

***“Exploring how the role of the key worker can support families in
the community who have experience of a loved one with a
Traumatic Brain Injury”***

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ABSTRACT

Objective: The National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland (2011) Report recommend further development of a case management approach utilising a key worker role to identify intensive users of unplanned acute and secondary care services. The report suggests that the key worker will anticipate, coordinate and join up health and social services to meet, and thus reduce, the burden of care. In addressing this form of practice, this study examined how the role of the key worker could support primary carers for people with a Traumatic Brain Injury (TBI) within the community after leaving hospital.

Methods: The study employed an action research approach in which the researcher worked with six primary carers of people with TBI. Through a participatory approach, the role of the key worker was introduced and developed as a pilot project over six months. The developing involvement and role of the multi-disciplinary team members within each case study was examined.

Findings: Identified roles of the key worker ranged from providing TBI Education to families, Case Management Services, development of a Support Network, Professional Guidance, Empowering the primary carer within the case management process to offering Emotional support. Due to the holistic nature of the identification process of needs, findings reflect the collaboration of a multi-disciplinary team with the key worker was paramount in addressing the intrinsic needs of the family within each activity system. The outcome suggests that the majority of the six primary carers were satisfied with the set-up of the key worker service and found both the support received and the information sharing helpful.

Conclusion: In addressing the continuous intermittent need of support for families over time, the research suggests the allocation of a key worker to form part of a multidisciplinary team of rehabilitative services within the community. This recommendation supports the British Society of Rehabilitation Medicine National Clinical Guidelines (BSRM, 2003) model of TBI Rehabilitation referred to as the “Slinky” Model currently practiced in Ireland.

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Glossary

ABI	Acquired Brain Injury
AT	Activity Theory
CAT	Computer Axial Tomography
CBR	Community Based Rehabilitation
CWO	Community Welfare Officer
DM	Disability Manager
FLC	Family Life Cycle
GCS	Glasgow Coma Scale
GP	General Practitioner
MPAI	Mayo-Portland Adaptability Inventory
NAI	Neurological Alliance of Ireland
OT	Occupational Therapist
PCC	Primary Care Centre
PCT	Primary Care Team
PHC	Public Health Centre
PHN	Public Health Nurse
PTA	Post Traumatic Amnesia
S&L	Speech & Language Therapist
TBI	Traumatic Brain Injury
WHO	World Health Organisation

Philips Report:

CUH – Cork University Hospital
HIPE – Hospital In-patient Enquiry System
HSE – Health Service Executive
NSU- Neurosurgical Unit

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INTRODUCTION

For the past 14 years, the researcher has worked in Ireland for a charitable organisation, called Headway as a vocational rehabilitative training officer for people with a TBI. Part of the researcher's job involves working with individuals with a TBI and their families within a key worker role capacity. The aim is to support and guide the family and their loved one towards services and professionals to maximise the rehabilitative process. Over the years of working within the field of TBI rehabilitation, the researcher has come across many different disciplines, opinions and ways of providing care and support for the individual with a TBI and their family.

Reasons for deciding on this topic

When considering why this topic was chosen, different factors influenced the decision. One such influence was that families over the years have expressed to the researcher the need for support to be flexible and timely, depending on the individual family needs and circumstances. This becomes more evident at the post-hospitalisation stage when families have expressed distress and emotional strain after recalling their experiences on leaving the hospital setting, often feeling isolated and abandoned. Below are some citations from families who have commented during case conference meetings on their experience post-hospitalisation:

"You don't realise how dependent and vulnerable you are whilst your loved one is in hospital on the medical staff, but you soon realise things change once you leave the hospital. I was left on my own to look after my husband without any support from anybody. I didn't know what to do, where to go. I felt so alone and angry at the health centre for abandoning my family".

Ref: Family One

"health care system, what health care system. It does not exist. Once you are in the hospital, you are fine. However, when you are discharged you are out of the system, therefore totally alone without any support whatsoever".

Background on key worker work

When considering what perspective to take for the research, consideration was given towards the need for the key worker to provide education to families and professionals involved in the research. The National Institute for Health and Clinical Excellence (NICE, 2004) defines the key worker as

“a person who, with the patient’s consent and agreement, takes a key role in co-ordinating the patients care and promoting continuity, ensuring the patient knows who to access for information and advice”.

NICE provide clinical guidelines on recommendations of appropriate treatment and care of people with specific diseases and conditions within the NHS in England and Wales. The guidelines aim to support healthcare professionals in supporting patients throughout their recovery.

Placing the research within an educational perspective supported such a need. In the researcher’s experience, families have voiced how there exists a lack of understanding and education about TBI within the local community and amongst different disciplines. Families have cited:

“Nobody knows about TBI, not even my doctor. So who can I turn to?”

Ref: Family Three

“My husband was attending speech and language therapy as a result of sustaining a Frontal Lobe TBI. The therapist proceeded to give out to him for getting distracted during her session. I needed to inform her that my husband’s lack of sustaining attention was part of his brain injury. I should not have to inform professionals of this, they should know and understand”.

Ref: Family Four

Academia

Having completed a Masters in Education within the University of Birmingham on the needs of those who have experienced a TBI, the researcher wished to conduct research on support for the families. Specifically surrounding how the role of the key worker could support families of those affected by a loved one with a TBI within the community.

Overview of Thesis

- **Literature Review**

To promote a foundational understanding of the research content, the thesis begins by presenting current literature on TBI and its complexities. Literature on research studies on the identified needs of families of those who have experience of a loved one with a TBI is presented. Literature exploring the role of the key worker is introduced to deepen the understanding of the role adopted within the research. To support the involvement and collaboration of primary care teams within each case study, global and national literature on primary care research is introduced.

- **Methodology**

The methodology consists of various sections, outlining the exploration, development and implementation during the action research. To present the implementation of the flow of the action research into practice, Lewin's (1946) model of action and reflection is introduced. Methods of data collection, predominately Qualitative and Quantitative research methods were considered to identify the most appropriate for the research. Ethical and Practical Issues of moral principles or values are presented which governed the conduct of the participants of the research. The theoretical framework considered and adopted within the research is the Activity Theory. The final methodology section describes the use of the Case Study format within the research. Different categories and selection methods of case studies, as proposed by Yin's (1984) are considered, along with variations in sources of data.

- **Findings**

Due to the various areas of the research, findings are broken down into two main areas, Chapter 3 (focussing upon data related to families) and Chapter 4 (focussing upon data related to professionals).

- **Family needs – Chapter 3 (Families)**

Data is presented on the impact of the recovery process on each of the case study family primary carers, utilising Stambrook et al (1994) family crisis stages; life-cycle and role changes. The section concludes with the presentation of findings recorded on the identified needs of the six case study family's primary carers.

- **Key worker – Chapter 4.1 (Professionals)**

The key worker role findings present data on the level of time post-TBI for each of the six case study families to establish different implementation stages of the key worker role as suggested by Lees (1988). Roles performed by the key worker within the research for each of the six case study families follow which correspond with research conducted by Greco et al (2005).

- **Multi-disciplinary Team – Chapter 4.2 (Professionals)**

Within this section, the different professionals from the voluntary, community and medical sector that assisted within the development of the research are recorded. However, it is important to note how data presented is taken from the professional functional involvement only along with the researchers own personal reflection as the professionals involved did not wish to be cited within the research.

- **Activity Theory – Chapter 4.3 (Professionals)**

The analysis reviews Engestrom (1987) proposed model of components of each activity, underlining assumptions to finally the dynamics towards identifying how the Activity Theory Framework impacted on the research.

All findings are presented in the form of written detail, tables and graphs to enhance the understanding of the data recorded. Upon reflecting on the research findings, limitations,

recommendations and conclusions are presented in Chapter 5 to formulate conclusion to the overall thesis.

Aims of the Research:

The aim of the research was to investigate how the role of a designated key worker could support families who have experience of a loved one with a TBI in their community. To present this possible relationship, the research adopted an action research approach, incorporating the case study approach of six family primary carers affected by TBI.

CHAPTER ONE – LITERATURE

Section 1.0 Overview of Literature Review

Introduction

The structure of the Literature Review encompassed different areas of supporting families who have experience of a loved one with a TBI from the background literature.

TBI

The researcher begins with reviewing current literature surrounding TBI. Epidemiological and incidence data on a global scale are introduced to aid the reader in understanding the prevalence that exists in gender and age and how such age categories can indicate the need for long-term care due to the longevity of the effects of TBI. Definitions on TBI are considered along with different measurements to determine the severity of a TBI. As the research took place within Ireland, the section concludes with an introduction to the current TBI services available within Ireland.

Family Needs post TBI

The next section explores the effects on the family following the experience of a loved one with a TBI. Areas of consideration from the research reviewed mainly focus on family reactions, the change in family roles, family life changes, family emotional distress, family reactions to the rehabilitation process and friction experienced by the families of individuals who sustained the TBI.

Key worker Role

Even though a proportionate amount of public expenditure supports the needs of people with TBI, the families are, as argued by Allen et al (1994) and Knight, Devereux and Godfrey (1998) are those who provide the majority of care. This concept is further explored by Stebbins (1997) who notes how families provide such care, often without adequate professional support and intervention. In addressing possible inadequacy of external support

the research focussed on the exploration of the designated specialist key worker role into the community. Definitions and models of services of the key worker are introduced. For the purpose of the research, the term key worker is utilised as the supportive person for the family throughout the research process.

Primary Health Care

Global developments within health care and the promotion of a primary health care strategy have been mainly driven by the WHO Report in 2000. Within this report, the WHO (2000) identified how many countries were falling short of providing adequate health care for their population. To explore and understand such need for developments, the literature review considered the limitations and effectiveness of such a primary care centre (PCC) system towards catering for the needs of the family out in the community. The section concludes with an introduction to the current PCC situation within Ireland.

