with the agency in question, and other negative costs involved in this work. Within our professionalized time-poor society, and an increasing cost of living, many voluntary organisations no longer can access volunteers as in the past. Thus, a Taskforce on Active Citizenship was set up by the Office of The Taoiseach in April 2006.[191] Adding to this, in this era of increasing professionalisation, bureaucracism and managerialism, including charity regulation, more agencies seek paid 'professionals'. The Irish Charities Bill (2007) also places increased demands on voluntary organisations.[192] While I did

[190] For example, the Association of parents and Friends of Mentally Handicapped was established in 1955 with a national umbrella organisation (NAMHI) formed in 1961 (McCormack, 2004, p.17).
[191] Reports and policies of this Taskforce are available on www.activecitizenship.ie.
[192] "The Wheel is a support and representative body connecting Community and Voluntary organisations across Ireland. Established eight years ago, The Wheel has evolved to become a

not find any studies about people with ABI working as volunteers in Ireland, neither was there any data about them being either self or collective political advocates.

Advocacy

The new Advocacy Bill for Ireland is operationalised through the agency Comhairle where advocacy is

> …concerned with getting one's needs, wants, opinions and hopes taken seriously and acted upon. It can take a number of different forms including self-advocacy, self-advocacy groups, citizen advocacy, patient advocacy, peer advocacy (family and community), professional advocacy, and public policy advocacy (Comhairle, 2003, p.34).

There are numerous forms of self-advocacy groups in Ireland, especially within the disability sector. For example, the first self-advocacy group for people with learning difficulties was established in Ireland in 1993[193] by the Brothers of Charity. Although there are differences between advocacy groups, peer support and self-help groups, some groups combine all functions as a desired way of all their working or only in their early stages. Self-advocacy is now becoming part of the ABI discourse and services. Claire, Annie and Sinead in this study are keen not only on self-help, but also on advocacy. John attended the public meeting in Cork which was the first step to establish an advocacy group and he remains an active member of this group. Annie meanwhile attended Cork city meetings for some time, and she is now one of the main leaders in her local disability group. Self advocacy, at a personal level, and at a collective level often involves advocacy work for recognition and to be more involved in "making and influencing

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resource centre and forum for the Community and Voluntary sector". Retrieved 11 March, 2008 from www.thewheel.ie

[193] This agency now has twenty formal self-advocacy groups, while other major organisations in this sector, St. Michaels House, St. John of God's and Enable Ireland have also initiated self-advocacy groups.

decisions" (Comhairle, 2003, p. 37). People with ABI are not seen as political beings generally because they are viewed mainly within a deficit framework. Annie however has worked for some time on trying to get an identity card for people with ABI. As she explained

> *First of all, I asked the Health Board worker…and your one said, there's no such thing* [card], *and I said what do you mean there's no such thing, am I the first person that has brain damage in Ireland? So she said no. Well I said, what do you mean there's no such card? So then she said, do you think you are able to go on the train to Dublin for free? so I said…for the little bit of my life that I was able to work, I said I never got anything free, I didn't expect things for free. It's only a card. So she said, no, it was never heard of. So my friend then tried to explain it, so I said, look, leave it off. I began to realise…in the normal bracket of people, who knows about brain injury?*
>
> (Annie 1, p. 3).

Her struggle for an Irish 'identity' card continues, although the BRÍ Group have introduced an identity card but a European card may soon be introduced.[194] Fear of abuse of such a card seems to be the difficulty for the Irish situation. But as Annie said,

> [The Minister for Health and Children] *should sanction the card for anybody who has a brain injury. The card will be there if they want to use it. If they pick it up and they never want to use it, that is their choice…I presume at the beginning we wouldn't have the ability to make choices…but as the time goes on*

[194] Following that conversation, in 2004, I rang Headway England head office on that day. They forwarded me three identity cards without any hesitation for a person who is a 'survivor of a brain injury'. I also rang Headway Ireland Head Office in Dublin that same day, to be informed that they do not issue such cards.

> *whether the people adjust or not that's, everybody is different but at least then they can decide…* (Annie 1, p. 8).

Annie, Sinead and three other local colleagues with ABI worked on developing their own support self-help group in Kerry. They met alone for some time, although in order to develop somewhat, takes time, support worker perhaps, a venue and some money. As McColl and Boyce (2003) wrote

> the irony of advocacy is that the burden of eliminating barriers and inequities inevitably falls to those who are the victims of those inequities, and therefore may be the least well equipped to exert influence or wield power (p.390).

Clare, too, is trying to be and would long to be a greater political activist. On my first meeting with her, she said "p*erhaps someday I'll help other people with ABI by going to the* [then] *Cork man Minister of Health with others on ABI. I could be well able for him for an hour, but after that I could flag out"* (Clare 1, p.7). But, on my second visit, she was having a brain-shut-down as she calls her '*black-outs'*. Her impairment effects at body level impact on her social activism, as noted in an earlier Chapter. Many people who do attend BRÍ meetings can not attend regularly because of fatigue, lack of time, other commitments or a lack of interest in disability politics. But numbers in attendance need not be the outcome measure of the benefits of such groups. The benefits of self-advocacy are according to the Forum of People with Disabilities, (2001, p.15, as cited in Comhairle, 2003, p. 35).

> it allows people the space to name their own world and experiences in their own way; it can lead to employment, educational, economic, social and cultural opportunities; and it can lead to a greater sense of self, increased confidence and can be a prerequisite for other models of advocacy.

Developing self-advocacy can enable peer and collective advocacy to develop. Disability advocacy is a vast maze or jungle, however, because of the various demands of single-impairment groups and umbrella disability groups. And for various reasons stated above, the participants perceive ABI to be at the lower end of the disability hierarchy. Annie is very sceptical about disabled people's rights and all the funding for disabled people mentioned in our recent budgets. In December 2004, she predicted that the financial resources that were then being made available from the Irish Government would be for other groups of disabled people, with little going to ABI services or directly to people with ABI.

Some of the difficulties in disability politics are found within the problems of solipsism, and because of the ongoing changes at body level over time for many people with ABI gaining some or much recovery. The Chairman of BRÍ, Mr. Michael Clavin, a person with ABI himself, has stated at various public BRÍ meetings that "*to know what people with ABI need, ask a person with ABI*". This I find correct or appropriate, but only in certain conditions and for certain issues. This is a continuation of the '*you must be one to know one, or know it*' the solipsism argument. Older disability theorists now realise that this is limiting or incorrect, although some of these same writers may have helped develop this argument in the past. As Oliver stated once, disability activists or theorists almost made non-disabled people feel guilty for not being disabled. Not all people with ABI will ever know all their needs, their partner may know much more. Their doctor or therapist may also have a fair idea of the possible future or the broader story of their impairment. The broad future of an ABI is also generally something totally unknown to most of the public in Ireland because of the lack of public awareness of ABI. At a certain stage post injury, most people with ABI may be or should be in a position to state their needs but again, this may only be about their own particular situation. This should help in the individualisation of service-planning, yet service-providers however cannot provide for all of the needs of all persons with ABI or with any other particular area of need, I feel.

The social good, social solidarity and collective resources must also be considered, thus a 'rights'-based view on life can conflict with the social good. This is not to state that no change in our present status quo of government spending is required. Much change is required but few people if anyone, is granted this gift, that all of their needs are met by the government. While material needs of disabled people ought to be met, and conditions for positive identity improved, governments cannot legislate for positive attitudes towards disabled people in society. Negative actions can be prevented through the fear of legal action, but this does not mean positive actions will occur.

At a micro level, volunteerism and advocacy though could be included more in occupational therapists' work directly or indirectly. Like occupation itself, voluntary work could be a means or an end. Both forms of occupation would allow for social becoming, participation and community inclusion at a level for those interested in these two activities. In advanced welfare societies, which are generally individualised societies, leisure is becoming one major way of expressing oneself, or of occupying time, keeping body fit whatever about being beautiful, and for finding meaning in life. Advocacy or volunteerism while not as popular today could be considered appropriate for some part of people's free time. Jenkins, Douglas and Chamberlain (2008) suggest even "compulsory volunteering" to enable occupational therapy students learn more about community volunteer groups as part of their experiential learning for college. [195]

Enabling people with ABI to volunteer themselves and participate in the local community could be a topic for planning inclusion in community services, as much as the need for other volunteers (or friends) to help perhaps at times with/in ABI community services. There are disadvantages as well as advantages as having mainly paid professionals and paid carers in your life. The self-help peer-support group could become a space where people with ABI have the possibility

[195] I also plan somewhat similar but much shorter learning opportunities in the Cork area for Year 4 University College Cork occupational therapy students. This is a balance made on how the host groups are 'used', while the term 'compulsory volunteering' is not used.

of social becoming, while being a conversation partner, another goal sought by many participants. Voluntary work or advocacy work is already seen as gainful employment by and for many. But as mentioned in Chapter 5, people are not of value merely because of the work they do, or the function they have (Ryan, 1999). But present funding for services does not allow many health or social care workers take much time to talk with service-users for any long period of time, beyond those functional goals within the parameters of the organisation.

CONCLUSION

This is the last of the four Chapters about the embodied and embedded lives of the participants in this study. The focus in this Chapter was on some life projects involved with providing or finding meaning for their lives. I have written here about social adjustment, developing collective recognition for gaining status, being different and being the same, and using advocacy and volunteerism as one form of occupation often discussed within citizenship. As there are different senses of 'meaning' (Fay, 1996), I tried to link the significance of their meaning of their stories and events into my interpretative scheme, with what those meanings may hold for us, health-social care workers or fellow citizens.

These topics are all linked in with the broad theme of my whole research which is moving on with an ABI towards a counter-narrative for citizens living with ABI. This involves, however, managing personal and social identity needs, individual and collective recognition with material services and structures. Identity and recognition are enabled or disabled by material services, rituals and power and vica versa. As I am not seeking to place my themes in clearly defined boundaries or boxes, I held onto fuzzy edges which accept some overlap and contradictions. Initially I wanted to merge sameness and difference, body and social, micro and macro, the agency and structure divide or framework. But in the end, I had to go through and present them in the past three Chapters 5, 6, and 7, in order to go

beyond them a little in my concluding Chapter and in life after this thesis. These old concepts are still important as they are, I believe, the cornerstone for practical policy-making and service-provision. In health studies, as in disabilities studies and womens studies, we need as Wallace-Scott (1996) stated, "ways of thinking that do not insist on the resolution of opposites" (p. 175).

Able-bodied or disabled academics, with status, money and networks, can accept dualisms and the blurring or blending of boundaries. But in everyday life, people with ABI are not worried about blurred boundary issues. They seek competent action and useful outcomes. Generally, I would think that most people with ABI and their families do not mind which professional carries out which job or role, once their personal and/or social needs are being listened to and acted upon with competent expertise. But in our age of increasing specialisation, the increasing numbers of specialists will impact on how well they can and will all provide and manage their holistic approach. There are however a cadre of workers all searching for and enabling others to find meaning, quality of life, lifestyle balance, health promotion, social inclusion, etc. In addition, all health and social care workers aim to be person-centred, holistic and a team worker. An overabundance of holistic workers may emerge, leaving few available for some of the more basic reductionist work. A new form of oppressive practice could emerge, if some professionals, even in my own discipline who now include the voice of the users, etc., still seek to be all things to all people.

My concluding Chapter will aim to provide my overall conclusions and practical recommendations on managing differences, and searching for sameness beyond giving money to people, although money still talks and is important. Achieving full citizenship rights may never get past the usual provision of 'reasonable accommodation, within the resources available'. For example, in 2005, a group of disabled people revisited a video on disability issues made in Ireland twenty years earlier.[196] The most significant changes that they noted were "only additional

[196] Personal communication with A. Ryan, September 2005, a new professional disability advocate.

financial packages". Yes, their welfare payments had improved, but there was little or no change in attitudes, in improved team work, or being seen and accepted as an person with knowledge. For Oliver (1996), the failure of all citizens to gain their citizenship rights, "calls into question the idea of citizenship as a means to the social integration of individuals into society" (p. 49). Citizenship involves duties and responsibilities, which Oliver claims receives less coverage (ibid; p. 59). Citizenship remains one important concept.

The last three Chapters have explored issues linked with participants' stories of adjustment, accepting, making do, having a quality of life, being content enough. As Barnard, Towers, Boston and Lambrinidou wrote in *Crossing Over: Narratives of Palliative Care* (2000), "the definition of a 'good death' is highly variable" (p.11). So, too, I believe is the definition of 'a good enough slow and content life with ABI', even though I am not seeking a definition of this. Yet, neither do I want to give all to relativism or the eye of the beholder. Non-naïve realism reminds me that hidden or deeper mechanisms are often at work maintaining the status quo and/or blocking change(s) that needs to be made. The above writers note that variations in the socioeconomic status of patients are more likely to affect the quality of palliative care than their diagnosis. Status, too, has much impact on causing ABI, but, as these three findings Chapters above show, material and social status also impacts on living with your ABI.

Plus ca change, plus c'est la meme chose.

CHAPTER 8 CONCLUSION

This study was undertaken against a backdrop of major aspirational transitions in Irish health and social care services in general, and an increasing awareness about the situation and practices impacting on people living in Ireland with ABI. However, a counter-discourse on ABI and on disability is required if citizens living with ABI in Ireland are to be included in a more participatory manner in local and national disability forums and in local community events. Such participation is also necessary in creating knowledge on how ABI is represented in society and in 'the academy' as people with ABI have much to add towards theorizing various dimensions of disability (See Williams, 2001, and Chapter 3). While not accepting personal or experiential voice is all, people with ABI and their families can still inform us in an important manner on how ABI is embodied and experienced for them twenty-four hours a day, 365 days a year. This study has presented my critical interpretations of analysis across many stories or narratives about ABI embodied and embedded. As Zahavi (2004) [197] stated, the "results of empirical research should not be the only measure of our endeavours" and this thesis is just one of the measures of my particular endeavours. Numerous other learning experiences and activities occurred, and continue to occur simultaneously with this study, and remain undocumented. As stated on p.14, the aims of this exploratory research were to:

1. interpret narratives of personal experiences of disability from adults living with ABI;
2. explore theoretical issues linked with theorising disability and the application of this theorising for people with ABI; and
3. provide some new insights for policy-makers and service-providers in this sector.

[197] Zahavi, was introduced in section 1, Chapter 4.

The longitudinal narrative approach in repeat interviews used in this study enabled me to articulate a different focus of how ABI is embodied and experienced in this local area. Many of the above findings may not have been 'uncovered' if focus groups or structured or semi-structured interviews had been used. In addition, and as part of the research design, the timing of seeking stories of and from people with ABI and their family or friends also proved to be very important. Most ABI studies focus on the major difficulties in the first three to five years with ABI. This study, focused on the longer-term, and opened up many new questions for me, not only about 'coping', problem solving or services, but more about our shared humanity itself. While studies using critical realism "cannot predict occurrences or anticipate situations: reality is much too complex for that… we can provide insight into the mechanisms and tendencies that make things happen in society" (Danemark et al., 2002, p. 204). As the social phenomenon of ABI is complex, as are most issues in life today, causality of tendencies and patterns when living with ABI is linked with numerous factors and concepts. This study claims to provide insights only into certain tendencies impacting on the lives of people living with ABI in Ireland. Critical research, in itself, may be neither better nor worse than other research, but critical researchers are generally more "willing to state unwilling unwelcome truths" (Hammersley, 1995, p.21). As Danemark et al., (2002) stated, it is "not a question of different ways of seeing things, but that we see different things" (p. 29).