Section 1.1 Traumatic Brain Injury

Introduction

Eames (2001), Greenwood (1999), April (1997) and Lezak (1995), note how TBI is considered to be one of the leading causes of brain damage worldwide. They go on to present how TBI is considered to be one of the leading neurological disorders in persons under the age of 50. TBI is considered by Alfano (1994) and more recently by Hampton (2011) as a hidden silent epidemic which constitutes as a major social health problem presented within western society today. It is considered a major cause of death, especially amongst young adults (Maas et al, 2008); with those who survive experience a lifelong disability. (Roozeneek et al, 2013). In a study conducted by Thornhill et al (2000) on 3000 with serious head trauma cases, findings reflected how 52% of survivors (154/100,000 population) were moderate to severely disabled after one year. Another study conducted by Jacob (1988) reported how many survivors of a TBI live with their families and neither worked or attended school after four years.

During the 1970s medical services and science improved with the development and availability of high-quality emergency treatment which increased the survivor rate. Such developments in medical science were as the result of the advancement of technology in areas, for instance; Computer Axial Tomography (CAT) scans and microsurgery which enabled the early identification of a diagnosis and supported the implementation of a sophisticated treatment as emphasised by Marion (1999) for the patient with a neurological injury. As a result of such medical advancements, there is a substantial increase over the past few decades of individuals surviving neurological injury. (Stein et al, 2010). Stein et al (2010) conducted a meta-analysis study of 207 case series, involving over 140,000 patients with severe closed TBI, over a time of nearly 150 years (1885-2006). The analysis revealed an overall decrease in mortality rate in TBI by 50%, with a suggestion of the introduction of CT Scanners and advancements in detection of TBI and patient care contributing to the reduction in mortality rates between 1970 and 1990.

Residual Deficits

When considering residual deficits following a TBI, Barnes (1999) emphasis how many people who survive a TBI will have a normal life expectancy. However, Lewis and Horan (2013) highlights how TBI can often lead to residual impairments that persist beyond the hospital level of care. Such residual impairments can consist, as outlined by Strub and Black (1988) of physical, cognitive, emotional, behavioural, and functional systems complications. Lewis and Horan (2013) suggests during the acute stage of recovery (0-6months), improvements can occur, but not equally across the different categories of symptoms. For instance, physical impairments can improve quicker than cognitive improvements. He notes how emotional features can be dulled during the acute stage of recovery due to the patient's impaired insight and awareness and how they may become more prominent after 6 months due to the patient experiencing and becoming more aware of the impact of the residual deficit on everyday functioning.

Another study conducted was by Lewis and Horan (2013) on 285 participants who attended rehabilitative community based facilities throughout America. One of the aims of the study was to describe the nature and severity of residual deficits experienced by TBI survivor's utilising the Mayo-Portland Adaptability Inventory (MPAI). The MPAI was designed to assist clinical evaluation of individuals during post-acute/post hospital period following a TBI. (Malec and Lezak, 2008) The top 4 most severely impaired skills reported in Lewis and Horan (2013) study by participants were 51.9% surrounding residence and level of independence in the home, 49.1% difficulty with money management, 40.4% accessing and participating in leisure and creational activities to 34.4% reporting severe problems with social contact. Cognitive deficits, including memory, attention/concentration, novel problem solving, and awareness of deficits were found to be highly correlated with disruption in performing everyday societal roles. (Lewis and Horan, 2013).

In an older follow up study conducted van Zomeren (1985) of 57 patients, 84% of patients reported some residual deficit in their psychological functioning after two years, with forgetfulness being the most common complaint with a reported percentage of 54%. Other reported residual complaints were irritability 39%, slowness 33%, poor concentration 33% to fatigue 30%.

When considering studies on residual deficits following a TBI in Ireland, the NAI Report (2010) suggests figures of at least 127,894 people living with the sequelae (a condition which is the consequence of a previous disease or injury) of TBI in Ireland today. The report outlines residual deficits following a TBI can result in physical, communicative, behavioural, emotional and cognitive problems. However, concerns are raised in the report surrounding how statistics in Ireland on the identification of incidence and prevalence of Acquired Brain Injury (ABI), is fraught with difficulties. With some studies reporting figures for stroke, some for traumatic brain injury while others use a generic ABI category. Statistical data is based solely on hospital admission with no standard method of data collection in place. Failure to record diagnosis is common. Consequently, Hospital Inpatient Enquiry (HIPE) figures are likely to significantly underestimate the number of ABIs. (NAI Report, 2010).

Financial Burden

The area of studies considered within the literature surrounded the financial burden experienced by families' post-TBI. The increase in survival rate following a TBI, as suggested by Humphrey et al (2013) places a huge financial burden on a nation's health care system. Humphrey et al (2013) study reviewed literature relating to psychosocial costs associated with TBI. The study found that little research was published on the economic burden that mild and moderate patients of TBI pose on their families, carers and society as a whole. The study suggests further research is required to estimate the economic burden of these patients on healthcare providers and social services and how they can impact on current health policies and practices.

Murray and Lopez (1996) study on The Global Burden of Disease (GBD), conducted on behalf of WHO drew the attention of the international health community to the burden of neurological disorders and many other chronic conditions. This study found that the burden of neurological disorders was seriously underestimated by traditional epidemiological and health statistical methods that take into account only mortality rates but not disability rates.

The WHO (2006) Report on Neurological Disorders Challenges, suggest how TBI economic consequences tend to relate to the cost of hospitalisation which only makes up a proportion of the total costs. To address this shortfall, and identify a more complete cost of the consequences of TBI, Berg et al (2005) outlined how the cost of TBI can be broken down into:

- Direct costs: hospitalisation, outpatient and rehabilitation
- Indirect costs: lost productivity, especially after mild to severe TBI
- Intangible costs to patients: families and friends related to death or reduced quality of life.

Within Ireland, The National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland (2011), indicate how significant financial resources are required for the rehabilitative care of people with a TBI. In The National Service Plan of 2014, financial challenges were recorded due to a reduction in the funding base at a time when the demand for health services is increasing every year. Some of the drivers of demands on costs recorded since 2006, are an increase in population of 8%, of which, there is an increase by 14% of the number of people over 65, to the cost-intensive advancement in medical technologies.

This concept, emphasised by Ragnarsson (2002), Rose (1999) and Wood (2001), created a new population of individuals who were in need of long- term treatment and rehabilitation from their traumatic injuries. It wasn't until the 1980s that initiatives in dealing with the challenge of caring for such a population were formulated (Marion, 1999; Wood, 2001). However, Rose (1999) raised concern over how such developments are still lacking a comprehensive TBI rehabilitative system that meets the needs of the individual with the TBI and their families.

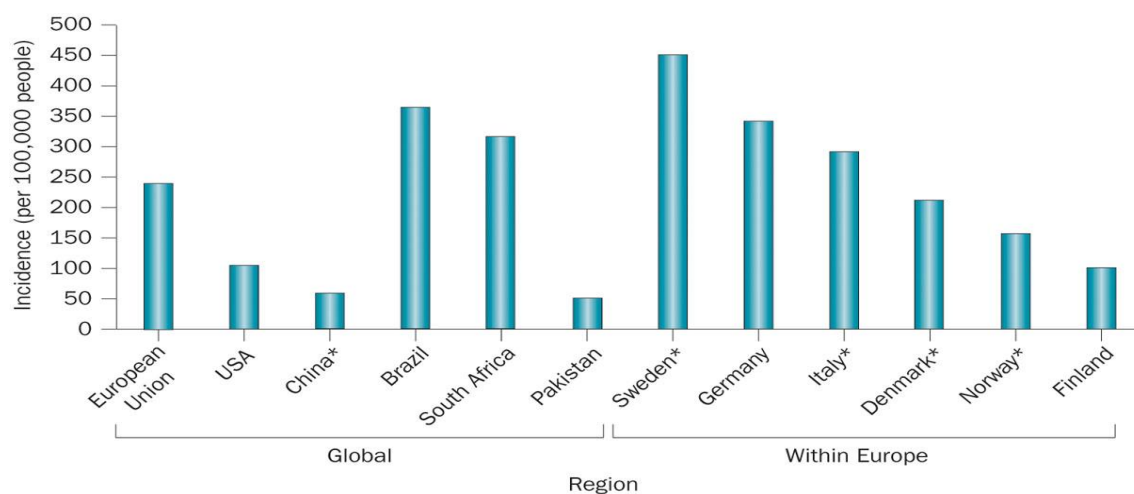
Incidence

When reviewing studies surrounding the incidence of TBI, Hyder et al (2007) estimate that in the European Union, TBI accounts for 1 million hospital admissions. Tagliaferri et al (2006) study suggests that TBI accounts for the majority of trauma deaths in Europe. Within the Tagliaferri et al (2006) meta-analysis of 26 studies, 23 European reports met inclusion criteria

which included national studies from Denmark, Sweden, Finland, Portugal, Germany, and from regions within Norway, Sweden, Italy, Switzerland, Spain, Denmark, Ireland, the UK and France. The meta-analysis findings reflected the aggregated (fatal plus hospitalised) incidence rate was 235 cases per 100,000 people per year, the average mortality is 15/100,000 per year, the fatality rate was 2.7% and the ratio of mild to moderate to severe TBI is 22:1.5:1, which equals approximately 10 cases of severe TBI per 100,000 per annum. The report raises concerns surrounding the consensus on the epidemiological findings across the 23 published European studies because of clinical differences in methods employed across the reports.

A more recent study conducted by Roozenbeek et al (2013) on the global changing patterns in the epidemiology of TBI is presented below:

Figure 1 - Changing patterns in the epidemiology of traumatic brain injury



Ref: Roozenbeek et al (2013)

Some of the studies included in the above estimates will now be briefly introduced. The European Brain Injury Consortium (EBIC) core data, was conducted by Murray et al (1999) and consisted of 847 participants with a median age of 38, 33% under the age of 50 years and presented a mortality rate of 31%. An observational study in Austria conducted by Rusnak et al (2007), consisted of 415 with a median of 48, 45% before the age of 50 years with a mortality rate recording of 38%. Within the Netherlands, a study conducted on Prospective Observational Cohort Neurotrauma (POCON) by Andriessen et al (2011) on 415, with a

median age of 48, 45% under the age of 50 years reflected a mortality rate of 46%. (Roozenbeek et al, 2013). Finally, data derived from a study conducted by Faul et al (2010) with the Centers for Disease Control and Prevention (CDC) in America records a figure of 1.7 million individuals will sustain a TBI each year in the USA. Out of this 1.7 million, 1.4 million will be treated in an emergency department, with around 275,000 hospitalisation and 52,000 fatalities. However, Roozenbeek et al (2013) report concludes with raising concerns over variation in the incidence of admissions recorded in each study and country, which could be attributable to differences in inclusion criteria and/or policies and/or practices for hospital admissions.

Upon looking at the incidence reports in the United Kingdom (UK), Yuriko et al (2000) calculate how with a health population of 250,000, it is likely to generate 44 moderate cases of TBI to 18 cases of severe brain-injured cases per annum. Whilst in Japan, Yuriko et al (2000) suggest how there could be a possible incidence of 200,000 individuals who sustain a TBI who will need admission to a hospital care environment. In Australia, post-hospitalisation stage, Stebbins and Leung (1998) report how within the Australian Bureau of Statistics of 1993 there were over 148,800 individuals who were in need of support from a family member, for instance a spouse, child, or other relative following the results of their TBI.

Within Ireland, it is estimated by the year 2021, Ireland will have a population of 869,143 persons living with a neurological condition, rising from a recording of 762,960 in 2011. (HSE 2007, Strategic Review of Neurology and Neurophysiology Services in Ireland). The NAI Report (2010) presents Ireland's statistics on Acquired Brain Injury as 30,000, with ABI Ireland suggesting that each year, 11,000 people are admitted to hospital with a head injury and a further 10,000 suffering from a stroke. (Wren et al, 2014). Additionally, ABI Ireland estimates that up to 35,000 people between the ages of 16-65 have an ongoing disability as a result of a brain injury. The report further notes that those between the ages of 15-29 of age are three times more likely to sustain a brain injury.

Gender variation in Circumstances of TBI

When considering gender variation in circumstances of TBI, the researcher found a lack of literature on the incidence of trauma outlining both genders. One identified literature was El-Menyar et al (2014) narrative review of 71 articles out of 1150 on TBI among females. Different incidence and mechanism of traumatic injuries were reviewed. Within the Motor Vehicle Crash (MVC), WHO Fact Sheet No:358, March 2013 reported how 77% of road traffic deaths occur among men, with fatality increasing three-fold among young males (<25 years of age). When reviewing literature on Gender and Falls, El-Menyar et al (2014) reports how men and women are at equal risk of fall related injuries, irrespective of age groups and regions. However, the WHO (2002) report indicates fall-related mortality rates are highest amongst men in the low and middle-income countries and non-fatal falls related injuries are more common in women. El-Menyar et al (2014) review concluded with raising concerns surrounding how women are under-represented in all kind of studies including non-trauma medical disorders, which as emphasised by Makama et al (2012), Hoel et al (2009) and Jagsi et al (2009) studies may be due to social-cultural barriers.

Within Ireland, two sources of literature were reviewed. The first was the NAI report (2010). Within this report, O'Connell (2010) stated how, within a given year, three quarters of those who sustain a brain injury are aged between 18-35 and 75% are male. The second literature reviewed within Ireland was the Philips Report of 2008. The Philips Report (2008), outlined how over one third of TBI's occurred within the home, with half of the injuries affecting women and third affecting men. The highest rate of injury occurred during commuting and reflected an overall rate of 15% (Female: 13% and Male: 16%). Other incidence of injuries recorded was as a result of a recreational activity, with a rate of 14% (Female: 9%, and Male 16%). Less than 10% occurred during sport, education or employment activities. Ten times as many men were injured in an occupational setting when compared with women.

Another study which reflected gender breakdown was conducted by Mauritz et al (2008) on 13 centres located in Austria, Bosnia, Croatia, Macedonia and Slovakia. Data was collected between January 2001 and June 2005 on patients for more than 3 years. Hospital-based epidemiology, trauma mechanism and trauma reflected gender breakdown of the total patients of 1169, as 23% (270) female and 77% male (899).

Epidemiological

When considering epidemiological studies on global incidence of TBI, Roozenbeek et al (2013) raise several limitations on existing studies. Firstly, there is a lack of high-quality epidemiological monitoring of data. Estimates are based on registration of emergency registries, hospital admissions and discharge registries, all of which can utilise different definitions/criteria for the recording of TBI data. This limitation is supported by the Philips Report (2008) conducted in Ireland, where concerns were raised surrounding how such European statistics on TBI present with significant variation due to the local interpretation of injury severity and how there exists different methods of case identification.

Secondly, another limitation surrounds the under-reporting of the number of people who sustain a TBI. Roozenbeek et al (2013) outline how this is more likely for patients who sustain a mild TBI and who may not seek medical care, to individuals who live in rural areas or in countries with less developed health care systems.

Mortality

Within the WHO (2006) report on Neurological Disorders Public Health Challenges, mortality rates were recorded utilising the study conducted by Tagliaferri et al (2006), indicating the average rate estimated to be 15 TBI-associated deaths per 100,000 populations per year. The rate of around 10 in Scandinavia, 20 in India, 30 in the United States, 38 in China, 81 in South Africa and 120 in Columbia. (Berg et al, 2005). Within Ireland, the Health Service Executive (HSE) 2005 information on head injury reflects TBI-associated deaths per 1,000 of those who attend the emergency department in hospital to be 0.2%.

Definitions

So far the literature has introduced incidences and epidemiology surrounding TBI. However in order for professionals to best support the needs of the families and the individual post-injury out in the community, the literature will now surround information that defines the

different classifications and possible implications following a TBI in order to promote a greater understanding. Abosch et al (1990) define brain injury as when there is damage done in which the cranial contents have been damaged. The term “brain damage” can take on many forms, and can occur at any stage of an individual’s life, from conception to old age. Within a report conducted by Thurman et al (1995) on behalf of WHO, TBI is defined as an occurrence of injury to the head with at least one of the following:

- Observed or self-reported alternation of consciousness or amnesia due to head trauma,
- Neurologic or neuropsychological changes or diagnoses of skull fracture or intracranial lesions that can be attributed to the head trauma;
- Or an occurrence of death resulting from trauma with head injury or traumatic brain injury listed in the sequence of conditions that resulted in death.

Ref: Standards for Surveillance of Neurotrauma 1995

More recently, Masel and DeWitt (2010) considers TBI to be a chronic disease process as it fits the World Health Organisation definition of chronic diseases, presenting with one or more of the following characteristics: it is permanent, caused by non-reversible pathological alterations, requires special training of the patient for rehabilitation, and/or may require a long period of observation, supervision, or care.

A TBI (craniocerebral head trauma) can occur as a result of a blunt or penetrating trauma from acceleration or deceleration force to the head. Associated signs that can present themselves following the incidence are: decreased level of consciousness, amnesia, other neurologic or neuropsychological abnormalities, skull fracture, diagnosed intra-cranial lesions or death. McAlees (1987) goes onto define how a TBI occurs from a physical trauma to the head, which results in a functional disability and or psychosocial impairment. In developing our understanding further on TBI, Bekker (2000) and April (1997) note how TBI can be classified into two sections, open or closed injury depending on whether or not the skull was penetrated and brain exposure has occurred. The nature of the injury and the different classification of TBI, whether “open” or “closed” impacts as outlined by Lezak (1995) and Povlishock and Valadka (1994) on the difficulties that may be sustained following the incidence.

Severity of TBI:

In developing the understanding further, different levels of severity of a TBI exist. Marion (1999) classifies the levels into mild, moderate and severe categories. Further categories of classification noted by Lezak (1995), Marion (1999) and Sousa (2006) are associated with the length of Post Traumatic Amnesia (PTA) or the level of Glasgow Coma Scale (GCS). Furthermore; Giles (2001) notes how the length of unconsciousness can also be used as an indicator in evaluating the severity of the injury.

Finally, when considering the impact of a TBI on an individual, the implications and complexities are vast, from cognitive and executive aspects, (McAllister, 2011 and Dikmen et al, 2009), changes in personality for instance, impulsivity, irritability apathy (McAllister, 2011), a lack of awareness of deficits (McAllister, 2011), emotional-behavioural and psychosocial aspects as outlined by Karver et al (2012), Khan et al (2003), to physical aspects as outlined by Khan et al (2003), Ragnarsson (2002). Sleep disorders which can affect sustained attention as suggested by Bloomfield et al (2010). To difficulties within social cognition which can as suggested by McDonald (2013) impact on the individual's ability to predict the behaviour of others, share experiences and communicate effectively. As a result of the serious nature of a TBI, an individual may experience an array of deficits from behavioural problems that may co-exist in conjunction with physical difficulties. These functional behavioural problems such as anger, and/or low motivation, distractibility and social skills impairments may only be recognisable to those close to the individual. Such a relationship between behavioural problems and daily functionality is highlighted by Rao et al (2009) who note connectivity between the executive dysfunctions, social interactions and conversational behaviours.