This story about the generic social construction of disability for Irish people with ABI emerged mainly from the participants, but also from literature, from myself,[198] and from my limited involvement in the BRÍ advocacy-support group. This engagement allowed and continues to allow me to remain in contact with ABI issues, beyond fieldwork for this study. As discussed above in section four of Chapter 3, moderate generalisations are used in this thesis. Such generalisations allow us to live with each other, and to be social everyday, allowing me at times to

[198] My research supervisors enabled much of my critical thinking, yet personal responsibility is taken for the focus of themes or findings discussed in this thesis.

go beyond the six disabled participants in this study. Details on many wanted or unwanted generative mechanisms underlying wanted or unwanted supports are discussed above throughout Chapters 4 to 7. These are all based around the four themes of this research which are:

1. identity and social becoming with ABI;
2. beyond assumptions embedded in ABI rehabilitation;
3. opportunities and barriers for participation in local community; and
4. living a slow life in a fast world.

While all of these themes interlink in practice, they are important in enabling the narrative self of people with ABI and their self-sameness, two important theoretical concepts emphasised in this study. A narrative self and self-sameness may be part of and expected in everyday discourse for the majority of our society, but they are not (yet) part of the dominant ABI discourse. As McCarthy (2007) said, "[a]ny narrative account of a human life must view the identity of the self in relational terms" (p.239). Practical enabling supports based on a more positive and alternative discourse[199] of a self with ABI could enable families better to learn to live with the same partner, parent or child that has had a major acquired disruption to their life. Perhaps then the label or identity marker 'stranger' may be removed and replaced, an implicit aim of this research.

Searching for the social in the participants' narratives has also allowed me to explore many of the obvious and hidden mechanisms impacting on the private-public lives of people with ABI here today. "A negative picture of current services and societal reaction to those disabled by head injury has emerged" was how Krefting (1987, p.223) summarised her findings from her ethnographic study of people in Canada living with ABI. This is still much the same overall story or narrative gleaned from this study in Ireland, remembering that the participants

[199] The term 'discourse' here is used both as a verb and a noun, and includes questioning assumptions and our taken-for-granted norms (Crossley, 2005, p.60-64)).

were and are not determined fully by these issues. Many aspects of the lived and told stories of the participants were based on or around the limited health and social care services in Ireland in the past and today. But rather than highly specialised brain injury interventions which are required, generic disability services such as accessing transport, income or personal assistance, improved social relations, public awareness and education were noted as urgently required. A large number of their problematic issues are caused by the presence of unwanted mechanisms or the absence in Ireland today of wanted social mechanisms or factors. Such mechanisms are linked with the demi-regularities of life, those domains in society that are slow to change, e.g. disablement, marginalisation, and racism in society. Time was also a major part of the narratives of the participants. As noted in Chapter 6, unlike living with certain other impairments, time allowed for much recovery following an ABI. Yet in everyday living, the disabled participants were often not given enough time to talk or walk slowly

A discussion on the main significant findings is presented below in this first section of my concluding Chapter. Significance was determined by (i) my interpretation of the above findings within the framework of the aims of this research (see p.14 and p.253); (ii) current interagency policies, and, (iii) my hopes for future practices and scholarship. Many theoretical and practice issues were discussed throughout the Chapters above, so only very limited new research or writings will be introduced here. Irish grey literature naming new work or developments since 2004 when this study commenced is also included. In addition, some issues or findings that fail to support my claims are considered.

In section two of this Chapter my focus is on the implications of this research for conceptual theorising and for practice linking with literature on recent developments. I conclude that a counter-discourse on ABI, including the narrative self of people with ABI, based on their self-sameness, is required. And while a counter-discourse on ABI may be necessary, it is not sufficient, as numerous other changes are required also in generic social and disability services and practices and

in particular brain injury services. The recommendations I seek include those sought by the participants and articulated by disabled people in general, for decades now. Those needs and issues that have been conceptualised for decades under the social model of disability are still very relevant today for the category of Irish people diagnosed with ABI. But most planning in Ireland focuses on good individualised clinical care and neuro-rehabilitation as if this is the main and/or only need. However, while such individualised work is important for a particular period, it allows social change off the hook.

To summarise my significant findings briefly, I use the headings of material rehabilitation practices, discourse and social relations as used by Chouliarake and Fairclough (1999).

Material rehabilitation practices

The participants in this study lived within a time and space where limited rehabilitation professionals were available, still some had their own social capital, including close extended family or a social network. Home-based and/or community-based rehabilitation services were very scant in the past. But, in the short and long-term, generic collective disability services such as accessible information, accessible housing, and assistive technology were also required by the participants. The paradox of fewer professionals in their lives may actually account for the quite high level of mainstream community inclusion that four of the six disabled participants' experience(d). The two male and two female participants involved also had long times of much loss of function and reduced 'personal competence', but they did have good social networks, whether extended family, church or local community groups. Even with the dichotomous situation of negative general public social discourse about ABI, and with little or no community based rehabilitation, Annie, Joe, John and Vivienne participate fairly well, and are in general, content enough, in their broad local network. This inclusion was not and is not available for two participants with more complex care needs, although their complex needs are not all linked with a loss of mobility, of

speech, of memory or of substantial recovery. This pattern or tendency of difficulties often linked with those generic disability issues mentioned above, from transport, information, to housing, as well as individualised therapeutic supports are repeated often in various ABI meetings or conferences that I have attended.

Discourse

While not all events and practices are discursive, the impact of the local discourse on ABI was and is significant. Discourse affects our words, meanings, categorization and boundary formations, thereby impacting on research, media, public imagery, attitudes and understanding of how disability is produced, as well as the development of personal identity as a disabled person. This study has shown that most of the participants have learned and accepted the traditional quite limiting discourse on ABI, often medicalised with little hope offered. The participants also found that they had to live within a negative social discourse and stigma about disability, made harder when their body impairment was hidden and linked with cognitive issues. Years later, however, most of the participants have reframed or are reframing the experience of disability when living here with ABI. But this is a very low tone and a low key voice, and now may be subsumed by a growing number of service providers which can in turn create ownership problems. From having no organisation or support, a few privileged persons with ABI may now be able to benefit from a growing number of ABI, disability[200] or community organisations. There are also a growing number of ABI information sites and consumer products available[201] on the internet. Again, this creates the need for more discernment by the disabled persons and families.

The dark side of ABI as highlighted by some participants for certain time periods, should not be forgotten. People with ABI do often get annoyed, 'down' and even angry, but they cannot be expected to be (almost) unemotional. But emotional

[200] Headway Ireland, PBF, Brainwave for people with epilepsy, Rehab Care, BRÍ, IWA, Enable Ireland, etc.
[201] Many new 'special' consumer products are available to or marketed to people with ABI, some very useful but higher costs are often charged if product deemed 'special'.

outbursts need not determine or dominate the discourse within ABI practices, as most people have, to varying degrees, '*a dark side*'. Also, causality of such personal emotions are seldom linked to our disabling society. I claim that ABI is greatly exacerbated by life in our fast world, fast rehabilitation practices, negative attitudes, discourse and the constant search in society for perfect memory and the perfect body. Yet, as requested for decades now by the social model theorists and activists, collective changes are researched and discussed less. It is the disabled person and their family that are expected to do almost all the changes.

Identity and self with ABI

Identity with ABI, like typical identity, is not fixed, yet strategic salient essentialism[202] is often required when living with ABI, to cover both the brute impact of the brain injury and all that may accompany this. Difference(s) may be more marked during that first or second year post serious ABI, when people are coping on their own, trying to live through chaos, with limited family centred supports. But as said above, much body changes can occur and recover, yet attitudes and social relations do not always change. Following the unwanted real fragmentation of self-awareness and of personal identity, many of the pre-injury characteristics, habits and interests of the disabled participants in this study returned or re-appeared in time. And as McCarthy (2007)[203] stated, a narrative model of self today needs to, and "can accommodate a very wide range of human experiences of selfhood…from the very stable to the radically fragmented" (p.263). Thus, while many aspects of personhood continue in and through time within the continuity of selfhood (C. Hughes, 2002, p.182), the fragmentation of selfhood also needs to be allowed for. A broader concept of self and/or a model of narrative self need not involve seeking the full integration or coherence sought by Erikson (1968) (as cited in de Peuter, 2002, p.37). (See also Broks, 2003; Jennings, 2006; McCarthy, 2007; and O'Connell, 1999). Autonomous selfhood is

[202] "Postmodernism opposes all forms of essentialism" (Letherby, 2003, p.51). I do not essentialise the impact of ABI in people's lives, yet their ABI may be a stable part of their lives and cannot be denied.

[203] In her accessible critique of Dennett and Ricoeur on the nature and narrative of the self, McCarthy includes the importance of first person narratives especially in health [/social] care.

not required or recommended either. The common good is still important for me, with a focus beyond unique individualised circumstances, although within post-modernism today, "foundational appeals to the common good…are no longer seen as carrying rhetorical authority" (Watson, 2004, p.109). Bhatkin's dialogical narrative model of identity or selfhood allows for change in self along with participation with others through an ongoing dialogue (de Peuter, 2002).

The lives of the participants in this study, while embodied and embedded with ABI today, holds much self-sameness with some or much of their pre-injury selves. This could lead, I claim, to a more positive and realistic discourse. This concept of self-sameness challenges certain unwanted consequences of the 'new self' metaphor or discourse used today, as this discourse often creates 'an other', a stranger, and may even lead to create and maintain unnecessary dependency. The consequences of self-sameness were not discussed with partners of disabled participants here because of any possible ethical issues which may have emerged. They have lived with and through the 'old' discourse. It may have been easier for the two couples who have separated to accept that their partner with ABI is totally different now, and not their same beloved partner, especially if or when little or no family, practical or emotional supports were available to them. For some participants, there was then and still today, little time available for creating or sharing any loving moments. In addition, because of the difficulty in coping through those early years post-injury, it may have been easier to blame everything on the ABI, never looking at problems in our social services or structures in our society. Caring for the carers is becoming an important topic in Ireland today. See below.

While discourse, material practices and social relations are just three elements of 'the social', values or beliefs, institutional rituals and power are also part of this (Chouliarake and Fairclough, 1999, p.28). Often the disabled participants in this study felt not valued by both professionals and 'the public'. Traditional rituals were used to inform certain programmes used, some positive and enabling, and

some of little benefit. Problematic rituals include the hierarchical evaluation of assessments, non-attendance of professionals at appointment times made, abuse of bureaucracy and of power. Power is, implicitly or explicitly, within all our social moments and relations. In the lives of the participants, power intermingled not only in many of their moments of living with their difference(s), but also in their search for sameness. Power was in those moments when the disabled participants and their families did not have access to basic real facts, or knowledge of options if any, or lacked basic autonomy in decision-making. The abuse of status or influence or a lack of discretion used by certain health care workers when working with some of these participants are examples of the moments of the negative use of power. Still, throughout this study the disabled participants often appeared as political beings, although being a person with ABI and being political are seldom discussed together. The participants have also had to do much reflection on their own lives at a very deep level. Most of them have also reflected in their own way and pace on their own friends, local society, and their place or absence of place within this society or culture. Some participants found themselves excluded from informal local community for varying lengths of time.

The local inclusion of disabled or different people in their community is often lost when societies become more professionalized as Illich (1977) and Freire (1972) argued decades ago. This leads many groups to have to organise to regain their voice, their place and space. As Rickard (2005) stated when discussing Habermas's theory of communicative action, "advocacy only needs to exist where equal communication does not" (p.10). This unequal state of affairs is noted to be more prevalent where market orientations inform social and health care practices, replacing the sense of the 'common good'. Such market orientations are developing in Ireland today as mentioned in Chapter 1, but ABI advocacy is also growing to seek greater collective recognition in order to gain better resources and status. While many of the participants and I may see a need for citizenship advocacy, some participants felt outside even 'the disabled community'. Another participant does not wish to identify as disabled and did not seek collective

recognition as a disabled person. This participant's abilities, rural home location, material wealth, a supporting extended family, close friends and neighbours, along with the timing of urban-based meetings, may also have had a part in this decision. Others with greater or deeper personal/body and social needs did not have the same home-based resources or social network and often felt unvalued, whether as a citizen or local community member. In addition, yet linked with, the professionalisation and bureaucratization of our society, advocacy groups are expected to use mainly professionalized programmes, with little funding being made available for non-professionalised supports.

Care, Caring, Interdependence: Quality of Life

The issue and politics of care and caring impacted on and informed the lives and stories of the participants in this study. Both male and female non-disabled participants were full-time carers in the 'early days' post injury. O'Morain (2008) claims that Irish Census 2006 figures show that "forty per-cent of carers are men" (p.14). The disabled participants in this study had many positive and negative experiences in both being 'cared for' and being 'cared about' in both formal (paid) and informal (unpaid) care. Annie, Clare, John and Vivienne experienced under-protection at times, while Joe and Sinead stated they felt over-protected as noted in section 4 Chapter 5. They all valued the care 'received' from their families, as they now understand more about what their families went through around the time of their injuries. Some participants have now worked their relationship with siblings or with partners back into a loving interdependent bond.

According to Barnes, (2001), the word care can be "misleading", though, because of the two broad meanings involved, 'caring for' and 'caring about' (p.14). When applied to disabled people, however, Barnes claims, care is usually only linked with 'to look after', to supervise and/or to protect, generally ending with either over-protection or under-protection. These contested meanings of care interlink with personal care relations, social and welfare policies, power, control and conflicts impacting on those 'doing caring' and those being cared for

(Chamberlayne and King, 2000; Fink, 2004). But as Thomas (2007) stated, care systems and even supports for independent living often remain an important part of "disablist structures and practices in society" (p. 96). McCluskey (2004), for example, found in her study on care and caring of people with ABI, that while many of her participants needed less care over time (p.75), they still continued to have "limited involvement in care decision-making" (ibid: p.77). Care and caring by or provided by disabled people themselves is seldom studied. As Frank (1998) stated, "…there are many openings for those who are cared for to reciprocate by caring for others and thus to sustain moral agency" (p.39). My study could have focused more on the care-work of the disabled participants, but this was not my aim. As Barnes (2001) stated, our 'culture of care' and our 'culture of disability' needs to be reviewed (p.25), especially today when care, like health in Ireland, is becoming a major business.[204] McCluskey (2004) noted that "care agencies [in Australia] are big businesses working more for profit often not of advantage to the family involved" (p.75). Other models of paid care include those carers organised in worker co-operatives or as consumer co-operatives in many parts of the United States and in Scandinavia. Changing family formats and working patterns in Ireland also affects community/home care, while a rights-based culture within various minority groups, seek equality and a rights-based legislation for all issues, for all people living here.

Until lately, "independence [had] almost become synonymous with improved quality of life" (McCluskey, 2004, p.85), yet the importance of and the need to enable greater interdependence and loving moments emerged for me through this study. As Shakespeare and Watson (2001) stated, "aspiring to independence reinforces rather than resolves a historic problem" (p. 560).[205] Independent Living, for example, could and often does mean 'lone living', removed and on the margins

[204] Private companies such as Meret, Touchstone and Vista have invested in for-profit primary health care projects in Ireland, and the numbers of investors in Nursing Homes has also increased.
[205] A focus on independence means that disabled people were/are expected to be or become 'independent' from an individualized liberal male-dominated perspective of life. Any sense of solidarity, shared caring or interdependence was missing. With this overemphasis on sameness, disabled persons then not be allowed to be different, they should be strong and independent.

of life in a community. While this may actually suit some people with ABI, this does not appeal, and indeed, is not possible for many disabled persons. Another unintended consequence of independent living means that attention must be paid also to the needs of a "new class of domestic servants" (Shakespeare, 2000, as cited in Thomas, 2007, p.102). These are the poorly paid disempowered personal assistants or paid carers who are now employed "to liberate disabled people through Independent Living" (ibid, p.102). Empowering the lives and work practices of paid and informal carers is important as noted above. But with increasing individualism and a deep narcissism (Gardiner, 1998, p.129) in society, it is very important that inter-dependence and family-centred practice remains on and is enabled further through the disability/rehabilitation agenda. While personal functional independence is important, the broader framework of interdependence aims for, demands or allows for a more holistic and better 'quality of life'.