Services within Ireland

As the research took place within Ireland, the researcher felt it was important to briefly outline some information surrounding TBI rehabilitation and the services offered there. One of the major reports completed in Ireland called the Philips Report (2008). The Philips Report (2008) was research carried out over a two-year period on the epidemiology and demographics of traumatic brain injury in Ireland of over two thousand patients with significant TBI identifying causation, injury detail, management, contributory factors and outcomes. The study was funded by a grant from the Department of Health and Children to Professor Jack Philips, Consultant Neurosurgeon. The research group was composed of clinicians from neurosurgery, emergency medicine and public health medicine, nursing researchers and medical informatics. All TBI cases referred to the Neurosurgical Services in Beaumont Hospital, Dublin and Cork University Hospital were included. Cases were identified either following admission to the unit (NSU) or from the national telephone based advocacy service log. Case report forms were generated and entered onto the project database. Data collected as per guidelines set out by the Good Clinical Practice for Clinical Trials. The aim of the report was to inform discussion and promote change.

Summary of findings

- Men are three times more likely to be injured than women. One in six patients was aged between 16-24 years.
- 59% or 3 out of every 5 TBI resulted from falls. The median age for falls was 55 years (95% CI 52-57); 8% of patients were less than 5 years of old and 37% were over 65 years. The male to female ratio was 2:1.
- Two in 5 patients with a severe TBI were treated in a NSU in Ireland; 3 of 5 did not gain access.
- The mortality rate within the NSU was 12%. The mortality rate after discharge from the NSU and the mortality rate for patients not admitted to the NSU were unknown.

Limitations/Recommendations

Even though the Philips Report has brought much needed information on TBI within Ireland, it did however have some limitations. The report only focussed on the early acute hospital setting and the events leading up to the injury. It did not address the patient's entire injury, their progress should they require long-term hospitalisation to an individual's transitional rehabilitation out into the community. The report recommends a national trauma audit would provide information on the outcome of patients who did not gain access to the NSU. The findings also raised concerns surrounding the level of care provided to some patients at times. To address the concerns, the report recommends future TBI management strategies must address both the prevention of injury and the provision of appropriate services in line with internal best practice.

Neuro-Rehabilitation Pathways

Within Ireland, when an individual is diagnosed with a possible TBI, they are referred to either of two Neurosurgical Service Units (NSU). The national unit located in Dublin is called the Beaumont Hospital, while in Cork; there is the Cork University Hospital. Both of these centres provide in-patient care and a telephone based neurosurgical advice service for both traumatic and non-traumatic illness.

Beaumont Hospital founded in 1987

The information below is adapted from the Philips Report (2008):

Beaumont Hospital is a large tertiary referral centre, located on the northern periphery of Dublin city. The hospital provides acute care service across fifty-four medical/surgical specialities. It has a total of 620 acute care beds and is the national referral centre for neuroscience in Ireland. The hospital provides neurosurgical services for a population of approximately 3.4 million people within 22 counties. There are 81 protected neurosurgical beds, including a 10 bed neurosurgical intensive care unit. There are currently 7 consultant neurosurgeons and seventeen non-consultant hospital doctors within the neurosurgical service. There are three designated neurosurgical operating theatres and 116 whole-time

equivalent nursing staff in four neurosurgical wards. An additional 18 allied health professionals provide dedicated service to neurosurgical patients.

There is one neurosurgeon for every 470,000 people. In any year, a consultant neurosurgeon provides out-patient services for approximately 750 new and 2,900 return patients. There are over 2,000 in-patient neurosurgery discharges per year, with an average length of stay of 12.4 bed days. More than seventy per cent of all admissions to the national Neurosurgical Centre are emergencies, and include a large proportion of patients with head injuries. The volume of truly elective admissions to the NSU in Beaumont Hospital is restricted by the exceptional demand for emergency and urgent elective care.

Cork University Hospital (CUH), founded in 1978

CUH is the major tertiary referral hospital in the South-West of Ireland. CUH, NSU serves approximately 1 million people (4 counties). The hospital has 556 acute in-patient beds. The service in CUH is provided by 3 consultant's neurosurgeons and 8 non consultant hospital doctors (including 2 specialist registers). Each consultant performs both adult and paediatric procedures. The NSU CUH has 25 neurosurgical in-patients beds and no dedicated ICU beds. There is one designated neurosurgical theatre and general theatres are used in emergency. In 2004 there was 1357 neurosurgical in-patient discharges from CUH of which 770 (57%) were elective and 587 (43% were emergency. 1327 neurosurgical procedures were undertaken.

Once a patient is discharged from the acute hospital, the rehabilitative system begins to falter. Some of the individuals will be referred to the only National Rehabilitative Hospital (NRH) for intense multi-disciplinary rehabilitation. The NRH was founded in 1831 by the Sisters of Mercy. Information below on the NRH was taken from the NRH's 33rd Annual Report 2013.

The NRH provides the national, and only, post-acute hospital Inpatient Complex Specialist Rehabilitation service for people with an acquired brain injury in the Republic of Ireland. (NRH 33rd Annual Report 2013). Referrals are received nationwide from acute hospitals and the HSE. The Brain Injury Programme within the NRH works in collaboration with the patients, their families and carers towards providing a specialist brain injury rehabilitation

programme designed to lessen the impact of impairment and to assist the individual to achieve functional independent, social participation and community reintegration.

NRH Report (2013) records:

- A total of 269 people were served by the Inpatient Brain Injury Programme in 2013, compared to 243 recorded in 2012.
- The average waiting time was reduced in 2013 for patient admissions to 63 days from a recording of 73 in 2012.
- Of the 269 patients discharged from the Brain Injury Programme, 250 were admitted to the Comprehensive Integrated Inpatient Rehabilitation Programme (CIIRP), and 19 patients were admitted for various interventions such as short period of assessment or review.

The Demographics, Activity and Outcomes for the 250 person served within the CIIRP show:

- 32% (81) had a diagnosis of TBI, 30% (74) Non-Traumatic brain injury, 36% (90) Diagnose of stroke to 2% (5) other neurological conditions.
- Gender recorded 62% were male and 38% were female.
- Age profile of inpatients served by the BI programme was 46.5 years.
- Discharged locations of inpatients served by the BI programme for 2013 show 70% were discharged home, 9% to Acute Care hospital, 14% to residential care and 7% to other.

In a report conducted by the HSE in 2007, the Strategic Review of Neurology and Neurophysiology Services in Ireland, Ireland was noted as having the lowest number of consultant neurologists in Europe, with people waiting up to 2 years to see neurologist to be diagnosed with a neurological condition. The report also recommended that Ireland should have a minimum of 26 consultants in rehabilitation medicine. However, as recorded in The White Book of Rehabilitation Medicine in Europe (2007), Ireland has only 6, with a ratio of

.17 per 100,000 (Shannon, 2011). Another reported conducted by the HSE, Rehabilitation Medicine Programme in 2012 indicates how HiPE data from 2010 shows approximately 30,000 individuals were discharged from hospital presented with a neurological condition and/or amputation with 50% requiring specialist rehabilitation services. Of these, only 510 patients gained access to a specialist rehabilitation service.

Section 1.2 Needs of Families post TBI

Introduction

“Her first words were: “don’t you dare attempt to change my mind about me keeping my husband at home!” Instead of challenging her decision regarding her husband’s care, the psychotherapist asked the wife to explain her position, what she was experiencing, and how she felt her husband’s needs could best be met. After several weeks of discussing her view of her husband’s needs, the questions eventually emerged: What are your needs and how are they being met? This question immediately resulted in the spouse crying intensely. After she was able to clarify her position about her husband’s needs, she could get in touch with what she herself needed”.

Prigatano (1999) pp220

The above passage outlines the complexity of rehabilitation following a TBI of a family member. Such a process is very diplomatic, with the key issue being to help meet the patient’s needs, while simultaneously supporting the family’s own individual needs. As a result of experiencing a TBI, the family and the individual need to deal with a loss of normality which is often, as outlined by Prigatano (1999) considered to be a formidable task. Prigatano (1999) goes on to discuss how rehabilitation professionals ranging from different disciplines include Public Health Nurses, Occupational Therapists, Physiotherapists, Speech and Language Therapists, Clinical Psychologists and Rehabilitation Consultants aim to assist and support individuals and their families through exploring and implementing various individualised interventions in order to promote some form of sense of meaning in life post-injury. Such a process involves guidance, support and courage by all those involved. Furthermore, the more knowledge and understanding as outlined by April (1997), Bekker (2000) and Prigatano (1999) the professional holds about the needs of the family post-injury, the more they will be able to support the family towards re-establishing some sense of meaning in their lives.

During the 1980s and 1990s considerable attention was paid by Degeneffe (2001), Webster, Daisley and King (1999) and Serio, Kreutzer and Witol (1997) towards exploring the burden placed on the family post-TBI with particular emphasis on rehabilitation. In exploring the

family needs following the experience of a loved one with a TBI, it is necessary to consider rehabilitative best practices when facilitating family needs within the rehabilitative programmes. When addressing this consideration, a list regarding rehabilitation best practices for people with TBI was developed by the National Institute of Health (NIH) Consensus Statement (1998). The objective of the NIH Consensus Statement was to provide information regarding effective rehabilitation measures for persons who have suffered a traumatic brain injury (TBI). BSRM National Clinical Guidelines (BSRM, 2003) also developed a model of TBI Rehabilitation referred to as the “slinky” Model. The Slinky Model is currently adopted by Headway and ABI Ireland rehabilitative service providers in Ireland. The model of best practice emphasises how the goals and measures of outcome should be to reduce disability within the hospital and home environment and enhance participation out into the community. Vogenthaler (1987) identified five principles unite these guidelines noting how rehabilitation should begin early after injury, be provided within a holistic manner to include the family, adopt an interdisciplinary approach, therapies to focus on providing support within a treatment setting and out in the individual’s own real-world environment, and for the rehabilitation process provided to be systematically evaluated. Ragnarsson (2002) and Rose (1999) further support TBI best practice of the individual and their families having a pivotal role in the development and planning of rehabilitative programmes.