Quality of life, that much-used and contested concept, was also directly and indirectly always part of this study. This included considering some of those small, important, but hard to access options in life, such as choice, fun and time for (some) nagging or complaining. Aspects of quality of life include doing, interdependence, participation and community-life (Ackerly, 2000).[206] (See also Kuhling and Keohane, 2007). Such concepts are real-world issues for the participants here and for Irish people with ABI in general. Quality of life can be operationalised as having a reason to get out of bed in the morning, and is therefore linked with the concept of social adjustment used in disability studies weaving the concept of life events with a disability career. This would facilitate "an understanding of the wide variety of personal responses to [acquired] spinal injury" (Oliver, 1996, p.138). Three major features or factors are required for this adjustment: meaning, life history and material dimensions, all of which were involved in this study. These are also important issues for occupational therapists and other disciplines including political theorists in their work or research. In occupational therapy, the terms used to describe quality of life, are 'fulfilling

[206] Ackerly's work is based on Nussbaum's Capabilities List'.

potential', 'gaining occupational engagement' or 'balance', finding and holding some 'meaning in life', wellness, well-being and even health. These concepts are also linked to the concept of 'occupational adaptation', one of the primary assumptions in occupational therapy where service-users and their occupational therapist aim to "maximise their internal adaptation process" (Hagedorn, 2001, p.146). Numerous standardised measures are now available to measure quality of life, but the subjective meaning is expected to be paramount (See Bowling, 2005). Although this was not a quality of life study, I would claim that overall, most of the disabled participants in this study appear to have reached a form of good enough contentedness with most domains of their lives today. At least four of the six people are enjoying life in many ways today, but this is only after much suffering and hardship in their lives. But as quality of life is a broad changing continuum, their present is not always good enough for these participants.

Time and Othering

Time emerged in this study as another important support, but also a barrier or a need for everyday living. While chronicity or time post-injury impacts on the results of all ABI research, time was also a major factor in co-constructing the knowledge gained here. Slow research methods enabled me to gain deeper insights into the participants' lives, and why things are the way they are. The divide between our fast world and the slow world, or pace of some people with ABI, showed Time emerging again as a creator of 'othering', just as Fabian (1983) stated two and a half decades ago. The role of or need for time and more time within all aspects of the social organisation of rehabilitation programmes also emerged as very important. But dominant rehabilitation models, based on 'linear male time' (C. Hughes, 2002, p.176), block aspects of the framework, discourse and practices required for healing and recovery. In addition, 'market profits', value for money, accountability and managerialism are demanding quicker throughput in rehabilitation centres. Slow rehabilitation seems to be considered only when all other options fail, but people with serious ABI do not want more pressures added to their lives.

The transdisciplinary study of Time, using 'time use' studies, is now becoming very popular with occupational therapists today, yet according to Fabian (1983) these studies could be involved in developing an 'other'. (See also Juster, 1985). Time-use studies are perhaps one of the many new forms of reductionism today, although occupational therapists generally seek a more holistic view of being and becoming. "The linear model of time is central to the organization of paid work" (Hughes, 2002, p.182) where time has to be competitive, hierarchical and bureaucratic. Fabian cautioned in 1983 about the use of studies on how others use time, because "their behaviours can be tricked into servicing our goals" (1983, p. 51). Although Fabian was speaking about, and to, anthropologists, the ethical issues involved are still relevant today for all researchers. Time and tempo are now part of health, well-being and business professional discourse with health workers, self-help gurus, tourist operators, the slow food movement, and the slow movement asking people in the rich countries to slow down. Difficulties with living in this age of speed, greed and rage in our fast world are often deemed to be improved by living the slow life. Honore's book, *In Praise of SLOW* (2004), documents many benefits of slowness, including slow (enjoyable) learning, slow eating, slow cities, slow sex and raising an unhurried child. The SLOW movement claims that "the great benefit of slowing down is reclaiming the time and tranquility to make meaningful connections-with people, with culture, with work, with nature, with our own bodies and minds" (ibid, p.277).

Thus, all of the above findings link in with Young and Fraser's summary schema of oppression which includes cultural imperialism, marginalisation, powerlessness, exploitation and violence (See Thomas, 2007, pp. 74-75). These are now discussed very briefly. For example, a form of cultural imperialism is created when people with ABI are generally assumed to be a homogenous group. Yet, even with the small number of participants in this study, numerous differences exist. In addition, within the generic society, and even within the disability movement, the dominant ABI discourse often marks people with ABI as inferior. This population are often marginalised and/or represented as always needing very special care, while their

agency and citizenship capabilities' issues are often reduced or ignored. This may only increase their dependency. Yet many of the needs expressed by the participants range from simple common batteries for Sinead for her Dictaphone, and basic information on ABI (John and Brid) to transport (Joe, Elizabeth and Clare), or more complex, individualised home-based occupational therapy (Sinead in the past, and Clare at present). People with ABI often experience powerlessness, especially in formal dialogue or interventions. Their cognitive deficits, based often on minor speech or memory deficits may be essentialised, and thus impacting on decision-making expected or required in fast person-centred planning meetings or in therapeutic interventions. Time is often not available or allowed to enable shared decision-making in the therapeutic setting or even in the local shops as Clare and Annie experienced. In addition, little support is provided for peer support or collective advocacy groups although four out of five of these participants also wanted to meet others with ABI, people like themselves.

Issues of exploitation were also implicit or explicit at different times throughout this study when some service-providers appeared to 'hold' on, perhaps more than is required, to people with ABI post neuro-rehabilitation. This may be linked with the need for high numbers of service-users required by service-providers in order to maintain funding and/or gain increased funding from public sources. With increasing focus on efficiency and/or value for money, high numbers are more important today. Thus one could ask if people with ABI are allowed to move into social citizenship work without always being assessed within a clinical discourse. Finally, fuelled perhaps more by fear and ignorance, many people in society seem to violate the rights and choice of people with ABI. Thus, people with ABI can experience certain forms of violence. For example, capacity issues linked with their decision-making in one particular area is often over-generalised to cover all areas of life. For one simple example from this study, Sinead may indeed have limited capacities in order to deal with her overall financial situation, but she does know how she would like to enjoy her Saturday nights. It is only in recent times that she is given such choice.

Following this overview of the findings in my research, I conclude this thesis by focusing on the implications of this study and some generic recommendations.

8.2. STUDY IMPLICATIONS

Not all studies are of equal value. Chouliarake and Fairclough (1999) claim that studies should seek "epistemic gains" where what counts is power to explain more about the social issue on hand and to contribute to meeting needs (p. 35). Using a critical perspective in research demands that "unwelcome truths" are stated, and that issues which challenge powerful professionals, including myself, are discussed. While critical realism claims that knowledge has an emancipatory objective, the limitations of 'voice' must always be remembered. As Craib noted when talking about 'better understanding', "it sometimes seems that if we could just understand each other better, then everything would be all right" (as quoted in Porter, 1998, p.152). Firstly, there is no one ABI voice, and secondly, life does not change because all people are given, take, or are enabled to develop their 'voice', even though this is very important. The continuing 'waves' or demands within the various feminist groups and within disability studies and groups illustrate ongoing struggles. Critical realism claims that abstract concepts should not be confused with empirical categories (Danemark et al, 1997, p.122) and as this was not a needs-based study, I therefore first discuss, briefly, significant concepts that have emerged from this study. Finally, recommendations are then made noting that there are numerous dualisms and/or paradoxes involved in theorising about and managing disability and ABI in society today.

The broad implications of this particular study include the need to challenge many assumptions and attitudes involved in the ABI sector or 'industry', in particular, and in society, in general. For example, the call to use 'self-sameness' and/or to see people with ABI as political advocates or as volunteers challenges the dominant discourse today. This study seeks only non-oppressive rehabilitation practice working towards '*self-sameness*', the removal of environmental structural

barriers, and social living allowing for difference, sameness and status for people with ABI in Ireland. In the text, *Disability and Psychology*, Lawthorn and Goodley (2006) call on psychologists to rethink impairment, promote socially valued understandings of disabled identities, assume an activist vision of person, critique their therapeutic assumptions, while seeking more radical theories (pp.187-206). These points could be said to summarise the implications of this study. While occupational therapists are working on some of these issues, I share the above call, but claim that a deeper attitude change may be required first by those involved in neuro-rehabilitation acute centres. For example, acute care staff may have to realise that more funding and research beyond scientific studies is also required to enable long-term community-based living with ABI. This step is required to enable the development and the empowerment of the self with ABI in the long-term and to advocate for a narrative self of persons with ABI. That is why one of my themes in this thesis is beyond assumptions embedded in ABI rehabilitation.

Disability can be identity constituting as noted above and in Edwards (2005). The starting enabling points are neuro-rehabilitation, with respect and dignity for all involved.[207] But these practices and concepts are not sufficient as noted above. Numerous other supports and resources are required in order to enable life and living, otherwise we are leaving people in their suffering and oppression. Sharing resources, time and funding amongst all requires not just abstract concepts such as justice and solidarity, but also for the community to "sustain a dialogue between the haves and have-nots, the included and excluded" (Heginbotham, 1999, p. 61). But greater recognition, respect, participation in decision-making, and status are required in order to participate in many aspects of local social-community living.

This study thus implicates the concepts of justice, status and citizenship in our society which underpin other themes of this study, identity and social becoming with ABI and the need for greater opportunities and fewer barriers for participation in local community. In turn, all of these personal, social, inter-subjective, micro

[207] See Chamberlayne and King, 2000; Kittay, 1999; 2002. Nussbaum, 2006.

and macro issues are important in order to finally enjoy living the slow life as a citizen with ABI in a fast world, the fourth theme of this thesis.

Justice and Status

The social practices informing and/or creating the material issues discussed in this thesis are informed largely by a justice of distribution and a justice of recognition. Past debates have often stressed either the need for greater rights, fairness, with more equal distribution of material resources and goods and sameness. The other side stresses identity, recognition, and the need for a politics of difference based on celebrating difference within cultural politics. Here disabled people must "reject a notion of sameness" (Shakespeare and Watson, 2001, p.559). Now many political and social theorists claim that both a 'justice of distribution' and a 'justice of recognition' are required in order to manage difference in society and seek social justice (Lash and Fetherstone, 2002). Both sides generally stress their particular focus. Debates and conflicts continue about rights and ethics, as against fairness and the good life, and such tensions or debates often include the reification of culture[208] and/or the essentialization of the people in question (Fraser, 2002).

According to Fraser (2002), there is too much emphasis placed on psychology, the psychic structure and/or self-esteem in issues dealing with recognition, especially Honneth's much used model of recognition (See section 4, Chapter 2). Fraser rejects the valorization of one particular individual or group identity (p.25) that may be required to gain recognition, yet the politics of difference and rights needs to be managed in some framework with fairness and a politics of equality. To manage difference as a basis of social policy, and to manage difference and sameness within social policy, Fraser developed a status model of justice. This

[208] It is often mistakenly assumed that culture is a fixed social structure, a system, something that can be managed, measured and changed easily. But rather than reifying culture, the concept of culture is best seen as an unyielding ambiguous concept and/or one form of social relations in various communities enabling structure and/or praxis (See Bauman, 1999).

model of justice seeks to go beyond identity and recognition, yet accommodates the continuing need for egalitarian redistribution or equality.

Fraser uses "a parity of participation" (2002, p. 39), where people are on a par with others, including the moral requirement that "members of a society be ensured the possibility of parity" (Fraser, 2002, p. 40). Parity follows therefore when the distribution of material resources ensures participants' independence and voice (objective condition), along with the intersubjective condition, when people are ensured that equal opportunity is available for achieving social esteem. This 'parity of participation' seems to me, however, to be similar to the 'equalisation of opportunity' debates throughout and immediately following the International Year of Disabled People in 1981. Then, the nuanced differences between the 'equalisation of opportunity' rather than 'equal opportunity' were also hotly contested. Now, nearly three decades since this 'special' year, much discrimination still occurs for certain people with disabilities, while a link between poverty and disability also continues in many cultures. Yet, many improvements have also occurred for certain sub-groups of disabled people in Ireland.

Social justice today is accepted as an overall concept or framework for managing recognition and redistribution issues, within educational, economic, political and personal and community development. Using Young's (1990)[209] argument on 'justice and the politics of difference', occupational therapists Townsend and Wilcock (2004) seek occupational justice for service-users. They claim that this form of justice[210] diverges from social justice in two main ways. These are, one, to accept individual differences as well as group differences in daily living, and second, to have a concern for enablement of diversity, contrasted with the distribution of equal rights and goods in social justice. Social justice also working on both the individual and the social, hold these features. Townsend and Wilcock claim that possession in a distributive justice is distinct from opportunity or enablement in a justice of difference, so they seek only opportunity. Social

[209] See also Young (2002).
[210] Occupational Justice focuses on relationships between occupation, health and quality of life. Wilcock (2006) does include scant reference to the justice of difference in occupational justice.

theorists who specialise in this area, and this thesis above has shown, that both redistribution of resources and goods, and recognition of difference are required (Bauman, 2002; Fraser, 2002). This broad concept of occupational injustice could be useful in certain situations, but in its present conceptualisation, the whole world could be included as Townsend and Wilcock include 'the unemployed', 'the underemployed' and those who feel over-worked. These writers also wonder if occupational justice could be achieved by using a system of 'guaranteed wages' or 'communal sharing' (2004, p.83). This seems an ahistorical and unrealistic expectation. It is important also not to over-stretch the concept of 'occupational injustice'.[211]

Although Honneth's model of recognition used above was not focusing on any one population group, transferring his model to the particular issues for the population with ABI is still useful I believe. The three elements of his theory of recognition, self-confidence, esteem and self-respect can be mapped on to the various stages and goals of recovery post ABI (See also Honneth, 1999). Thus, self-confidence, self-esteem and self-respect links with love, solidarity and ethics gained or expected through the family, civil society and the state respectively. These could be then considered as the pre-requisites and requisites for developing the individual and then collective recognition for improved status of people with ABI in our society. So, perhaps both Fraser and Honneth's models may have their role in enabling policy and in the living out of the 'equalisation of opportunity'. Fraser's model may be more useful then for adapting national macro social policy, while Honneths' work can enable the micro and mezzo, individual and local collective recognition issues.

[211] Deegan and Gowran (2007) for example, discuss the impact of back-pain on occupational performance of some clients as a cause of and within the framework of occupational injustice. While not wishing to negate people's pain, classifying back pain as 'occupational injustice' seems to me to be somewhat unnecessary.

Justice is linked with citizenship, whether taken from a social, cultural or status perspective and works on the second meaning of 'the individual', a person being the same as all other people, the abstract collective individual.

Citizenship and Disability

> "…inclusion does not mean assimilation" (Bates and Butler, 2004, p.129).

Positioning people with impairments as citizens has enabled many service-providers to change how 'impairment' is framed. Such re-framing for citizens with ABI could also impact upon how brain injury rehabilitation and community practices are planned and provided (See also Chapter 7). In the citizenship approach to service provision, disabled people would be "regarded as equal citizens with full rights and responsibilities within economic, political and moral dimensions of citizenship" (Oliver, 2004b, p. 28). But it must be noted that citizenship will not easily or necessarily bring about greater justice for people with ABI as this too is a long and winding road.

The theory of identification links in with state requirements for accessing appropriate supports and services, because there are public benefits in gaining the correct fit between the category of 'qualifying need(s)' and available public resources (Kyllonen, 2004). In order to use available knowledge, expertise and skills in varying ongoing specialisation of services today, there is a need therefore for classifying needs of 'service-users' as well as competencies of service providers. But these classifications are not generally fixed or eternal because as Kyllonen stated, "creating a qualifying need is a discursive strategy" (ibid, p.245). Yet the administrative categories of qualifying needs and the present accompanying bureaucracy involved in managing large numbers make it appear that people are pigeon-holed into unnecessary fixed categories. Disability studies theorists often deplore the use of such categorisation and labels on the body using Foucault's theories about gaze, surveillance and disciplinary structures to support

their claims. But sometimes there are personal benefits to be obtained by having individualised needs met within a 'fixed' category. Two participants in this study missed out on accessing appropriate services because of not being given the diagnosis ABI. People with ABI and their families and friends cannot afford too many slippages of meaning, nor wait for months in the ICU or the neuro-rehabilitation centre for the staff to agree on definitions.