In order to complement such possible collaborative development of TBI rehabilitative programmes, April (1997), Bekker (2000), Parker (1990), Ragnarsson (2002) highlight the need for future research to focus on the rehabilitative support, needs and effectiveness not just for the person with the TBI but also their families and significant others. They go onto emphasise that families of persons with a TBI should also receive ongoing support and education surrounding TBI throughout the rehabilitative process. Such support and education will enable the family to deal with the added demands being placed on them. However, it is important to acknowledge the uniqueness of each family and how their needs could differ. This concept is supported by Bekker (2000) who observes that there exists a lack of empirical derived information which often leads to assumptions and generalisations being imposed regarding family needs following a TBI.

Staffing

Within Ireland, the Health Service National Service Plan 2014 (NSP2014) followed the enactment of the HSE Governance Act (2013). The plan outlined the type and volume of services, as required under legalisation, to be funded by Government. The report recorded how the government policy on public service numbers required, that by the end of 2014, the health service operated with a workforce of approximately 98,000 whole time equivalents (WTEs). The forecast for numbers employed by the end of 2013 reflected a number of 106,000 WTE's. These figures highlighted the need of a net reduction of 2,600 WTEs during the 2014 to meet the target. These reductions were in addition to an overall reduction of 12,505 WTEs (-11%) since September 2007. Results of such a reduction in staffing could impact on service delivery of rehabilitation which places great intensity and repetition and therefore time demands on the professional and the family. Such demands placed on the therapist can often erode the alliance between the therapist and the patient, as noted by Fordyce (1994) and Prigatano (1999) who raise concerns on how therapists may have difficulty separating their work from their own personal lives. Prigatano (1999) goes onto highlight how such difficulties can contribute to staff burnout and can contribute to high staff turnover within the rehabilitative sector. This is an important area for the researcher due to her professional field of employment. The researcher has worked within the rehabilitative community sector for over thirteen years. In order to consider these implications, the researcher endeavoured to monitor her own personal feelings through the use of a personal self-reflective journal throughout the research

Family/Family cycle

Another area to consider within this exploration of literature surrounding family needs is on the theoretical background of the family and how it may evolve. This will then be followed through with literature detailing the needs of family following a TBI of an adult member and how that may impact on the family cycle itself. Camplair, Kreutzer and Doherty (1990) emphasise the need for the professional to be aware and knowledgeable of the family in terms of their reactions, functioning and needs when supporting a loved one with a TBI. Such a requirement is paramount, as quite often it is the relative who assumes the role of the primary caregiver for many years post-injury. Bekker (2000), April (1997), and Martin (1988) argue

how professionals need to obtain information on the family's needs in order to facilitate the family and the individual with the brain injury in the adjustment process following a TBI.

The definition of a family according to numerous family theorists, for example, Becvar and Becvar (2000), Angelo and Bousso (2001) and Wright and Leahey (2002), constitutes a group of two or more individuals who share a common goal and identity. They go on to state how such unity shares commonality through the concern of providing for certain physical and emotional needs to its members. For the purpose of this research, a family or family system included parents, spouses, partners, and children of extended family members as well as the person with the TBI. The approach taken by Bekker (2000) of valuing and recognising the individual with a TBI as being a member of the family system was used for this research.

Rivara (2015) notes how each family is a system of relationships, roles and delicate interpersonal balances which is characterised by "homeostasis", a state of balance or equilibrium. An internal change like a death or a divorce or an external change, like a job loss or a house move can disrupt this equilibrium and cause an imbalance in the family. Kay and Lezak (1990). In adapting to these changes, the family as outlined by Kay and Lezak (1990) will instinctively try to re-establish a new homeostasis, often involving altering a set of roles or relationships, for instance: a spouse adapting a carers role (Stambrook et al 1994), a parent re-engaging in a parent-child relationship to a sibling taking on additional duties within the home. (Degeneffe, 2001).

In making the relationship of such changes within a family, Daniel (1991) suggests the initial period of crisis after a TBI could be considered as an internal change due to the impact on the family's equilibrium. The family is prompted into an emergency reaction, resulting in normal routines being suspended for a period of time in order for the family to be able to deal with the situation or the event presented. However, in relation to a TBI, such an injury is considered to be a chronic disease process which involves one or more of the following characteristics: permanent, caused by non-reversible pathological alternations which requires special rehabilitative treatment for the patient, or a long period of observation, supervision and care. (Masel and DeWhitt, 2010). The need for such longevity of adjustment impacts not just on the patient but also, as emphasised by Lezak (1988), on the family as an entire unit. Such a concept of the longevity of adjustment for the family was recorded in research conducted by Ponsford et al (2003). The study examined long-term family and emotional

adjustments of 143 families who have experience of a close relative with TBI 2 – 5 years post injury. Findings reflected how the presence of cognitive, behavioural and emotional changes was the strongest predictor of anxiety in relatives and of unhealthy family functioning. Recordings also indicated how anxiety and depression were more likely to be present in those responsible for the care of their injured relative.

Furthermore, TBI is recognised as an instant, sudden and unexpected event within a family system. Literature outlined by Bekker (2000) and April (1997) often focuses mainly on the impact of TBI on the survivor and not the family. However, in the 1970s research began to explore the impact of a TBI on the family system itself. Barnes (1999) argues that, as a result of a lack in appropriate rehabilitation facilities, many people are in receipt of less than adequate rehabilitation which results in the family being placed with unnecessary physical and psychological burden. Historical literature by Stambrook et al (1994) outline levels of impact experienced by a family post-injury depends on:

- (1) the evolutionary stage of the family system within the development life cycle,
- (2) the development stage of the individuals within the family system,
- (3) the relationship of each family member to the person with the injury and
- (4) the shifts that the family have to make in order to cope with the impact of the person with the brain injury.

In developing this concept further, Jackson and Gouvier (1992) have identified eight primary TBI deficits that are likely to impact on the functionality of the family:

- (1) cognitive deficits,
- (2) physical deficits,
- (3) deficits surrounding communication,
- (4) frontal lobe behaviour which could present as the individual appearing with a flat affect, irritable or disinhibition,
- (5) emotional regression,
- (6) social withdrawal, social environmental deficits, when the individual presents with inappropriate social behaviour,
- (7) depression and finally

(8) when the individual is unable to resume the premorbid role in the family unit. Within this area, the family often experience feelings of grief and anger along with guilt.

When considering studies surrounding the impact of family functioning following a TBI, a study conducted by Wood and Yurdakul (1997) examined the relationship status of 131 persons with TBI reported that 49% of the sample had divorced or separated from their partners a 5 to 8 year following TBI. The study did not suggest a relationship between the severity of TBI and marital relationship, instead suggested how the neurobehavioural consequence may be a factor. Another study by Anderson et al (2002) investigated further the impact of neurobehavioural problems of TBI on family functioning and psychological wellbeing of 47 female and 17 male spouse/caregivers, using a cross-sectional design. They found that neurobehavioural problems adversely affected family functioning and caused psychological distress in spouses/caregivers.

In exploring the social impact on the family functioning following a TBI, a study conducted by Douglas and Spellacy (2000) reported 45% of carers' depression scores were related to a lack of social support, of money and excessive responsibilities in caring for the person with brain injury. While a study conducted by Winstanley et al (2006) of 134 close relatives reflected 50% of relatives reported heightened levels of anxiety as a result of fulfilling the care giving role for their loved one. Such caring for the person with the brain injury involves the carer aiding the individual with TBI in daily functioning. (Arango-Lasprilla et al, 2010). In a study conducted by Nampiaparampil (2008) on the prevalence of chronic pain after TBI, findings reflect how almost 50% of primary caregivers in families reported dedicating at least 5 hours a week to their loved ones needs.

In considering possible predictors on carers and family functioning in TBI, Brooks et al (1986) conducted a study on interviewing 42 families affected by a family member with a severe TBI. This research noted that a good predictor of strain on a family post-injury was closely linked with the level of personality and behavioural changes within the survivor. Families reported an increase in stress levels from 60% (year 1) to 74% (year 5) as a result of continuing personality changing, and a 15% (year 1) to 54% (year 2) resulting from increase in threats or gestures of violence from their loved one.

Another research conducted by Ergh et al (2002) examined predictors of family dysfunction and caregiver's distress among 60 pairs of persons who sustained a TBI and their caregivers. Findings reflected the strongest predictor of caregiver distress, with a percentage of 52% related to neurobehavioral disturbance in the person with the injury. Another predictor surrounded the impact of absence of adequate social support for the family, with a recording of 39% increase in caregiver's distress levels over time. The study suggests the importance of rehabilitative professionals promoting caregivers and families of persons with TBI to seek and obtain adequate social support within the community to aid with stress levels. (Ergh et al, 2002). In 2013, the Brain Injury Association of Florida, Inc. (BIAF) commissioned Well Florida Council (WFC) to conduct a needs assessment of 53 caregivers of persons with a traumatic brain injury (TBI) to better understand the barriers and challenges experienced. Findings from this study support Ergh et al (2002) findings on the importance of families accessing and maintaining a social support and network with a recording of (N = 18; 34.0%) towards reducing levels of stress experienced by caregivers following a TBI.

In concluding to this section, Katz et al (2005) considers how a family's coping strategies play a fundamental role in predicting how the family will manage the consequences of brain injury. It has been suggested that families who members support each other, openly express their feelings and are capable of being flexible to change demonstrate improved adjustment to the consequence of brain injury. (Martin, 1988).

Family Life Cycle

Golijani-Moghaddam (2014) defines a Family Life Cycle (FLC) as a framework for understanding family development and defining "normative" transitions within this developmental progression. Each transition involves different family tasks and roles/relations between family members over the normative lifespan. Stambrook et al (1994) outlines how it is important to identify where the family resides in the FLC as this may hold relevance to the impact a TBI may have on the family unit. To aid our understanding, information will now be briefly introduced on the FLC model.