Back in community living during this "time of the wars of recognition" (Bauman, 2002, p.143), and in order to become a right to entitlement, special needs have to be linked with 'difference'. This difference has to be created and shared by a group, using a "zeal for 'boundary erecting" (Bauman, p.142), but this starts or continues the self-perpetuation of difference. And yet, asserting difference is not sufficient. Multiculturalism, for example, focusing mainly on the celebration of difference, even if beautiful and colorful, often did or does little to encourage working together to share a common space and place, one world. This has led to a recent rethink on 'multiculturalism' in social policy in recent years.[212] Sameness needs to be sought and recognized as well in order to "negotiate difference and work across difference without suppressing it" (Chouliarake and Fairclough, 1999, p.134). As the contemporary philosopher Amartya Sen (2006) has stated, two contrasting views are often claimed or juxta-positioned about identity in humanity in general today. These are 'singular affiliation' and 'identity disregard' (ibid, p. 20). For disabled citizens, this can mean that their impairment is either fixated upon, or else is almost totally disregarded. They are thus 'not like all others' or 'like all people'. These terms can be linked also with 'over-protection' or 'under-protection' which was experienced by some of the participants in this study and could be said to be part of the specialized risk-averse ethos of ABI services. Outside the disabled identity, Sen claims that the numerous 'common identities' with the rest of humanity can be acquired, earned or discovered (p. 36 and p.186). Such discovery is not always easy for many disabled people, especially for many people with ABI or those with complex care needs. Ideas for acquiring and

[212] See Lewis, 2007, and the Commission for Racial Equality (UK) website.

discovering ‘identity’ could involve however non-oppressive practice in occupational therapy (Hammell, 1998), in community care services (Bates and Butler, 2004), dialogic narrativity (de Peuter, 2002) and legal and cultural rights (Toolan, 2003). At another level, the various issues in mainstream and focused mobilization as in/with other social movements also needs to be managed (Connolly and Hourigan, 2006).

The new discourse of a universalism of disability (WHO, 2001) also aims to manage the identification problems linked with disability. This may in time, and in theory, allow for improved mainstream technology and improved public access for all, but will access to technology really improve for those with limited financial resources? This discourse is based, as noted above, on the premise that most of us are only temporally able-bodied, although many people born with major body impairments will never even be temporarily able-bodied. (See section 1, Chapter 2 and section 3, Chapter 7). Other unintended consequences of this concept include some serious bio-ethical issues that the disabled movement and allies have considered under the ongoing categorisation and medicalisation of society. If all citizens may now claim this category, those with major and real disruption and suffering in their lives, may lose out on funds, time and services. In this era of medicalisation of wellness and/or the universal diagnosis of holism (Shapiro, 2008, p, 29), what were once social problems are now medical problems. For example, shyness, baldness and sexual dysfunction now have their medical diagnosis (See Moynihan and Cassels, 2005), while migraine as noted in Chapter 1 is mentioned as a brain disorder. The catchment net for depression is enlarging (Casey, 2005), while there is an over-diagnosis in attention deficit disorders (ADD) and attention deficit hyperactive disorder (ADHD) (See Humphreys, 2007;[213] Moynihan and Cassels, 2005). The sharp rise in numbers of students with dyslexia in University College Cork (Disability Support Services report, 2008) also raises this author’s concerns about the process and benefits of clinical labelling.

[213] Humphreys is a consultant clinical psychologist based in Cork City.

The negative impact of transferring clinical reasoning on to many of our social problems (Schriner, 2001, p. 652; Smith, 2003) will impact on the prioritisation of the use of public funding. While citizenship is important in disability studies today, Oliver reminds us that "too much time has been spent discussing [the social model of disablement] rather than attempting to use it to produce social and political change" (Oliver, 2004b, p.30). Few new recommendations are made here, as many required changes are already noted in our health and social care reports, research papers and existing knowledge and legislation that we already have on ABI, disability and social inclusion.

As people with ABI, their families, friends and service-providers are based within the changing health and social care systems in contemporary Ireland, as noted in Chapter 1 above, I note here only some particular new developments in the disability/ABI sector next.

Ireland yesterday, today and tomorrow

As discussed earlier, the market is determining much of the planning of health and social care services in our rapidly changing Ireland. But, can health or social care be treated the same as buying a house or a car or a holiday? Choice, quality and value are important in health and social care, but the "need principle of medical ethics [and the] principle of social solidarity" (Tussing and Wren, 2006, p. 87) are also required when planning public care systems. New developments may improve professional specialisation or practice, accountability and communications, but the logic of social solidarity and personal agency can ebb away. A bureaucratic privatised system works generally towards "the logic of individual interest" (ibid, p. 93), while an over-professionalised life-world can create dependency (See Swain, French and Cameron, 2003). Balancing the benefits of knowledge with expertise with service-users' own agency is an ongoing dilemma. Because of a long history of single-impairment and generic disability community-based organisations already involved in social care in Ireland, the market in the Irish

ABI/disability sector may be slowed or steadied (See Noonan Walsh and Gash, 2004). But having too many partnerships can also bring difficulties. Even with umbrella organisations,[214] members still have to focus on their differences, and stress that their group is so different and needy, in order to access resources.

Even within the above difficulties and transitions mentioned above, numerous incremental changes have occurred in disability services here. Some of these improvements are aimed at disabled people in general, while others focus on people with ABI in particular. The former include the increase in training and employment of specialised and generic service-providers, including greater numbers of occupational therapists, speech therapists, social care workers, and special education resource assistants trained.[215] The actual employment of these additional people with expertise is a separate major problem. Plans for a new National Rehabilitation Hospital are in the active planning phase again with political lobbying continuing for a medical rehabilitation unit in the cities of Cork and Galway (McDonagh, 2008; Roche, 2008).

Other improvements include the implementation of The National Disability Strategy (2004), strengthened by the Citizens [Advocacy] Bill (2007).[216] The implementation of both Acts is being phased in slowly, focusing on particular age groups initially. Disability advocacy supports and services are being improved,[217] with the first cohort of professional Personal Advocates having graduated in 2007.[218]Accessible information for all is now being introduced through the Citizens Information Board.[219] Formal and informal, university and technical education courses, or personal development modules are also more available for

[214] These include the Disability Federation of Ireland and the Neurological Alliance of Ireland.
[215] There are now four schools of occupational therapy in Ireland; one school up to 2003.
[216] Includes the Disability Bill, the promise of additional annual funding and disability planning across six government departments. The Advocacy Bill includes a personal advocacy service (PAS), which is slowly being implemented nationally.
[217] Informed by *The Jigsaw of Advocacy* (Comhairle, 2003), government publication on advocacy.
[218] Course based in Sligo College of Technology.
[219] See www.citizensinformation.ie Many agencies are now involved in education for all.

more disabled people.[220] Community inclusion services and leisure opportunities, especially for people with special learning and with mental health needs, are also undergoing further development. Individualised personal planning within all disability services is becoming the norm, with National Guidelines launched in 2005, already implemented in many services.[221] The National Disability Authority, formed in 1998[222], is responsible for providing expert advice to the Irish Government on disability legislation, policy and practice. This agency with their own library[223] carries out or co-ordinates disability research, and has also published guidelines for ethical research.[224] The Centre for Excellence in Universal Design, opened 16 October, 2007, and part of the Disability Authority, is responsible for improving the design, technology and buildings used in public places, spaces and systems. The Centre for Equality Studies and the Centre for Disability Studies, both based in University College Dublin, along with the Law Department, University College Galway, add other dimensions to the educational, health and sociological perspectives of studying disability in Ireland. The Health Information Quality Authority (HIQA) established in May 2007, will drive improvements in quality, safety and accountability. One of their first National Standards launched is the Quality Standard for Residential Care Settings for Older People (2007).[225] Increased financial resources, although insufficient, are being invested into personal assistance schemes, respite opportunities, and supported living options for adults with learning or physical disabilities, along with improved accommodation supports for mental health service-users. The call for specialists (only or mainly) to work with people with ABI (HSE (South), 2007), may mean that many people with ABI may not actually avail of some of these developments for some time.

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[220] First third level cohort of people with intellectual disabilities have graduated from UCD Dublin.
[221] For example, see NDA (2005a, 2005b, 2005c), the DFI, and Schizophrenia Ireland websites.
[222] The NDA was established to take over the National Rehabilitation Board. See www.nda.ie
[223] At the early stages of this research, library facilities of this agency in Dublin enabled me to access the journal *Brain Injury*, not available then through 'my' university.
[224] *Ethics in Disability Research* (2005). Available on www.nda.ie
[225] Because of negative publicity about particular Nursing Homes in recent years in Ireland, most, Home Managers are seeking to be inspected under this Standard, unlike the English experience. (Personal Communication with Ms. Ryan, HIQA Lead policy-coordinator for this Standard).

Many changes have also occurred within brain injury services and sector since I commenced this study**,** some mentioned above. See also Appendix 3. In 2008, Headway Ireland, Peter Bradley Foundation, Rehab Care, the Neurological Alliance of Ireland, and BRÍ are working often separately and sometimes together, to seek to improve the lives of local people living with ABI here. Peter Bradley Foundation, funded mainly by the Health Service Executive, now manages and provides supported living ABI group homes in twelve locations[226] around Ireland. This is an important step towards inclusive living. The above partnership agencies are paid to offer the services for parts of the pathway of care. There are more multi-disciplinary community-based-ABI teams in Tipperary and the Midlands, for example, being established also through partnership. See also Midland Health Board and BRÍ programme (2002).

As these developments are scant and the ABI population is very varied and dispersed, the above are inadequate for many individuals and/or families living with ABI. It is also the case that most of these services are playing 'catch-up' after years of limited or no investments in the sector with numerous developments occurring simultaneously. Not surprisingly, little money is getting directly into the hands of the families themselves living with ABI. Linked with the Disability Act (2005), it is expected that more home care packages will be offered directly to disabled people and their families. This will allow them to decide how best they want to use public financial support, although this assumes that the persons with ABI are granted the pre-requisite information in accessible format, time, appropriate political awareness raising or community development work first. Are these realistic goals within our present neo-liberal Boston model of efficiency and standardised measurable outcomes?

Are all of the new developments for the better? A separate study would be required to decide if this is the case for all people with ABI. Would Sinead and Joe be allowed the same number of weeks in the National Rehabilitation Hospital

[226] Five assisted living group homes are now in Dublin with seven in other parts of Ireland.

today as they had those years ago?[227] Would Joe be even admitted there, given that he was improving following some time in Cork Hospital?[228] And at local level, would John be allowed months of out-patient therapy at the local University Hospital?[229] As with all changes, there will be intended and unintended consequences of policies, some of which were experienced by Sinead and John, for example, some years ago with the then new policies, as discussed above.

8.3 RECOMMENDATIONS

The SEAwall of institutional discrimination, which includes **S**tructural, **E**nvironmental and **A**ttitudinal issues (Swain, French and Cameron, 2003), is a useful overall framework for my recommendations. The SEAwall includes:

Structural issues	social relations, disempowerment, structural inequalities;
Environmental issues	discourse, professional assessments; and
Attitudinal issues	cognitive, emotional and behavioural assumptions, prejudices and individual practice.

This SEAwall impacts greatly on and for many people with ABI and their families. And as in most areas of health and social care, a 'mosaic of solutions'[230] is required to manage innovations in health and health care. For Christensen, this 'mosaic' includes the need to democratitize access to care, simplify technologies while using existing ones more, and push work down the chain of command against the monopolies of knowledge. For system and life-world levels, change is required at the micro, mezzo and macro levels (Kemmis, 1996, p. 206). Based on

[227] Sinead was in this Centre for almost eighteen months. Three months is now the general length of stay although return visits may be accessed if one battles. (Personal communication with a 'partner' based in Cork city who has had to recently do this battle for his wife).
[228] NRH have to prioritise but the new block model of intervention is unjust if home-base and/or community based rehabilitation services are not first available nationally
[229] For months John attended occupational, physical and speech therapy in Cork University Hospital, two or three times a week. Now such out-patient service is almost non-existent. The impact of the three per cent quota for gaining his job was discussed in Chapter 6 as was the impact of the Home Help service for Sinead.
[230] Christensen, retrieved 22 January, 2008from www.changemakers.net/en/-us/node/20/mosaic

Kemmis's proposed changes required for an improved emancipatory education system, action is required in ABI services, at the individual service level needs, which include social practices, social organisation, along with refocusing on what knowledge, skills and values are imparted. Change is also required on social structures (culture, economy and political structures) and ideology or social media in language (discourses), work and power.

These link in closely with the recommendations for change required for a holistic health model based on critical holism (Tucker, [1996]). Derived from Tuckers tri-partite approach (knowledge systems, the social organisation of ABI services, and the practice of ABI care), a more critical holistic model of care is recommended here for ABI health and social care services, including occupational therapy services. Tuckers' three perspectives are used below as my headings for discussing recommendations following this study without repeating specific recommendations for improved individualised ABI services. Specific recommendations for individualised care or uni/multi-disciplinary work are well documented elsewhere, within the reports on needs assessments, service-agency reviews and/or uni/multi disciplinary professional guidelines, as noted earlier.

Knowledge

Dimensions for change within knowledge systems starts from research methodologies and the way we understand or explain ABI. In generating knowledge, greater inclusion of people with ABI and/or their families is required even in agenda setting for research planning, especially now that substantial funds are available for research. Theorising with social explanations, patterns or trends, not pure cause and effect are required for social health and social care policies, with a need to go beyond researching based on methodological individualism.[231] Critical-intersubjectivity about the process of inquiry as well as the outcome of the research is important also in all knowledge claims. Objectivity, when required at

[231]Methodological individualism discussed above in section 1, Chapter 3, focuses mainly on individual (professional or clients) experiences excluding social forces even when researching social phenomena.

times, does not mean pure 'truth', but rather a collective means of fair-minded social criticism with accountability, going beyond judgemental relativism claiming that all knowledge is equal (Fay, 1996; Layder, 1998).

The need for foundational knowledge at specific times, especially in the early days or months post brain injury, is important and accepted here. There is already much research on every aspect of neuro-rehabilitation to inform evidence-based practice. But much of this evidence post acute neuro-rehabilitation stage is still framed within the dominant clinical discourse and often can be contested. Evidence-Based Practice, while offering many benefits, almost reifies Class I evidence, and works mainly on a narrow agenda states Liz Trinder (2000), in her book *Evidence-Based Practice. A Critical Appraisal*. Yet such practice is presented often as dogma and having few if any limitations**.** While this approach may generally seek to provide 'sound current evidence' to try and narrow a theory-practice gap, it is assumed that all risk can be controlled and assessed and that only good information will emerge in our overload of knowledge today. It is also assumed that all of the difficulties of 'local' daily practice can be addressed by evidence from elsewhere, without the space allowed for new ideas, in those actual moments in question. Many of the issues discussed in this thesis are not suitable to the randomised control trial.

While much is written about individualised personal planning in rehabilitation in theory and sometimes in our practices, standardised and very routine rehabilitation programmes still appear to be the mean. The use of flow, chaos and artistry in our practice, while often included as theoretical concepts in certain texts, is seldom allowed in professionalized assessments and/or testing, often because of the search for best practice. Linking professional craft knowledge with our knowledge base is ongoing and a service-users' 'voice' is slowly becoming more acceptable in evidence-based-practice/research. Yet the gold standard remains, and is offered only to, the predictive standardised test(s) and the control trial. While acknowledging the need for quality research, less time and money could be focused on trying to predict and/or control many aspects of life that are not

predictable. As Beck (1994) stated, coping with dichotomies, uncertainty, risk and "side-effects" are part of our society today, while the use of differential power and the ongoing circulation of social knowledge allows no stability (Giddens, 1990).