The FLC model views symptoms and dysfunctions within a family system in relation to how events impact on the normal functioning over time. Developmental challenges that families may face over time as supported by Stambrook et al (1994) are:

- (a) A family with young children
- (b) A family with adolescents
- (c) Launching children and moving on
- (d) Between families and young unattached adults
- (e) Joining of families through marriage
- (f) The family in later life.

When incorporating the effect of a TBI within such a model, Stambrook et al (1994) measure how the occurrence of a TBI impacts on the FLC outside of the normal development. Families often deal with life stresses and developmental crises throughout a life cycle. Walsh (1996) suggest how some experiences will have a positive effect of bringing the family closer (i.e. centripetal forces), whilst others may have a negative effect and create distance amongst family members (i.e. centrifugal forces). Within the FLC, family members adopt different roles at different stages. Prigatano (1999) reveals how, as a result of a TBI, often the role of family members become disrupted and change, whilst trying to cope with the event.

Family Role Changes

When a family experiences a loved one with a TBI, it can impact on different family roles; parents, spouses, siblings, and children. The first impact could relate to a parent-child family role, when the parent may be thrown back into earlier developmental phase of caring for a dependent child. Another possible role change involves the impact on a spouse, when the equal adult partnership has being broken. The uninjured spouse is often thrust into the role of care-giver, both for the injured partner and for the family. Siblings whose parent has sustained a TBI may be required to adopt additional responsibilities. Finally, children may suddenly feel they have lost the nurturance and guidance of a formerly loving parent.

In exploring such family role changes further, April (1997) and Stambrook et al (1994) found that the parent-child relationship appears to be more capable of absorbing the stress of such a

role change as opposed to a husband-wife relationship. This may be due to the nature surrounding the parent-child relationship, as in essence, no role change occurs. However, what may occur is that the parent may re-instate the role of the active parent towards their adult child. In the reinstatement of the parent-child relationship, Degeneffe (2001) raises concerns over how the parents may be faced with an extended parenthood often at a later stage in their lives, for instance during retirement. When the individual injured is a child, this can place special burden and pressure on parents. Parents, as emphasised by Silver, McAllister and Yudofsky (2005) may find it difficult to apportion their time and energy to other children within the family, who as a result, may feel neglected by the parents. (Degeneffe, 2001). One study conducted on parents of adult children with a TBI was Karpman, Wolfe and Vargo (1985). The study conducted in-depth interviews with 10 individuals with a TBI and one of their parents. Findings reflected how demands of care giving were categorised as providing constant care and attention, difficulties with coming to terms with the TBI, providing constant guidance and struggling with the urge to be overprotective. However, consistent concern for parents of a child (Allen et al, 1994) or adult child (Degeneffe, 2001) following a TBI is the long-term future care needs of their loved one.

When considering the husband-wife relationship, once an equal partnership, one party may have to adopt a surrogate mother/father role. Such changes in roles, when one partner has to assume control over the other, as documented by Bekker (2000), Degeneffe (2001) and Willer, Flaherty and Coalier (2001) have implications on the effective functionality of the family unit. One such impact is noted by Willer et al (1991) whose research shows how spouses (20 wives and 11 husbands) of survivors of a TBI experience a dramatic life change, often with a reduction in financial resources due to a loss in income, loss of emotional support, sharing and companionship from their partner, to a feeling of being unable to meet their children's needs due to the time demands placed on them as a result of caring for their partner. In supporting such a role change, Powell and Wood (2001) emphasis the need for rehabilitation programmes to include spouse caregivers, and focus on the adjustment of both parties to their new circumstances and roles.

Finally, within role changes it is important to consider the siblings of people who have sustained a TBI. Siblings' needs are often neglected by parents at the early acute hospitalisation and longer term adaption to TBI. (Nodell, 1990). Families strive to adjust to

stabilise the family system in order to deal with the trauma and support their loved one with the TBI. Siblings may feel neglected by the parents who focus their energies on the injured family member. (Wesolowski and Zencius, 1994). As a result, Degeneffe (2001) outlines how siblings may be asked to perform certain duties and assistance around the home, for instance housekeeping (Wesolowski and Zencius, 1994) and assume a care giving role for their loved one. A study conducted by Willer et al (1990) amongst 7 siblings (5 sisters and 2 brothers) who had a brother who sustained a TBI identified how each sibling reported high levels of family distress, concern about the future of their brother, negative changes in the family's lifestyle after the trauma and an increase in their own personal responsibility. The impact on such a role change may cause the sibling to experience anger towards the injured person resulting from embarrassing behaviour (Hardgrove, 1991) to the disruption the injury has on their developing sense of independence and autonomy. (Sachs, 1991).

Another family role change to consider is how the role of the survivor also changes as a result of cognitive, emotion and behavioural sequel to injury. In relation to such role changes in survivors of TBI, Hallett et al (1994) research suggests that often the person with the injury is unaware or underestimates the extent of the impact of their role change in comparison to the reports from family members. Such dissonances often contribute to the levels of stress and conflict experienced between the person with the injury and their family members.

When considering the person with the TBI themselves, the injury may impact on their ability to play an active role within the family life. Tyerman and Booth (2001) report how persons with a TBI often contribute less to the practical, social and parenting roles. Such a decrease in functionality can often require the family members to adjust their lives to cope with their new reality and living with a “changed” person. Furthermore, Parker (1990) found how, as a result of the person with the brain injury requiring a lot of attention, the family member may struggle to accommodate their own needs.

Furthermore, as mentioned before, family members may take on the role of caregiver often without professional training. As a result of such lack in training, the family may find it very stressful to deal with the needs of their loved one. This concept of family strain and the impact on the FLC is raised by Kreutzer, Leininger and Harris (1990a) who highlight that the result of the family member being unable to meet their own needs is that they cannot deal

with the additional workload being placed on them. Family members often find their situation very overwhelming.

Family Crises Stages of Care

When exploring family crises stages, April (1997) notes how when a family is confronted with TBI, they have to deal with many areas, for instance: medical, psychological and social crises throughout the recovery process. As a result of this, the researcher will now introduce a brief literature overview on the major crises faced by a family following a TBI in relation to three interrelated stages developed by Stambrook et al (1994), namely; the in-patient stage, the discharge from hospital stage and the discharge from outpatient stage. It is important for all professionals working within the rehabilitation process to note how each stage presents with different crises for the family to deal with. Such recognition as supported by April (1997) and Lezak (1995) of the family needs during the different FLC stages is important for the professional to consider in order to best support them through each stage.

The first crises stage to explore is the *In-patient stage*. This is the initial trauma stage whereby the family as emphasised by Greer, Knack and Roberts (1992) is generally most concerned with whether their loved one will survive. At this stage all sources as per Kay and Lezak (1990) are placed on the survival and medical recovery of their loved one. April (1997) and Kreutzer et al (1990b) further maintain that at this stage, families will not address future care but tend to concentrate on the present. Sequent to the lifting of the coma, families tend to house high expectations and typically feel that their loved one will return to his/her pre-morbid stance. Furthermore, families tend to be very happy that their loved one has survived and now begin to focus on rehabilitation, believing as outlined by Jackson and Haverkamp (1991) that their loved one will make a complete recovery. However, as time goes on, the family begin to recognise and realise how their loved one has changed and how such changes may be permanent. Reactions to this realisation as introduced by Bekker (2000) tend to be frustration and anxiety and in some cases anger towards the medical professionals. Such anger and heightening of stress levels towards medical personnel may be contributed as emphasised by Martin (1998) to prognostic uncertainty when questions are posed by family members.

The next stage is the *discharge from hospital stage*, where the person is discharged from the hospital and the family is faced with the responsibility of patient care. Kay and Lezak (1990) refer to the early discharge stage as being a “honeymoon” stage where the family feel relieved that their loved one has survived. However, these feelings subside after a while when the family begin to identify possible deficits. Such deficits, apart from physical disabilities, could present as behavioural and emotional changes which Tyerman and Booth (2001) claim cause greater levels of stress and sadness. This concept is supported by Oddy et al (1985) who report how relatives indicate such difficulties as being more difficult to deal with. It is at this stage of crisis Serna and Sousa (2006) maintain that families go through the realisation of the change in the person with the injury and then have to assess their role allocation. To support such realisation, Prigatano (1999) suggests at this stage that professional counselling and guidance should be offered to the family to help them cope with the crisis.

Finally the third crisis stage occurs as outlined by April (1997) when the patient has concluded receiving therapy and is discharged from outpatients’ services. Families are now forced to deal with any further rehabilitative needs on their own. As a result of this, Stambrook et al (1994) notes how families can feel isolated, abandoned and scared of what lies ahead. Family members who take on the primary care role often neglect their own needs and may become resentful to the person with the injury. However, Stambrook et al (1994) go onto express how families are often afraid to voice this for fear of being seen as selfish. Another major crisis occurring within this stage surrounds financial distress. A study conducted by McMordie and Barker (1988) on 100 parents and 50 spouses of adults with TBI, found that family members may suffer a reduction in income, need to borrow money or change employment in order to support their loved one within the family system. As a result, families can find themselves in debt, struggling as recorded by Kreutzer et al (1990b) to cope financially. To prevent such financial stress, where possible, rehabilitation professionals should complete an assessment of needs to identify areas of support for the family during the long and costly recovery process.

When gaining an understanding of how families react to experiencing a loved one with a TBI, professionals need to understand that each reaction is unique. Some families, as discussed by April (1997), will cope with a situation which will seem impossible to deal with to an outsider, whilst other families will become crippled with the situation, even if the TBI results

in minor changes to the person with the injury. However, it is impossible to predict how a family will react when faced with a trauma. April (1997) and Lezak (1988) suggest that how the family react may depend on their premorbid cohesiveness, their attitudes towards illness and responsibility as well as their financial and social supportive structures.

There exist a number of studies surrounding how families react following a TBI. Panting and Merry (1972) were one of the first investigators to explore such a concept post-injury. Within their research, they focussed on gaining information through interviewing 30 severely head-injured soldiers who went through a hospitalised rehabilitation service within a five-year period. Their report found high levels of strain amongst family members, with particular high levels evident in patients' spouses. Panting and Merry also report that a high number of family members utilised potential harmful coping strategies, for instance using tranquilisers or sleeping pills whereby such medication was not prescribed pre-injury.

Another study conducted by Mauss-Clum and Ryan (1981) found, in responses to their questionnaire with wives and mothers of long-term head injury victims, high levels of frustration, irritability and annoyance. Later on in Serna and Sousa's (2005) research, it was found that most spouses reported feelings of depression and anger and voiced reduced levels of personal time for themselves. Almost 50% of the wives within the research related to the following statement:

"I'm married, but don't really have a husband"

Mauss-Clum and Ryan (1981) pp 168

Furthermore, the research findings of Mauus-Clum and Ryan (1981) show how 63% of the wives and 45% of mothers reported experiencing a sense of anger, and how approximately 50% of all of the wives and 20% of mothers reported a sense of guilt of their feelings towards their loved one with the TBI. Sander and Kreutzer (1999) support such findings by outlining how families experience a sense of guilt and anger when trying to come to terms with a loved one sustaining a TBI.

Another research study to consider was conducted by Machamer, Temkin and Dikmen (2002). Within this research the care giving experiencing of 180 family members with

moderate to severe TBI six months post-injury were examined. Their findings contradict the findings of April (1997), Kreutzer et al (1990b) and Stambrook et al (1994), who report a predominantly negative experience of families experiencing a TBI. The research findings of Machamer et al (2002) recorded approximately 80% of families reported an overall positive experience, with only 20% voicing negative experiences. In response to these variances, Machamer et al (2002) suggest that their findings may differ as a result of the possibility that they did not select a sample population that was so involved in the giving of care to their loved one. Furthermore, the early post-injury time of six months may not have given the family time to have experienced all of the caregiver responsibilities and challenges as a result of the TBI.

Finally another section of the family unit to consider surrounding their reactions to a TBI is the siblings. Stambrook et al (1994) report how the reactions of the siblings may depend on the reactions of the parents and on their level of understanding. One area for professionals to consider is how siblings are often inadvertently neglected and forgotten about, especially during the early acute stage of recovery of the patient.

A further point to consider is the family reaction to the rehabilitation process itself. The environment surrounding the rehabilitation of the person with the injury is crucial to the nature and extent of their improvement. Within this environment, Kreutzer et al (1990a) maintain how families can either promote or hinder the rehabilitation process in different ways. One such reaction from the families could be whether their expectations of the capabilities of their loved one are realistic or not, to how well the family cope with their hope surrounding the rehabilitative aspects of the person with the injury. Finally, as emphasised by Kay and Lezak (1990), another area surrounds how the family provide structure, guidance and protection for the loved one with a TBI. This structure and guidance could impact on the success of the rehabilitation should the family promote dependency of the person with the injury on them.

Family Needs

In the literature reviewed, Camplair et al (1990) and Willer, Flaherty, and Coallier, (2001) suggest how few researchers have attempted to rank and quantify family needs. One of the first to do so was Mauss-Clum and Ryan in 1981. Within their research, Mauss-Clum and Ryan (1981) conducted research on a sample of 30 wives and mothers during an initial hospitalisation stage following a TBI. Within their report, participants noted some important needs. These included easy non-medical jargon information on the condition of their loved one, an open and honest discussion surrounding realistic expectations and a form of emotional support for the family members to help them cope with the trauma at hand. However, consideration needs to be given, as noted by Camplair et al (1990), to how the Mauss-Clum and Ryan's (1981) research only addressed the needs of family members during the early acute stage and further research would need to be conducted following the acute stage of recovery. Another researcher to explore ranking family needs was Mathis (1984). The research carried out by Mathis (1984) involved distributing a questionnaire to 26 family members during a patient intensive care stay. Findings from this research recorded the family's need for information pertaining to their loved one's status along with reassurance that their loved one was receiving the best care possible to be ranked high on the family's needs. Mathis (1984) findings were further supported by Kreutzer et al (1990b), Jackson and Haverkamp (1991) and Greer et al (1992) who highlighted the necessity to prioritise the need for families to obtain easily understood information pertaining to the status of the loved one with a TBI. They went onto highlight the desirability of presenting the family with realistic prioritised needs of their loved one post-injury.

In concluding the literature review on family needs, it is well documented as outlined by Lezak (1978) for the need for family members to look after themselves and attend to their own needs whilst caring for a loved one with a TBI. Therefore professionals need to reassure family members that it is acceptable for them to do so in order that they retain their own strength during the recovery process. Without such strength, the family members will find it difficult to retain the level of need for the longevity of the rehabilitative process. In order for the professional to best support the family during this process, Kolakowsky-Hayner, Miner and Kreutzer (2001) stress the importance of the professional gaining an understanding of the existing and additional family needs in order to promote a better more efficient rehabilitative

programme. As mentioned earlier in the literature review, a rehabilitation model needs to focus on collaborating, participating and supporting the needs of the family in order to facilitate a more successful recovery for the individual following a TBI. (Forsch et al, 1997). However, consideration needs to be given, as highlighted by Tyerman and Booth (2001) to not placing the family in the role of needing treatment. Such approach could be met with rejection from families who experience their difficulties solely as a result of the TBI and therefore may refuse to engage in possible family supportive services.

Section 1.3 The Role of the Key Worker

Introduction

Within the National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland (2011), the person-centred approach has been found helpful for people with long-term conditions (Department of Health [UK], 2005a). The report argues how the implementation of the approach will support the individual's independence and improved quality of life, and will substantially reduce expensive and long or frequent hospital admissions (Department for Work and Pensions [UK], 2005; Health, Work and Well-being [UK], 2009). The report suggests further development of a case management approach utilising a key worker role to identify intensive users of unplanned acute and secondary care services. The key worker will anticipate, coordinate and join up health and social services to meet, and thus reduce, the burden of care. (National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland, 2011).

There exist a number of different terms that can be used to describe the role, for example; key worker, case manager, care coordinator, link worker and family support worker. Davies (2007), Sloper, Greco and Webb (2006) and Townsley, Abbott and Watson (2004) note even though different terms exist within research, commonalities in relation to describing the key worker role exist. For the purpose of the research, the term "key worker" was adopted.

Within Ireland, ABI Ireland (a service provider of community based rehabilitation services) utilises and defines the term case manager as opposed to key worker as:

".... a professional who serves as a point of contact for an individual with an Acquired Brain Injury and their family. The Case Manager will seek out and coordinate appropriate resources, monitor progress, and communicate with the person, family, and other professionals as appropriate"

Ref: http://www.abiireland.ie/services_manage.html. [Accessed February 23rd 2015]

Another service provider in Ireland of TBI rehabilitation is Headway who utilises and defines the term key worker as when:

... Each trainee has a key worker assigned to them whose purpose is to develop an individual learning plan in consultation with the trainee and act as a family contact point. The key worker will also liaise with any external agencies in researching further educational or vocational opportunities.

Ref: <http://www.headway.ie/services/servicesbytype/rt.html> [Accessed 23 February 2015]

Duties of a Key worker

When considering the duties of a key worker, the National Clinical Guidelines for Rehabilitation following acquired brain injury published by the British Society and Rehabilitation Medicine (BSRM) 2003 argue the main challenge of rehabilitation surrounds coordination and communication due to the multiplicity of services and professionals required within any given case. To address this challenge, the report offers guidelines surrounding the need of a key worker role to form part of the multi-disciplinary team of rehabilitative professional to act as a central point of communication, coordination and advocacy for the patient within team based. The key worker role should continue to provide case management service to support the individual and their family throughout the course of their recovery. (BSRM, 2003). This form of continuity of care by the key worker can be seen in a study conducted by Trexler (2010) of 22 patients with an ABI. The study allocated a key worker (referred in the study as a resource facilitator) who made contact with participants every 2 weeks (via telephone or home/community visits). The focus of the key worker was returning the patient to work. The control group received the usual care and was not allotted a key worker. The findings reflect that levels of participation improved in the intervention group ($F=9.11$) and more of the intervention group were employed at the time of a 6 month follow up ($n=7$ vs $n=4$).

Research carried out for ABI Ireland in 2009 on the North East HSE region considered the key worker services and cost effectiveness provided. The study showed how the role facilitated discharges from nursing homes (€311,060), and hospitals (€3,016,482), prevented admissions to nursing homes (€284,112), and reduced level of support (€100,232). Once salaries of staff were deducted, the report presented a cost saving of €3,496,444. (Whelan, 2010).

When considering the resourcing of the key worker role, the National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland (2011) advocate for the need of a key worker (typically within the community) to be assigned to intensive users of unplanned acute and secondary care services at the early acute stage to help reduce the burden of care and co-ordinate services. The key worker role can be represented by different professionals within a PCC team, for instance a Public Health Nurses (PHN) to specialised TBI case workers as seen within service providers, for instance ABI Ireland and Headway.

Designated role of Key Worker

When considering how the key workers are assigned, the researcher will explore two different approaches. The first approach refers to the designated role. Within this professional role, the key worker provides full time key working duties for the family. Such designation promotes the ease of more time to be assigned to the key worker enhancing greater availability of the service to the family. However, in contrast Greco et al (2006) raise concerns over how the designated role may support a hybrid of professions which can result in losing the skills base should the key worker leave.