Two decades ago, Krefting (1987) asked also that occupational therapists reconceptualise our production of standardised knowledge, which is used in our assessment and labelling processes. This is still very relevant today as then, in order to challenge people's underlying assumptions of homogeneity amongst people with ABI. Accepting chaos as part of life, in learning practices and our research methodologies and rejecting normative values on the impact of ABI on a person's life could be a useful start in our knowledge production about community living with ABI. Still, order and linear, fixed staged expectations, 'as if' systems, are dominant in much of our occupational therapy practice literature. Complexity and non-linearity issues are discussed at times, but are not accepted as serious for evidence-based-practice even in the community, within clinical discourse (See also Paley, Gail and Duncan, 2006). Searching for one ABI rehabilitation model (Wilson, 2004a), or one definition of participation (Desrosiers, 2005; Madans, 2004) could be of limited use to people living with ABI, if the meta-narrative in society is fast independent everyday living.

The disability movement and disability literature have much to offer the knowledge bases of ABI service providers. From my experience, it seems that if occupational therapists are working in the community, or enabling choice or independence for living in X, or working in an resource centre, they are assumed to be using the 'social model of disability'. Townsend and Whiteford (2005) and Townsend and Wilcock (2004), the main theorists working on occupational justice, claim to be using the social model of disability, but it often seems a simplistic version of this model. Real engagement with the social model would actually require a deeper critical inquiry of many of our own assessments and work practices. (See below, see also Hammel 2004a; 2004b; 2007a; Scriven and Atwall, 2004). We can learn much from Disability Studies, without aiming to

appropriate or plunder them. Some earlier theorizing from disability studies is now used in occupational therapy literature without regard to founders of this knowledge. This has led disability studies' writers such as Linton (1998) to state, "the health and occupational therapy program' appropriation of Disability Studies compromises the integrity of a field designed to explicate disability as a social, political and cultural phenomenon" (p.133).

The randomised controlled trial remains the (implicit) gold standard in occupational therapy because professionalisation interacts with power and bias in the sociology of knowledge production, and in the funding of services. Thus, my simple, yet practical ideas, to slow down for example, may not be attended to. Perhaps, the time has come to separate 'social' occupational therapy from 'clinical' occupational therapy, as has occurred between clinical, educational or organisational psychology. For some years now I have considered that this separation and/or specialisation within the curriculum would avoid transferring clinical reasoning into the social domains of living. Such a major change is recommended, however, only if our discourse and practices are non-oppressive as we work with other team workers in and with the community.

Social organisation of ABI services

> …unless we think imaginatively to create social and cultural structures that support proper care [lofty] suggestions remain mere ideals (Martone, 2006, p. 3).

Engels, a professor of psychiatry, is considered to be the main creator of the bio-psychosocial model which is now well embedded in medical and health care. (See also WHO-ICFDH, 2001). Like Meyers and many other medical authority figures in those early 1900s, Engels wanted to change the system in order to enable treating "the patient as a person", (Shorter, 2005, p. 6), a very popular 'new' concept then. Engels also reviewed the importance not only of personal relations,

but of all related systems. Then, as now[232], it was acknowledged that the pathway of health and social care systems can "make people sick as well as better" (Shorter, p. 6). Engels sought holistic interventions that would address "the personal, interpersonal and family levels as well as the biological systems" (Tucker, [1996], p.24). Like Engels, Tucker also critiques the limitations and roles of health care systems and the importance of linkages with both the social and personal determinants of health. These are well discussed today, yet status and funding for community issues appear less important than that required for institutional work.

The precise focus of the future disability services in the community here will not be known for sometime, given the amount of strategic change now occurring. (See Department of Health (2001), *Primary Care Strategy*; The Health Act, 2001). How specialist teams will interact with generic teams is not known yet. But the present distribution of financial resources for ABI services almost ensures that little will change in the community, especially for 'quality of life' issues. The funding of community services, advocacy and self-help groups today is limited compared to the funding of the individual focused vocational or paramedical services, even if these latter services are themselves under-resourced.

The HSE staff usually state that precise numbers and precise needs ought to be documented in order to plan and fund new services.[233] But, must precise numbers be known before a service is offered? Many numbers are already available from Hospital In-Patient Enquiry Scheme data, commonly called HIPE[234], and through various partnership agencies. There are also opportunities to extrapolate from English or other international data, as noted above. And as stated in Chapter 1, many completed Assessments of need documents are already available and sufficient to establish a national programme of community or home-based ABI rehabilitation services. An integrated continuum and pathways of care is requested

[232] National crises include MRSA, hygiene issues, and disjointed or miscommunication systems.
[233] For example, as occurred at the ABI PBF-BRÍ Public Conference, Cork, August, 2007.
[234] See Economic and Social Research Institute (ESRI) website on www.esri.ie

by Headway Ireland, Peter Bradley Foundation, BRÍ and all other agencies involved in brain injury and disability services In Ireland. A model for pathways of care following the Slinky Model[235] (as noted in Chapter 2) is slowly being developed here between these agencies and the national public service providers.

Following their national Irish Audit of Stroke Care, stroke-rehabilitation units are sought in each hospital (Irish Heart Foundation, 2008).[236] Neurologists and other ABI service-providers are seeking more rehabilitation facilities and ABI teams, generally discussed apart from a stroke unit. Given our small population, is it feasible to have numerous small stroke units as well as brain injury rehabilitation units throughout Ireland? As with cancer care, is there not a critical mass required? Must all people with traumatic brain injury be separated from those with a stroke, for example, and must they attend a separate special community service?

A review of the numbers on the team may also be required, as the team membership is increasing. This not only impacts on financial requirements, but also on the time, energy and emotions of the service-user and family, as they try and deal with numerous people. It is not possible for the one individual to have a rapport with all persons on the team. The key worker or generic worker could help alleviate this, at particular times, yet many therapists do not want to be generic workers, and fear loss of their role. Many service-users seek a more holistic service rather than a fragmented service linked with part x of their body, while there are additional difficulties emerging when three, six or nine people are involved with their body.

With all of the existing and planned developments now in Ireland, it is important that sharing of knowledge and resources occur even though uni-disciplinary and inter/intra-team politics, power and ownership could block this sharing. Because as Chouliaraki and Fairclough (1999) stated, our "networks of practice are held in

[235] See the ongoing Quality Requirements of *The National Service Framework for Long-Term Conditions*, Department of Health UK on www.dh.gov.uk/longtermnsf
[236] See Irish National Audit of Stroke Care 2008 on www.irishheart.ie; www.nai.ie

place by social relations of power" (p. 24). Through the stories on the experiences of the twelve participants in this study and through my own networks, I am aware of blinkered communication or planning systems that do little to improve the social organisation of our health services.

For example, for one year, I was involved voluntarily[237] with the HSE (South) and partnership services in preparing a Joint Regional Proposal for ABI services. In February 2007 and on target, as requested, this proposal was presented to the local health executive disability planning group. This very detailed proposal was informed by evidence-based research, local legislation, policy documents, etc., and negotiated between all local relevant ABI/disability policy-makers and service–providers. (Two community-based ABI teams were proposed, initially, to provide improved individualised rehabilitation outcomes for clients). Yet, in August 2007, at a major local ABI conference, the first public awareness ABI conference in Cork city, this proposal was almost sidelined by the official health spokesperson. A few brief sentences were mentioned about the possibility of two teams, but the focus was on people with ABI and their families to register on the Physical and Sensory Database in order to plan ABI services. Yet, ten people had met once a month for one year, with much research ongoing between meetings. Two short-term researchers also added much background data to this proposal. And now in early 2008, a different partnership group, Rehab Care, not involved in the above planning group, were named in the media as accessing funds to build regional residential ABI facilities. Even if small specialised residential services are required, it is unlikely that funding will be available for both expansion of both residential and community-based rehabilitation services, this or next year.

During this planning or research process above, BRÍ Cork sought an information officer and a community worker, to improve access to knowledge and to consider

[237] The HSE (South) ABI Planning Project Group met monthly for fifteen months. Representatives of all major 'stakeholders' in local ABI services were included. Two full-time researchers were employed for some of this period. I was asked to do this formal research work, but because of this PhD study I was unavailable, plus commencing research work for a post in UCC.

collective issues such as group advocacy and improved communication structures. It was also requested that the staff centre could incorporate a local drop-in resource centre, with the staff working flexi-time to include night-time and week-end access, and to move beyond the 9 am - 5 pm Monday to Friday organisation of services at present. An accessible and appropriate information centre was requested not only for present Irish citizens, but also to include relevant and accessible information for new immigrants to Ireland. As with the other members of that ABI Joint Project Group, I await news of both of these two proposals.

Improved communication systems and processes in our future service planning is also required to manage and reduce power struggles among and between service groups and health executives. At an organisational level, ownership issues of both workers and of clients can complicate the situation and causing major delays in certain programmes getting established. For people with ABI, gaining collective recognition from government sources can and will take time, as they/their agencies must work with and through the other disability groups involved and/or through the layers of bureaucracy and/or tradition. This process impacts also on the planners as they too seek to cope with all the networks and groups on ground level. As Skeggs (2004) stated, our everyday lived social relations "will always involve conflict, negotiation and tension" (p.11), even if the management and documentation of these groups may improve.

How individual people ageing with ABI will manage or be managed between all the various new Health Services Executive directorates, partnerships and teams could also be very problematic. Unless major adaptations are made to our communication structures both within and between government departments and specialized and generic partnership groups, the metaphor 'death by telephone'[238] will continue to be used. While virtuous goals about improved communications, discourse and material issues may be required and feasible, Martone (2006)

[238] This metaphor was used by one parent at a BRÍ meeting to represent all the numerous telephone calls that they had to make or wait for in order to access information or services.

reminds us about an important starting point. We must consider that for many, "especially the poor, even entering the [ABI] system is a challenge" (p. 3). At the moment, Irish people unlike uninsured American citizens, can access good Emergency Care and will access rehabilitation treatment. But with our centralised bureaucratic health system and with a growing emphasis on accountability, profits-making and risk-averse work, it is hard to envisage that an individualised integrated pathway of care will be available in the near future.

The Practice of Rehabilitation and/or Social Care

Ideas for better practice for ABI services at the various stages of rehabilitation are available from many countries, especially from Northern Ireland and United Kingdom, our nearest neighbours holding a somewhat similar public health care system. For example, Pickard et al., (2004), with their Slinky Model of ABI services as illustrated in Chapter 3, use a "twelve point classification system of rehabilitation services or resources using numerical codes–which proved less contentious than titles" (p. 388). Before transferring ideas for better practice here from American, Australian and Canadian programmes, it is important to consider our different health or social care systems, our public narrative on social inclusion, and on the family. In general, the Irish are still considered to have a sense of place, family and craic (fun), with a sense of community still present in many areas. It is important to hold on to these in all our rehabilitation and social care and social inclusion projects. Enabling the families to care and to then enjoy life as much as possible is urgent. Families should remain part, an important part, of the overall planning picture, and not based on the needs or working hours of professionals.

The block system of rehabilitation is being introduced into the National Rehabilitation Hospital[239] to improve efficiency and value for money, yet community-based and/or home-based services are not available. This block system is further evidence of the Boston business model encroaching upon the Irish health

[239] This strategy was named by a nurse from this hospital at the Cork ABI conference August 2007.

services. Many occupational therapists use a block model introduced in America often because of the process and history of re-imbursement plans by American insurance corporations, rather than care needs (See Crepeau, Cohn and Schell, 2003). Additional occupational therapists are recommended here, for enabling individualised home-and/or community-based everyday living, meaningful routines and variety, incorporating perhaps cognitive, self-care, leisure or work activities or issues. But the type of support, expertise, and/or practice or discourse they use and offer to individuals and families with ABI will decide if they are a major part of the solution as expected. The working hours, language issues and their power as agents of the state, in determining living places or work locations for example, may also need to be reviewed. Many participants and other BRÍ members dislike therapists or nurses who do not follow through on promises' made, who continuously refer 'clients' onto other services, who use patronizing words, or question carers about their own lives.

Disability awareness training may be required for many on our rehabilitation teams in order to push boundaries, partnerships and critical thinking. Even though many professionals are experts in their knowledge area, and may work with disabled people, this does not automatically mean that they are aware of critical disability issues. As much of this thesis is working towards a counter ABI discourse, strategies to improve everyday words used are important, although discourse is more than this. Throughout this study, the words remembered from neuro-rehabilitation are those that seem to be used and acted upon for years by the service-users and their family. Therefore, the rehabilitation centre may be the best place to start working for change, even though many other mechanisms are also involved in identity formation. For some time now, the focus of ABI discourse is on the new self, a new identity, rather than trying to rebuild the old life. This is still the key message from most therapists and psychologists and support literature mentioned above. I recommend, however, a focus more on self-sameness. This may challenge families more than professionals, but with improved support services, they could be enabled to care and perhaps love their partner, father or

mother, son or daughter rather than see him/her as a stranger. We need to work more on enabling family and friends to take home "…the same human being', now becoming in new ways - a self that needs new accommodations and new modes of articulation and expression" (Jennings, 2006, p.36). We, occupational therapists, may need to take more risks in our work beyond trying out certain activities in the home or in some leisure centre. But, rather than risk aversion informing practice, especially with the family, more gradual risk-taking even in thinking is required. Gradual risk-taking may help to prevent the fear of litigation dictating ABI practice (McCluskey, 2004).

McCormack (2004) summarises the trends for generic disability services in Ireland, which match closely the aspirations of our Health Services Executive today. The principles underpinning these trends includes: the service should be delivered and managed locally, this service should be for individuals and families with different needs and covering all ages, and be delivered by people not by places. I would recommend these also, even though action on the first principle, local management, is still proving difficult within our reformed health care system. More change in our knowledge systems about ABI, with improved social organisation and everyday practice within ABI services, could enable a stronger narrative self of future people with ABI in Ireland. A counter discourse using self-sameness within a slow framework could also facilitate more opportunities for people with ABI in Ireland to live a content or enjoyable slow life.

8.4 FUTURE RESEARCH

The use of critical realism in this study enabled the search for some of the numerous mechanisms within the various different strata and domains of our world that impact on people living with ABI. Relativism was reduced, while acknowledging against postmodernism, that some foundationalist meanings are available and required at particular times. And against the post-structuralists,

structures need not be over-deterministic. So, like Thomas (2007), I, too, would "welcome the development of critical realist thinking in disability studies [and in occupational therapy] with all topics of interest" (p.153). More qualitative research is also required in this area, acknowledging that holism can be as limiting as reductionism. There is a need to work on the part(s) of any phenomenon while also acknowledging the whole. Evaluations from service-users and their families are required about existing micro issues in our services, assessments, practices, forms and notices. This could include reviewing timetabling, communications, and accessible vocabulary on all texts. Disability proofing and process-mapping all aspects of our ABI rehabilitation services could make at least what we do do, and have, better. Beyond the formal neuro-rehabilitation stage, there remains a lacuna of knowledge, especially in Ireland, about community living from the perspectives of adults with ABI. But as Moore, Beazley and Maelzer (1998) stated, "all will not simply be well just because disabled people and non-disabled people conduct research together; integrity and credibility have to be carefully established in relation to both academic rigour and political commitments" (p.94).

Clinical researchers are, however, aiming to replicate randomised control trials in this domain because professionalisation, publication in elite journals and team membership are all interlinked with funding at a higher level. Many unmet needs have to be linked to a clinical discourse in order to have a (better) chance of funding. Yet, as most community workers know, and as Malec (2004a) stated, this RCT trial is not suitable for inquiries for community inclusion. Improved recognition of qualitative research in general and of narratives of people with ABI in particular is required within this sector. Once appropriate data generation methods are used, researching with people with brain injury needs to be managed so as not to be over-researched, especially by researchers who prefer the convenient urban sample.

Some specific ideas for research projects are:

A public attitude survey on the attitudes of the Irish public and towards people with ABI could provide a broad baseline as to how best to establish national and/or local public information ABI awareness campaigns. This could also include seeking some basic knowledge about the brain or about ABI from the public. As noted in Chapter 1, such a study in England identified that the public thought ABI was the same as having an intellectual or learning disability, and that people were unaware of long-term issues involved in ABI, even possible recovery.

A study on the use of different models of care within various rehabilitation units, including stroke units, is also recommended. Although the impact of a stroke may have certain differences for the individual compared to living with a traumatic brain injury, there are many issues in common. And now as more stroke units are to be established in Ireland, it is important to know the criteria for admission to these proposed stroke units and how these units are to liaise with ongoing ABI services. Other questions or puzzles are, what age-group are to be included or excluded, what in-patient and out-patient services are shared, how the multi-disciplinary CVA-ABI teamwork works, and what are the particular gender issues, if any, within such teams.

As the internet is a suitable tool for information for many people with ABI, another research question is, what is the use of the internet by people with ABI, and what are the long-term benefits, if any, of this resource? With improved information provision also emerging slowly, it is important to study the use of information packs by service users and/or their families post formal acute rehabilitation. .

A final research topic focuses on the inclusive engagement of people with ABI in local community especially generic social care services. While many local professionals and agencies claim to be working towards inclusion of/for all, and towards improved diversity, it is important to ask, is this happening? Studying the existing broader social services and resources, and identifying supports and

barriers which could be adapted to allow groups be more inclusive, allows for a more inclusive and sustainable programme. This could lead onto identifying the depth of mainstream social or community inclusion of young people with severe ABI, and/or of older people with ABI in a named area?

> The diversity of experience militates against the simplification of complex issues and towards a politics of hope that is both individually empowering and collectively emancipatory
> (French and Swain, 2006, p. 394).

Although many barriers are already broken down within our world of difference today, this thesis aims, like the writers above, to further the "politics of hope" with people with ABI in particular, to be "individually empowering" and "collectively emancipatory". By recognising the reality of interdependence in life, based on the relational self, the dichotomy between disabled people and non-disabled people may be broken down. Yet, the dominant discourse in neuro-rehabilitation focuses on goals of independence, and the idea of atomistic individualism, thus ignoring the reality of a caring solidarity required by all (French and Swain, 2006). The public script on ABI in Ireland needs to be updated and re-drafted in many places, allowing people with ABI to co-script a better more exciting plot for themselves. This could develop further the narrative self of people with ABI, allowing more of their self-sameness to emerge in slow time. While I hope that this thesis may be an important contribution to the Irish story on ABI, it is not as important as the need for more action and fun in community rehabilitation and social practices in Cork and Kerry. I hope for a time and place where people will not have to say, as Annie once said [240] *why bother waking people up, if there's nothing there to help people and their problems* (Annie 3, p. 2). THE END.

[240] At a time when Annie had no access to any ABI support group, although she was playing golf and the piano.

POSTSCRIPT

In the summer of 2003, in response to a call for clinical case-studies from experienced occupational therapists in preparation for the new Department of Occupational Therapy in Cork, I walked into a Professor's room in University College Cork (UCC). We discussed my work experiences in various countries including Ireland, England, Fiji, India and Kenya. I felt that I could co-construct some case-stories as a learning tool for undergraduate students. I also mentioned that I was interested in learning more myself, although not imagining a doctoral study. Yet, on 22 September 2008 just five years later, I walked into another room in UCC with my two research supervisors and two external examiners for my PhD viva to be examined on this thesis which had been submitted three months earlier. That first professor took a risk with me, as did her/my co-supervisors, three people to whom I owe much gratitude.

Much happened in those intervening years in the personal, professional, family, and social domains of my life. I have gained much deeper critical and empathetic understandings about the lives of the participants in this study and the Irish health and social care services, along with the various positioning, negotiations and conflicts that go on between these parties. I have learned much about the construction of knowledge itself, about myself, especially as a thinker, researcher and citizen, and about critical research, writing, and project management skills. Along the way I have had many moments of uncertainty and certainty, along with freedom and pain of being enabled and often blocked by professional and academic boundaries in knowledge production. Much of this was caused by not wanting to position the participants as objects in this study, nor construct them as *others*, yet needing to highlight salient differences in their lives which cause difference and discrimination. Was I creating others just by studying them? Learning more about social theory, and by searching more for the social in their narratives, enabled me to manage the dualisms and paradoxes involved in engaging with the participants as persons, while going public, on collective issues. My political and ethical perspective, which also informed my research design and theoretical framework, helped me to negotiate the personal difficulties between using people's experiences, yet going beyond them in this research process. I hope readers have found my discussion of these issues in the thesis, adequate.

Occupational therapists often write about issues linked with the therapist-researcher boundary. This was not a problem for me, because firstly, I had spent some years outside occupational therapy and did not think of myself as an occupational therapist, and secondly, during the fieldwork years of 2004-2005, this research study was almost, my whole life. Any other involvement outside these twelve people and books, especially research and social theory books, were sadly neglected, as my family can attest to. The researcher role was enabled by my years of experience with disability research and activism, along with enjoying the ordinary and extraordinary of everyday living, including celebration of difference, and sameness.

Being a people person with much experience of fun and suffering in life ensured, however, that I brought certain strengths to this research process, such as empathy, intuition, emotion management, and a sense of solidarity. Holding the ability to make and enjoy small talk about everyday happenings, disability issues and/or politics in Ireland in the past and today also helped enormously in starting this long conversation, as documented in part in this thesis. In addition, I did not deny the suffering of the participants yet I did not dwell on it, nor rush them to ensure that they told me all they know about feeling 'x' or experience or event 'y'. My use of my empathetic feelings is portrayed adequately in this thesis, I believe, even if they are sometimes implicit. They were the basis of deciding how to portray the lived and told stories of the participants and what final story to tell in this thesis. My belief in their tacit knowledge helped in ensuring that I was not creating any further unnecessary dependency. I also ensured that I refrained from any form of assessment, or from seeking to professionalize their lives. Incorporating time for tea or coffee together, as well as creating the opportunity and time or the transport required in order to meet almost all participants away from their home place at least once, also helped to develop our relationship. All of theses strategies, using my tacit personal traits, helped to develop a good working and friendly communication, which continues today with some participants. Other soft factors such as sharing a similar age, a shared sense of Irish identity and knowledge of Irish rural life also enabled deeper trust in our meetings.

However, there were challenges or role-tensions experienced in the academy more than in the fieldwork during this study. As Bloch (2002) has stated, in the academy "the deceiving game" (p.120) is often played out where all must show that they are always in control

and/or that their project or process was simple and easy. I partook in some of this game at times, especially when managing or hiding additional tensions if or when feeling as an outsider, especially when not using the dominant discourse of my professional discipline. Now, we are almost required to push the self more and more in our competitive world. For some, this means exposing all tensions or for others it may mean the need to almost boast about our production and dissemination of research findings. In the past, Bloch (2002) claims that academic writers felt they should not boast about their work. Instead, they had to ventriloquise one's pride (ibid, p.122). I often wonder if we have gone to the other extreme, as qualitative researchers and academics are expected to go public on almost every emotion and task in work, as well as doing research and/or writing constantly, or else perish. The competitive relations within academia are cushioned somewhat today by multi-disciplinary or inter-professional team research or writing, but constant anything diminishes creativity especially of thought. This could also create less time available for research utilisation, working on the issues involved in the need for the research in the first place. This begs the question, is all of life to be a (new) research project, with little time allowed for research application?

While I think it is positive that the feminist movement sought more on the inclusion of the researcher in the research process and/or product, such self-talk has not changed much for many women around the world. The continuing inequalities in our world illustrate the limitations of reflexivity in research, of voice, and some might say, this shows the limitations of much research itself. At the start of the fieldwork for this study, the Iraq war was on the headlines in the newspapers, and sometimes on the participant's television when I entered their homes. This war is still ongoing, and today as I write this postscript, the two United States (US) presidential candidates, Barack Obama and John McCain, are presenting their plans for ending US involvement in this and peaceful or negotiated withdrawal. Just as with my study, limited progress has been made with improving the scope of services for people with ABI in Ireland, since 2003. There are a small number of new or additional brain injury services available, with some improvement in inter-linkages between agencies in delivering neuro-rehabiltiation services and disability services. But little real long-term change has occurred for this population, and now with our current

global banking and socio-economic crisis, many development plans linked with quality of life issues[241] for disabled persons are being left aside.

The lives of the participants on whom much of this thesis is based, have changed little, and not all for the better. Vivienne was recently diagnosed with a very serious illness not linked with her ABI, while Joe has had a serious medical operation. John and Annie are managing to enjoy life and work as much as they can, although everyday ageing issues are confronting them also. Annie cannot play as much golf as before. Little has changed for Clare and Sinead since I finished my fieldwork with them. In our last telephone call together, both are 'making do', feeling they have very limited choice, and little energy for resistance or otherwise. I will always be indebted to these participants who have welcomed me into their homes and lives throughout this research study. I look forward also to continuing on the road with some of the participants to challenge and change some of the negative aspects of the disability-ABI discourse in Ireland. Still, I think often about those lives stood still (almost), as I proceeded with this study.

My future responsibility to the population of people with ABI in Ireland is only commencing in many ways I feel, although personal reciprocity with most of the twelve participants in this study will continue. I will continue work with others on developing some of the theoretical and applied issues named in this thesis to help develop improved inclusive services and a more positive disability-ABI discourse. But all of this needs to be lived out within another important message from this study, the importance of *slow living*.

[241] For example, local media along with public national and regional protest marches in October 2008, highlight the impact of recent reductions in social and health care funding regarding the employment of personal assistants and teaching assistants who work with disabled people. The lack of employment opportunities for graduating occupational therapists and speech and language therapists especially in 2008 also impacts on quality of life for many disabled people and/or their families.

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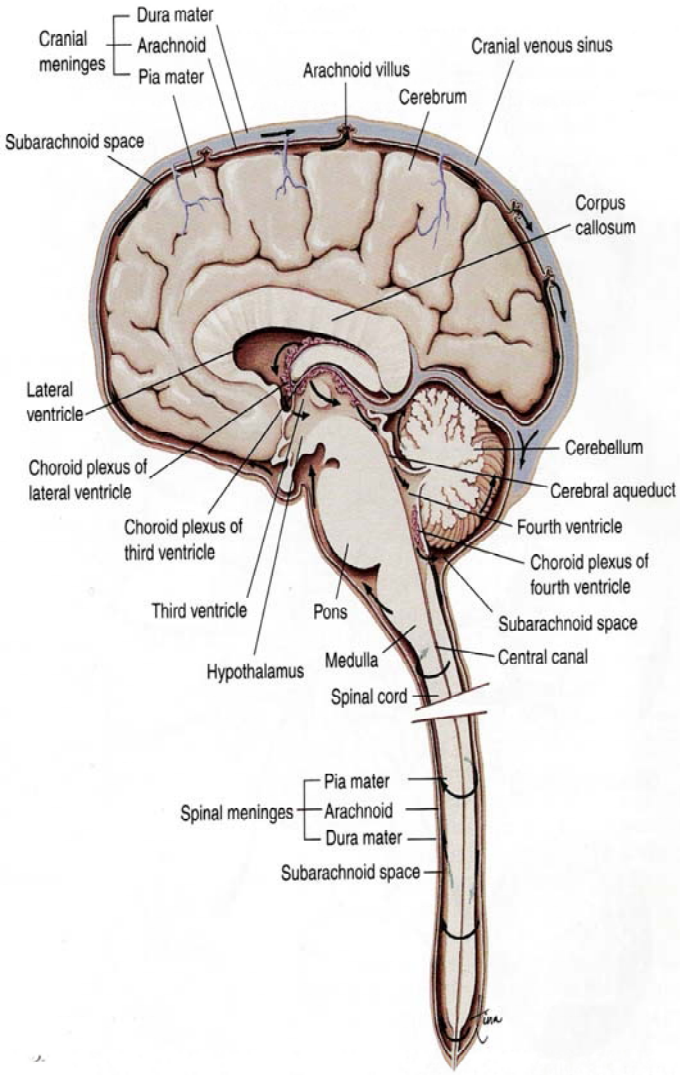
APPENDIX 1 THE PHYSICAL BRAIN



Source: Retrieved 27 June, 2008, from www.webmd.com

The Brain Stem Pons, medulla and cerebellum, links with spinal cord.

The Diencephalon Includes the thalamus, hypothalamus and epithalmus.

The Cerebellum The little brain at back.

The Cerebrum. The largest area of the brain. Cortex membrane covering frontal, parietal, temporal and occipital lobes.

APPENDIX 2 CHRONOLOGY OF DEVELOPMENTS IN ABI / DISABILITY POLICIES, EVENTS OR SERVICES

1993 Headway Ireland starts service provision in Dublin

1996 "Strategy for Equality for Disabled Persons in Ireland"

2000 Peter Bradley Foundation established.

2001 Mental Health Act 2001

2002 Freedom of Information 1997 Act Amended

2003 National Disability Strategy published. Personal Assistance System introduced
BRI established and Peter Bradley Foundation established
Professional Clinical therapy degree courses opened in three universities.

2004 Equal Status Act 2004; BRI Cork established

2005 Health Service Executive replaces the eight Health Boards.
HSE (Southern) establish an ABI Project Group (November).
Disability Bill passed in the Dail. Health and Social Care Professionals Act .
Peter Bradley Foundation established in Southern region.

2006 Cork launch of the Person Centred Planning Guidelines for disability services.
Monthly meetings of HSE (Southern) ABI Project Group re development of future ABI services in region. Plans for two ABI teams in southern region.
1 year public awareness project re ABI Funded by Dept. Justice and Equality
Project included twelve one-day workshops around all regions of Ireland organised by PBF and BRI with local HSE and Headway staff if appropriate.

2007 Centre for Universal Design opened in Dublin: NDA management project.
Disability Bill implemented for 0-5 years old children with a disability.
Quality Framework for mental health services published.
Staff freeze on new appointments in HSE from September.
Public calls for more neurologists, clinical therapists and personal assistants.

2008 Plans for 230 bed NRH hospital (224 million euro) re-lodged with authorities.
Rehab Care propose five regional residential facilities with 300 beds.
Improved programme and cooperation for ABI Awareness week March co-ordinated by Neurological Alliance of Ireland (NAI).
Additional regional ABI community teams established by PBF~HSE.

APPENDIX 3 NOTE ON BRAIN INJURY SERVICE GROUPS

Headway Ireland is one of the main national service organisations for people with ABI in Ireland today and is funded largely by the Health Department and the Trade and Employment Department. Limited family support services and group therapy are offered in Dublin with individualised counselling, occupational, vocational and social services available in a small number of regional centres.

Peter Bradley Foundation, founded with the establishment of one group home in 2000, now provides limited rehabilitation community and/or home-based services and assisted living group home projects throughout parts of Ireland. This agency also manage residential care packages on behalf of the health services.

Rehab Care established in 1949 for people with TB, now provides vocational training, employment, or employment supports for disabled people in many parts of Ireland. In 2008, this agency aim to commence providing residential rehabilitation facilities for people with ABI in five locations around Ireland.

BRI is an advocacy-support group developed from a public meeting in the National Rehabilitation Hospital in 2003. The name BRI, is an Irish word meaning strength and understanding, seek to offer support through advocacy with and for people with ABI. BRI also seek the consumer's voice in service planning and reviews and in improving public awareness. A small BRI support group commenced in Cork in Summer 2004 and in Kerry in 2006.

The Neurological Alliance of Ireland is an umbrella organisation for over twenty voluntary organisations representing people with neurological conditions throughout Ireland (www.nai.ie). This alliance primarily seek an increase in the number of neurologists working in the Irish health care system.

APPENDIX 4 TABLE OF SOME LONGITUDINAL STUDIES WITH PEOPLE WITH ACQUIRED BRAIN INJURY

A summary of particular chosen studies from different countries used to inform this study is presented in Table 1. Although there is much overlap, the studies chosen, highlight different issues that can affect the outcome of living with an ABI.

TABLE : Details on a sample of chronicity studies used to inform this research.

COUNTRY	AUTHOR(S)	DATE	CHRONICITY	FOCUS
Sweden	Erikson et al,	2007	1 month- 1yr	Daily occupations for memory recovery
Global	Abreu	2006	Long-term	Meta-analysis of qualitative studies
USA	Ylsiver and Feeney	2006		Self-Identity
Australia	McCluskey	2004	9.9 years	Risk-taking/ risk management in/and care
Ireland	Heary, Hogan and Smyth	2003	Average 5.5 years	Needs assessments of families with children with ABI
USA	Trombly, Radomske, Trexel and Burnett-Smith	2002	>3 months to <12 months	Self-identified goal-setting
Canada	Grey	2000	Long-term	Slow to recover ~ rehabilitation outcomes review
Canada	McColl et al.,	1998	11.5 years (average)	Community Integration
USA (NY)	Gordon et al.,	2000	8-10 years	Sensitivity of self-reported symptoms
Australia	Fleming et al.,	1999	2-5 years	Voc. Rehab & comm. integration
Finland	Asikainen Koskin	1998 1998	5 years + 10 years	QOL Late Outcomes
Hong Kong	Man	1998	Not stated	Family empowerment
Canada	Heatherington et al.,	1996	5-10 years	Reaction Time
France	Masson et al.,	1996	5 years +	Prevalence of Impairments
England	Eames et al.,	1995	4 years +	Rehabilitation Outcomes
New Zealand	Smith and Godfrey	1995	2 years +	Family Support Programmes
Canada	Krefting	1987	7.4 years (average)	Re-integration into the community

APPENDIX 5 NAMES OF A SAMPLE OF ASSESSMENTS TESTS and/or SCALES

COMBI

The Centre for Outcome Measurement in Brain Injury. Numerous featured scales. First retrieved 12 April, 2005 from http://tbims/combi/list.html

The AMPS (Fisher, 1999).

The Assessment of Motor and Process Skills as used by occupational therapists.

The BICRO (Powell, 1998).

The Brain Injury Community Rehabilitation Outcome Scale**.**

THE BECK DEPRESSION INVENTORY

See Wallace and Bogner (2000).

THE CARE AND NEEDS SCALE (CANS) (Tate, 2004).

This scale is used to measure the amount of supervision and care a person requires, especially people with ABI.

THE COMMUNITY INTEGRATION QUESTIONNAIRE (CIQ)

A twelve item self-report measure on home integration, social integration and productivity.

THE COMMUNITY INTEGRATION MEASURE (McColl et al., 2001).

This CIM is used to measure subjective views about the needs and state of community integration around main concepts of belonging and social participation.

APPENDIX 5 continued

THE FUNCTIONAL INDEPENDENCE MEASURE (FIM)

An eighteen-item tool used to measure everyday daily function linked with care needs.

THE FUNCTIONAL ASSESSMENT MEASURE (FAM)

Twelve items aimed at the particular needs of people with brain injury or stroke, often used in conjunction with The FIM above.

THE MAYO-PORTLAND ADAPTABILITY INVENTORY

The MPAI- 4 is available for people with ABI on-line for free from www.tbims.org/combi/mpai

THE MOHO ASSESSMENTS

A range of assessments used by occupational therapists informed by the *Model of Homan Occupation* devised by Kielhofner and others in the 1980's. There are now at least nineteen assessments linked within this model.

QUALITY OF LIFE MEASUREMENT SCALES

Numerous quality of life scales and measurements issues are discussed in Bowling (2005).

THE PATIENT COMPETENCY RATING SCALE

A thirty item questionnaire to assess lack of awareness of deficits which can be completed by the person with ABI and another measure for a relative.

THE SF-36 Health Survey measure

Used initially to measure costings or cost benefits across health systems, this SF36 is now the most frequently used measure of generic health status across the world (Bowling, 2005, p.63).

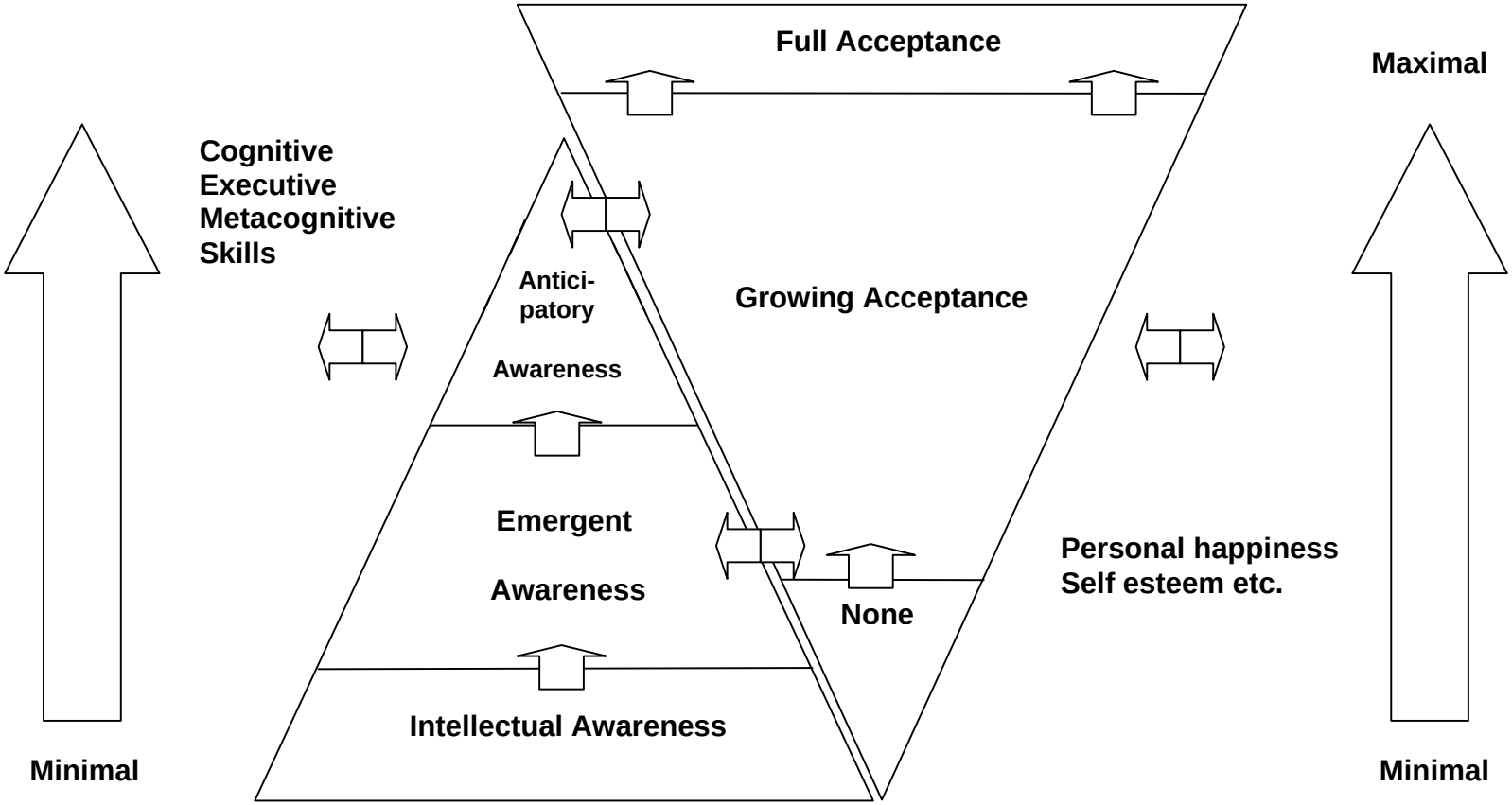
APPENDIX 6 SAMPLE OF ABI REHABILITATION GUIDANCES

(British data referenced as the British health care system is more similar to the Irish health care system).

Uni-Disciplinary Guidances:
Occupational Therapists National Associations Guidance available from the American, British, Canadian Associations of Occupational Therapists.

Multi-disciplinary Guidances:
Cognitive Rehabilitation Services www.cogrehab.com
Mapping Rehabilitation Resources for Head Injury (UK).
National Framework for Long-Term Conditions (NHS- UK).
National Institute for Clinical Excellence (NICE) (UK). www.nice.org.uk
Neurological Association of Ireland (2002). *Standards of care with disabling (progressive and static) neurological conditions in the hospital and community*. Dublin: NAI.
Neurological Association of Ireland (2002) *Standards of care with non-physically disabling neurological (and associated psychiatric) conditions* Dublin: NAI.
Society for Cognitive Rehabilitation www.cognitive-rehab.org.uk
Survey of UK Social Service Final Report (UK) ABI Forum Project Team.
The British Society of Cognitive Rehabilitation (2005). *The Recommendations for Best Practice in Cognitive Rehabilitation Therapy*.
The British Psychological Society Clinical Neuro-psychology and Rehabilitation Service for adults with acquired Brain Injury.
The British Psychological Society Clinical Neuro-psychology and Rehabilitation Service for children with acquired Brain Injury.

APPENDIX 7 AWARENESS AND ADJUSTMENT MODEL



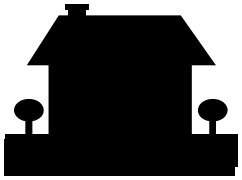
Modification to the original Barco Model (Malia, 1997). Adapted from British COT Neurology Group (2006).

APPENDIX 8 SEEKING/RECRUITING PARTICIPANTS
[Plain English]

ABOUT THIS STUDY

I am a mature occupational therapist who is trying to find out about your day to day experiences of living with a head injury. This is a doctoral study and I hope to use the findings to understand your needs and also to try to seek better services in Cork and Kerry for people with ABI. I would like to visit you several times to hear about your stories of *how you are managing.*

WHERE WILL WE MEET?

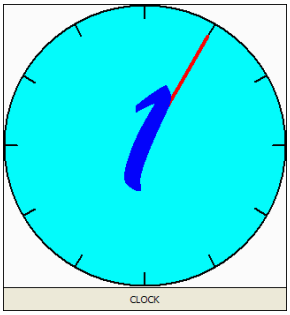


IN YOUR HOME?

HOW OFTEN?

2004	2005	2006
Meet 3 times every three months	Meet twice (2)	Meet once (1) to end the study

HOW LONG WILL THE MEETINGS BE?



We will meet for about one hour at each meeting.
I need to audio-tape your story and that of your partner as these tapes will be the basis of my study.

PRIVACY GUARANTEED

YOU CAN PICK A DIFFERENT NAME FOR THE RESEARCH THESIS.

If you are interested in telling your story or would like more information please telephone Phil (Philomena) McGowan 021-477XXX or write to me at p.mcgowan@ucc.ie or to The Rxxx, Kinsale. Co. Cork.

APPENDIX 9 INFORMATION LETTER

Address
Telephone. March 2004

Dear Member of Headway Ireland

SEEKING VOLUNTEERS FOR RESEARCH INTERVIEWS ON LIVING WITH ABI IN RURAL IRELAND TODAY

I am an occupational therapist, and for twenty years, I have had a particular interest in community and equality issues for people with disabilities. I am now doing a PhD study in the Occupational Therapy School in the University College Cork (UCC). I have chosen to learn more about the lives of a small number of adults from rural Cork and/or Kerry who sustained a brain injury or a stroke about five years ago. I would like to listen to their experiences and to their partners, about living with brain injury or with stroke in rural Ireland today.

Through the co-operation of Headway Ireland (Cork/Kerry) office, I am seeking six (6) people with brain injury or stroke, aged approximately 40-60 years, and their partner to volunteer to take part in this interview study. I need volunteer participants to meet with me, separately, for **five** meetings in their own homes throughout the years **2004 and 2005**. These interviews will be held every three months and may last for about one hour or more. It would be appreciated very much if interview participants could tell me about their experiences since their injury and about life in general today on a day to day basis. It will be left entirely up to the participants to decide what information they talk about and what they leave out for the start of all interviews. At the end of the interviews I will need some time to ask particular questions based on what you have told me.

If you agree to participate in this study, I need your permission to tape-record the interviews as this will allow me to listen better to you. After each meeting, I will write out what is on the tape - this is called a transcript. All these transcripts and notes will form the main basis of information for this study. You may have a copy of your tape or transcript if you wish. A final sixth meeting is planned for 2006, so I can share with you and review together my

summary of your story and close the interviews as I write up the final research document. I also seek permission to make notes of any information relevant to the study that may arise from telephone calls or letters between us and notes made on events or observations in your home around the time of the interview.

As this is an academic study, an academic thesis will be prepared during the following two years. It will be based on literature, parts of your stories and my interpretations of them. **Your own name or home location will not be used in or associated with the research findings in any way.** Confidentiality is assured throughout. **You may pick a research name that will be used for the final document.** All the tapes and transcripts will be kept locked in a safe place with the researcher until the year 2015, as per UCC guidelines. You are free to decide to participate or not to participate. Taking part in this study will not affect any service(s) you are involved in now, or in the future. This is an independent study as I am not employed by any agency, Health Board or UCC, to carry out this study. It is hoped that this study will help develop greater understanding and new insights about living with brain injury in rural Ireland. In turn, this may help future students of therapy studies, disability and social studies and general service providers.

So, if you are between 40-60 years of age and had your ABI about 5 years ago and live in rural Cork or Kerry, I would love to hear from you. Please telephone me or write to me using the enclosed s.a.e. Please also, do ring me if you are anyway interested in taking part in this study but would like more information first. (You may also ring me at any time during the research period). I need your written consent if you wish to participate - accepting that you know the nature and purpose of this study. I will ask your partner for his/her consent separately. You will both be given a copy of your consent letter. The original consent letter will be kept with me in a separate place from the research documents. Headway Ireland will not know who replies to this request letter seeking volunteers, unless you wish to share the information with them.

Thanking you in anticipation. Phil McGowan

APPENDIX 10 CONSENT INFORMATION NOTES FOR PARTICIPANTS

1. This particular study is aimed at developing new insights into how people manage living with ABI years post-injury in rural Cork or Kerry.
2. Individual tape-recorded interviews in the form of story-telling are being held with 12 people (6 pairs or couples) to gain information.
3. The interviews on the audio-tape will be written out onto paper by the researcher herself. These pages are called a transcript. From these, she Will work out the final research document for UCC, the thesis.
4. You may have a copy of your tape or transcript, along with my summary of your story, after the fifth interview.
5. You have the right to withdraw consent or participation during the study, at any time.
6. Confidentiality: You may choose a research name which will be used on your 'file' and on any quotations that may be used in the finished thesis.
7. Guidelines from UCC Ethics Committee and the National Disability Authority Ireland, (NDA) are being used to carry out this research study, in an ethical manner.

Thank You for helping me in this study.

Signed: _____

Phil McGowan. Tel:
UCC PhD Student.
Address.

APPENDIX 11 CONSENT AGREEMENT FORM

CONDITIONS OF AGREEMENT

1. The research study 'Living with ABI in Cork/Kerry' by Phil McGowan has been explained to me as fully as possible.

2. I have had the opportunity to ask questions about the study.

3. I am aware that my participation is voluntary and I know I can withdraw from the study at any time.

4. I understand access to the tapes and transcripts is restricted to the researcher, Phil McGowan, unless specific additional agreement is obtained.

5. I agree that the material on the tape and in the transcripts may be used to provide the basis for the final document on this study.

6. I accept that the researcher may write or talk about this study in other academic situations but always showing confidentiality and respect for me.

7. I request that my own name will not be used in the research documents. I choose the name _____ as my name for the study.

I agree to take part in this study. I understand that if I have further queries regarding my participation in this study, I may contact the Ethics Committee, UCC. Tel. 021- or Headway Ireland (Cork office) Tel.

Signed:_____

Initials:_____

Home Location:_____

Date:_____ Witnessed by:

APPENDIX 12a DATA ON THE TWELVE RESEARCH PARTICIPANTS: MARITAL STATUS, RELATIONSHIP TO PERSON WITH ABI, RESIDENCE

People with ABI Research Names All over 40 years of age.	**Partner or significant other and their relationship**	**Home Location**
Annie	Mary Friend	Both live in Kerry in or near large town.
Claire	Pat Husband	They live together in semi-rural near city suburbs.
Joe	Elizabeth Wife	Live together with family in north Co. Cork. Rural area.
John	Brid Ex-wife. Seperated.	Both live in or around Cork city and suburbs.
Sinead	Paddy Husband. Live apart.	Sinead lives in a supported living unit approximately sixty km from family home in rural Co. Cork.
Vivienne	Helena Friend.	Vivienne lives in Cork City. Helena lives about 100 km away.

APPENDIX 12b MACRO, MEZZO AND MICRO ISSUES

(Adapted from Parker et al., 2003, p.171).

MACRO	
Society	In transition, largely modern, wealthy per GDP knowledge - body society
Economic system	Capitalism
Type of state	Welfare state
Neuro- rehab sector	Dublin, Cork mainly
Community rehabiltation	Emerging
Disablism	Yes (NDA)
Work	Knowledge/Finance/Technology/Construction near full employment - until 2008
LESS MACRO	
Family background	Two - wealthy
Locality	Cork/Kerry
Residence	Urban and Rural
Organised professional support in or near the home	Only for two people when they needed it
Disability advocacy	Emerging -three involved in such activity
Movement in public space	Three dependent, three independent moving around local towns
MICRO	
Injury level today	Five accept ABI embodied
Marital status	See Table
Living with	See Table
Dependent children	Four have children Two families live together Two families, who had small children at home at time of ABI, have since moved apart
Support network	One depends on paid care. One seeks a PA
Age range	40 - 65
Religion	Three very active in local RC church. One would like more participation in their church
Education	Two participated in a third-level course
Employment	One working through quota scheme Two in 'special' community projects One helps with family business One not working, Three involved in volunteering
Self- projects on hand	Leisure, group work Personal development and adult education
CULTURAL	
Attitudes to ABI	Unknown - little public knowledge re ABI
Socialisation opportunities	Four socialise mainly with non-disabled friends and family.

APPENDIX 13 TABLE OF INDIVIDUAL INTERVIEW DATES

generating data with twelve participants in ten locations

*Research name of person with ABI is in **bold font**.*

Participants Research Name	**Interview No. 1** **2004**	**Interview No. 2** **2004**	**Interview No. 3** **2004/5**	**Interview No. 4** **2005**	**Meeting No. 5 2005** Nov/Dec. Focus In	**Final Meeting 2007** with disabled participants only
Annie *Mary* friend	7 May 28 May	17 Aug. 22 Sept.	10 Dec. '04 24 Jan. '05	11 Mar. Tel. & Post.	9 Dec. 9 Dec.	10 Nov. Telephone Post and Meet
Claire *Pat* husband	30 April 2 June	14 & 24 Sept. Tel. calls Sept-Oct.	3 Dec. '04 (silence) 19 Jan. '05 14 Feb.'05	7 April 7 April	25 Nov. 1 Dec. 25 Nov.	29 Nov. Post and Telephone
Joe *Elizabeth* wife	5 May 4 June	15 Sept. 15Sept./ gate 13 Oct.	6 Dec. '04 19 Jan. '05	8 Mar. 12 April .	14 Dec. 14 Dec.	30 Nov. Post and Telephone
John *Brid* ex-wife	26 April 8 June	11 Aug. 23 Sept	14 Dec.'04 5 Feb. '05	22 Mar. Tel. call	17 Dec. 26 Nov.	26 Nov. Telephone Post and Meet
Sinead in her 'flat' *Paddy* husband in family home	19 April 26 May	16 Aug. 8 Oct.	10 Dec. '04 9 Feb. '05	11 Mar 19 May	9 Dec. 22 Nov.	30 Nov. Telephone
Vivienne *Helena* friend	29 April 28 May	24 Aug. 22 Sept.	9 Dec. '04 24 Jan. '05	7 Mar. April	16 Dec. 17 Dec.	21 Nov. Telephone Post and Meet

APPENDIX 15 HEADINGS USED IN FIELD JOURNALS

One small copy called 'a field journal' was used for each participant to note observations and comments during or after our audio-taped interviews and other meetings. The following headings were used in the twelve research journals for the first interviews.

Date

Time

Location

Weather

Major local, national or global events in news (these events often gave a good starting talking point, as did the weather or local environment, e.g. garden).

Space (Private space, Public space, Circulation space, Access, Colour, General overview)

Facilities (bathroom, cooking, laundry, TV, mobile phone, transport…)

People present during interview and/or any interruptions

Neighbours

My focus today

Technical issues: (tape, batteries, recorder).

APPENDIX 16 BIO-DATA FACT-SHEET

(One fact-sheet was completed by the researcher for each interviewee during the research process. This page recorded hard data or background knowledge on each participant. Each fact-sheet was stored by the researcher in that participant's file in a filing cabinet in the home of the researcher).

Initials:

Name chosen for this study:

Home Location:

Place of Birth:

Occupation/Employment:

Marital status: if yes, since year

Present household details: Lives with
Since

Ages of children if any:

Own extended family: (parents, sister, brother)
if appropriate, do they live nearby:

Hobbies or Interests:

Member of any sports, community, political or church club:

Car ownership:

Member of any disability group (self-help/service provision or advocacy):

For persons with ABI:

In what year did your brain injury occur?
What was the cause of your ABI? (e. g. Fall/RTA/Stroke)
Are you presently attending any specialist hospital, rehabilitation or vocational service?
Have you any remaining personal needs (speech, writing, memory…)
Any other relevant comments:

Thank you for your co-operation.

APPENDIX 17 MAJOR LIFE EVENTS FOR SINEAD AND PADDY

approximate dates here as precise months/years not offered or remembered. Major policy initiatives given in top line

1993 *Headway Ireland starts service provision*	**1994** -	**1995**	**1996** *"Strategy for Equality for disabled persons in Ireland"*	**1997**	**1998** *The Nt. Disability Authority (NDA) established*	**1999**	**2000** *Irish Equal Status Act*	**2001**	**2002**	**2003** *Personal Assistance system introduced in Kerry*	**2004** *National Disability Strategy launched*	**2005** *Disability Bill*
In Co. Cork one busy family. Six children under 14 yrs. Family business opens 10-10 7/52 **13 Dec. 3p.m. Sinead (mother) aged 32 in a car crash. She has a serious ABI**.	In coma in CUH. Husband in CUH 10 hours a day… waiting for Sinead to wake up 1 hour drive from home Months later she goes to NRH Dublin	In NRH Dublin 18 months in total	Sinead comes home. Kids noisy Paddy busy in shop… he goes to Headway meetings… Housekeeper an old friend Sinead dependent. nothing to do, no-one visits, Nowhere to go except to Respite Care places many week-ends.	Home and/or Respite Care	Sinead moves to Cheshire Home Compen-sation paid ('97/98) Made Ward of Court.	**[6 year plateau of recovery time post ABI -for Paddy]** IWA day centre Started going to Lourdes (1week / Summer)	Paddy helps her with shopping …..most Fridays		Training course starts for Sinead Sinead gets a new solicitor	Sinead to ABI Support group PA service commences 2.5 hrs./wk Finishes with housekeeper at home. He is not paid from compo for her costs for this year. Paddy bought holiday home in Spain.	No PA for 6 months approx. Few Sat. nights out. Support group stopped. Nov. PA hours extended OT visit. New counsellor Gets Dictaphone Sinead to Spain for 2 weeks with daughter	PA -5hrs/wk for shopping (Fri) and Sat. p.m. After 6 years has check-up with Neurologist New wheelchair. New H'way Counsellor Stops after 2/3 sessions Given book on ABI Group meet at times Sinead to Spain for 2 weeks with family

APPENDIX 18 SUMMARY FINDINGS SEVEN APPENDIX

Summary of main issues arising from interviews with participants in research study *About Living with Brain Injury in Cork and Kerry*

These 'issues' are not in order of importance. Please read them and rank them in *your* order of importance. Thank you very much for your time and ideas shared with me to date during this study, and again today.

Access to and participation in leisure, cultural events and/or work (paid, voluntary, supported, etc).

Public awareness campaigns on ABI with positive aspects included

Need for the person with the ABI to have some risk and time alone. Allowed time to do things slower

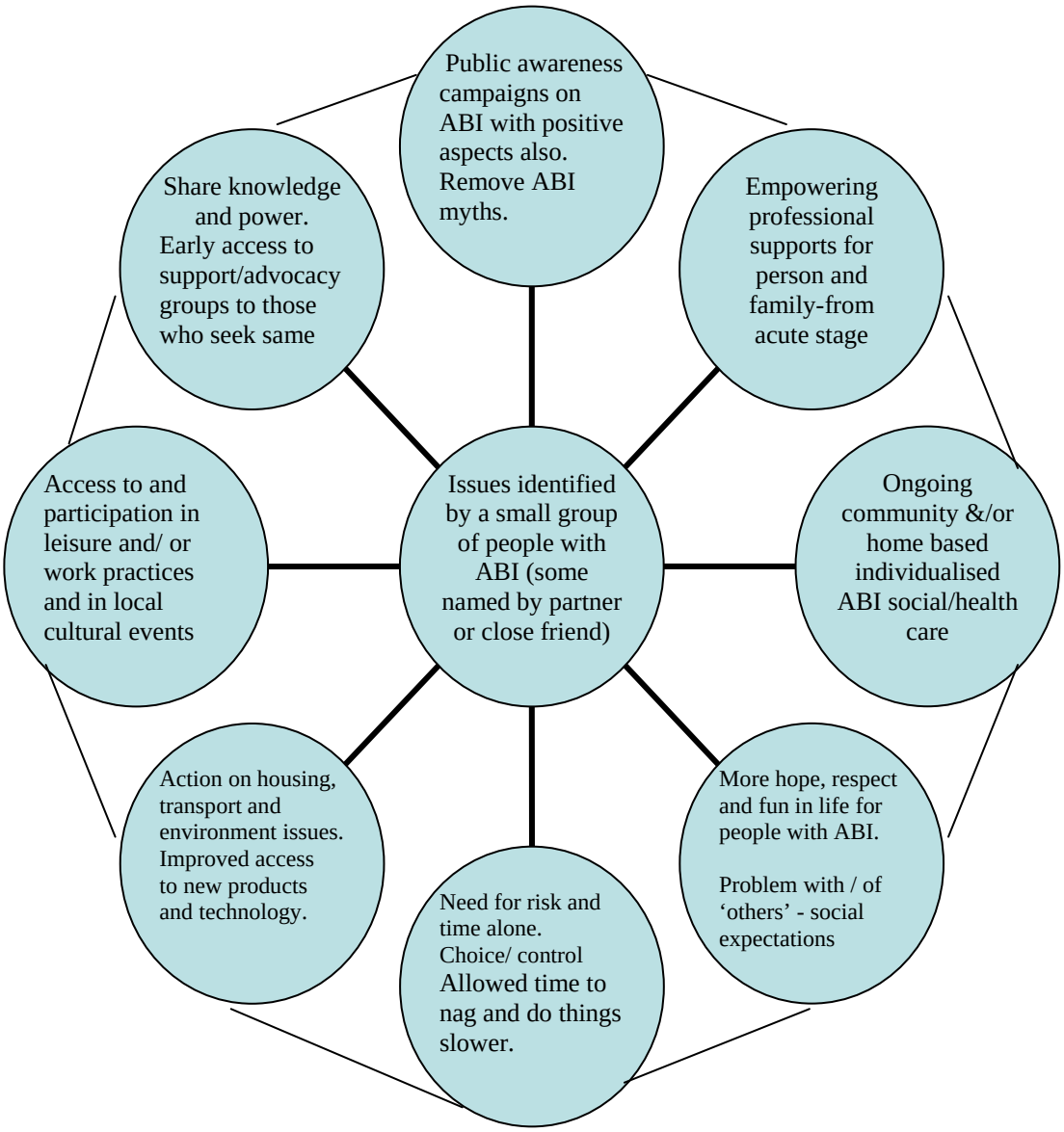
Early access to support and/or advocacy groups

Empowering hospital or rehabilitation centre based professional supports for person and family- from the time of injury

Ongoing community, home-based social health care plan for person with ABI and/or family.

Action on transport and environment issues with improved access to new products/technology and living options

APPENDIX 19 DIAGRAM OF SUMMARY OF FINDINGS



MAJOR ISSUES and/or NEEDS ARISING FROM PARTICIPANTS STORIES in research study entitled

ABOUT LIVING LONG-TERM WITH ACQUIRED BRAIN INJURY

as noted by Phil McGowan. 17 November 2005.

APPENDIX 20 CONTENTS PAGE FOR FINAL ANALYSIS REPORT ON FOCUSING IN

Copy of contents page of Report as presented to my research supervisors January 2006

Focusing in:

> how I constructed, used and reviewed the summary sheet to further the involvement of participants in interpreting and/or finalising data analysis, and to prioritise findings of my study

CONTENTS PAGE

THE 7 STATEMENTS 1

DEVELOPING THESE CATEGORIES / SUMMARY STATEMENTS 3

RANKING THE STATEMENTS 6

FIRST TASK TOWARDS ANALYSIS 8

COMMENTS ON GIVEN INDIVIDUAL RANKINGS 11

STEP 2: CHRONOLOGICAL ORDER ANALYSIS 12

FURTHER ANALYSIS THE TOP 4 RANKED ITEMS. 18

DISCUSSION 19

Phil McGowan January 2006.

APPENDIX 21 Copy of one page of report to Supervisors

INITIAL SAMPLE OF DATA ANALYSIS. Date: October 2004.

Task: to analyse and discuss four samples of transcripts depicting strong, weak and/ or useful narratives.

Report on how I carried out this exercise:

Once I had decided on the four participants, I marked out the required pages from their full transcripts with neon page markers. These pages were then printed out with additional space given to the left and right hand margins of the pages for my comments. Reading more on analysis from Frank (1995), Fraser (2004), Mattingly(1998) and Ryan and McKay (1999) and thinking about these people and rereading the chosen pages, I started to pre-code the transcripts by underlining or marking very interesting words. As Layder states, they were just interesting but I had "no awareness why so" (1998, p.54), perhaps intuition, knowledge and experience at particular levels of the research topic. I then reread most of their full transcripts again and that of the partners or their 'significant other' to remind me of certain details or background. Fraser (2004) recommends scanning stories for 'four different domains for experience' to seek the interlinked **intrapersonal, inter-personal, cultural and structural aspects of their stories**. This technique was used as it should cover all that I am interested in at the moment. Obviously there is overlap but for the purpose of this exercise, words or chunks of data, which in my perspective link intra and inter-personal domains, are named on the **right hand margins of the pages.** Social and cultural domains are noted on the **left margins**. This was not always appropriate for every transcript as so many issues are interlinked, requiring more than 'neatly' divided margins. Other ideas, linkages and theories that came into my head when focusing on a particular person were written elsewhere on the page with a box around them.

How transcripts are written is another political choice. I chose large pieces of text here for the basis of analysis as I am not doing content or discourse analysis and am interested in the content rather than the form of their stories plus I do not wish to fragment their life-stories any further. Linear transcripts do not show the ordinariness, the laughs or the flow of our conversations.