Non-designated role of Key Worker

Alternatively, the second approach reviewed concentrates on the professional adopting the non-designated key working position. Within this position, the professional provides key worker activities in addition to their primary professional role. The advantages of a non-designated key worker position vary, from providing a variety of roles for the professional to possibly increasing the professional's knowledge and skills base. However, when exploring possible disadvantages, areas surrounding conflict of priorities between different roles to the availability of practice need to be considered. Within a study conducted by Greco et al (2006) on the views of staff, findings reported staff interviewed expressed difficulties towards the allocation and justification of time for their role, the implications of juggling two roles, to how such a dual role can place large emotional demands on the key worker. In developing this last concern Greco et al (2006) note how key workers may be at risk of becoming too emotionally involved, especially when there is no professional supervision and support in place for them. In addressing such a concern, Greco et al (2005, 2006) highlight the need for

key workers to meet with other key workers for peer support and for the promotion of shared learning through the transfer of skills.

Model of Service

In developing our understanding of the key working system further, two different models of service will now be briefly explored; the Transdisciplinary Model and the Multi-Agency Model of Service.

- **Transdisciplinary Model**

The first model to explore is the *Transdisciplinary Model*. Within this model of service, the key worker role is seen as an essential component in the provision of a coordinated integrated service for families. The model acknowledges and promotes the importance of the need for flexibility in the application in order to respond to the unique individual and family needs. Such a model is considered by Harrison (2007) as effective in the short term when providing reassurance and empathetic support quickly. Furthermore, the model, as highlighted by Davies (2007), promotes the sharing of knowledge and the building of trust amongst the team. This concept is further supported by Foley (1990) who describes the transdisciplinary model as a system that involves a:

“deliberate pooling and exchange of information, knowledge and skills and the crossing and re-crossing of traditional disciplinary boundaries by various team members”. Foley (1990)

Such a system of collaboration is considered by Foley (1990) as a paramount component of an effective transdisciplinary team. The practicality of this system involves the team members being committed to educating, listening and working collectively together across different disciplinary boundaries. The adaptation of flexibility, as outlined by Davies (2007) further promotes the encouragement of role release of all disciplines so that an effective implementation of coordinated services is achieved. Moreover, there is a requirement from

the team to commit to each other and accept responsibility for their own discipline, as well as other responsibilities not usually associated within their role. However, Davies (2007) raises concerns surrounding how such role release could generate challenges and go against the more traditional approaches adapted by therapeutic staff. The Transdisciplinary Working Model is seen as a cost effective way of delivering a service, particularly when there is a shortage of therapists. This concept is supported by Davies (2007) who notes how the model promotes a more multi-skilled, shared learning team, whilst also enabling less staff to be involved with the family at any one given time.

- **Multi-Agency Working Model**

The next model of service to briefly explore is the *Multi-Agency Working Model*. Within this practice, Townsley, Abbott and Watson (2004) emphasise the need for services, for example; the Department of Health, Social Services and Education, to counselling services to work together and develop the multi-agency model, so that services may be coordinated in a beneficial factor. Within Ireland, the National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland (2011) support this practice by raising the need for professionals to have the ability to work as part of a team, whilst addressing the challenge of supporting continuous upgrade of knowledge and skills.

Another area to consider within the key working model of service, as outlined by Greco et al (2005) is the need for key workers to be allotted with sufficient time to fulfil their role. In developing this consideration, Holmes (1990) raises concerns surrounding the complexity issues of facilitating the needs of families with a loved one with a TBI, whilst noting the already high existence of case loads for staff. Within the National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland (2011), emphasised one factor underpinning the planning and service delivery of neuro-rehabilitation is how it is highly labour-intensive and requires a lot of clinical, managerial, administrative and support skills. The report highlights how HSE services or in non-statutory agencies operate in increasingly pressured situations and struggle to address the growing demands for services within the existing available resources. To address these demands placed on service delivery, the plan supports the attachment of any health worker in neuro-rehabilitation to be attached to a

rehabilitation team. (National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland, 2011)

Furthermore, Holmes (1990) goes onto argue, how in order to support the family needs, there exists a need for vast amounts of time to be allocated to the key worker so that they may facilitate each need. Greco et al (2005) further explore this need by recommending how a “non-designated” key worker should work with three families, whereby a “designated” key worker could work with around thirty families. Within Ireland, staff ratios of case managers recorded by ABI Ireland in a presentation titled *innovation, effectiveness and value for money surrounding rehabilitation services (2011)* indicated a national picture of 9 ABI Case Management Services who were providing a key worker service to 1000 individuals within the community. Within Headway, the key worker ratio varies from 1:10 within the Community Based Rehabilitative Training programme to 1:20 in the Day Rehabilitative programme.

Stages of Implementation

When considering when the key worker service should be implemented, it is necessary to consider the recovery process of the individual and their family with a TBI. Initially, during the hospitalisation stage, families would receive support internally within the hospital setting. They would often experience decisions about their loved one being made for them by the medical practitioner. Moreover, the professional as outlined by Mubarak (1997) adopts the dominant position of the expert, noting how the theory of the “doctor knows best” may be instigated. Within this decision-making process, the family may be viewed as a secondary capacity, adopting the sole function of providing the necessary information so that the professional can make the decision. When considering this practice of decision-making, thought needs to be given to how families, at the early intense traumatic stage of a TBI may welcome such relief from the decision-making process. It is important to note how such relief from the decision-making process may reduce the family’s levels of stress and strain due to the total responsibility being given to the professional. However, an opposing argument could be how such a practice can lead to disempowerment and dependency of the family on the professional. Furthermore, consideration raised by Goodinge (1998) and Murray (2000) concerning the implications of practising such a decision-making process

may, following the post-discharge stage contribute to how many services still fail to empower families within their role as carers. It is at this stage, following the discharge stage from hospital that the system for families in Ireland begins to falter. Many families leave hospital, after becoming dependent on the medical professional without any “flow through” support service. They often feel abandoned without any form of support or guidance. This lack of support is noted by Maia, Terra, Coimbra (2003) who outlines how patients may be discharged from hospital without guidance being given to their family on how cognitive changes could affect their loved ones acting or thinking, for instance: forgetfulness, poor attention span and concentration, fatigue, sensitivity to light or sound, changed taste and smell. In support of such considerations, Beresford’s (1995) study surrounding the exploration into the complex framework of services encountered by parents of children with disabilities had various worrying findings. One such finding was how 60% of parents had seen at least five professionals in the past year. They went on to discuss how less than half of the parents commented having access to a social worker fewer than six times in the previous twelve months. Furthermore, the study highlighted issues of dissatisfaction with the professionals the families had contact with, reporting how half of the parents commented negative non- collaborative relationships with their contact.

In addressing such a gap of need, it was the researcher’s intention that the development of a “flow through” model of the designation of a specialist TBI key worker would provide the support and guidance required for the family. According to Wilkinson (1999) and more recently corroborated by Tyreman and Booth (2001) little has been written about the best way to provide support for families post-TBI, especially when there exists long-term cognitive and personality changes. To address such a challenge during the research, the researcher considered possible suggestions outlined by Angelo (1999) in educating, partnership and building on knowledge. In addressing the first possible challenge of education, the researcher ensured all professionals participating on the research were sensitive and appreciative to the complexity of the family unit when educating the family on their service. The second possible challenge to consider was to encourage and promote collaboration with the families involved in the research. Finally, the third challenge was addressed by encouraging professionals to self-reflect and build on their knowledge concerning the needs of the family. Such an approach is also seen in a study noted by Tyreman and Booth (2001) carried out in the UK, which showed how families need support initially through listening and identifying

the needs of the family through an assessment. This was then followed through with educational workshops to work in collaboration and partnership with the family in the development of the rehabilitative plan.

One such method of addressing these possible challenges in relation to the family was to present meetings within an empowering manner as emphasised by Dunst, Trivette and Deal (1994). The aim of the meetings was to offer support and empower the family by mobilising suitable resources, whilst identifying and developing the family's own unique strengths. This practice is further supported by studies conducted by Kreutzer, Serio and Bergquist (1994) which involved a Family Needs Questionnaire (FNQ) being administered to 119 family members of people with a TBI. Within this study, findings supported the need for the family member to receive honest and accurate information within a respectful supportive manner. However, in contrast, consideration needs to be given to concerns raised by Purves, Riddell and Weedon (2008) about how professionals can have their own worries and preoccupations which might pre-dominate the family needs meeting. Therefore questioning whether it is possible for the needs of the family to be placed at the heart of all of the planning and review meetings.

The "Flow Through" model of key working adopted as indicated in *Appendix One - Designated Specialist Key Working Model* addressed the exploration of the family needs through the appointment of an independent designated specialist key worker within a multi-disciplinary service. Such a designation was adopted, initially through the independent key worker status to accommodate concerns raised by Hall and Hill (1996). The intention was by adopting the independent key worker position, families would feel free to openly voice their opinions and not be in fear of their loved one losing the placement. The designated key worker position was adopted to support more time being allowed to concentrate on the family, rather than being torn between possible conflicting responsibilities – the family and the agency. Furthermore, the allocation of a specialist TBI key worker, as highlighted by Goodinge (1998) enhanced the alliance by bringing knowledge and expertise within the unique field of TBI to the partnership.

Finally, the decision to utilise the multi-disciplinary approach within the research was as the result of acknowledging how such collaboration would ultimately provide a more coherent

service which will be more beneficial and supportive towards the family's needs. When deciding on adopting the multi-agency approach, consideration was given to how professional disciplines may differ and cause alienation amongst the team. Such alienation may present itself as a result of how different professionals may not share similar language and ways of thinking. Furthermore, different disciplines may contain different ways of working to achieve their aims. In addressing these concerns and in support of The Care Co-Ordination Network UK (2006) practice; the researcher incorporated a proactive inter-agency approach towards addressing possible pitfalls as they occurred. Furthermore, the practice could also provide an opportunity to pool together resources and knowledge in order to gain a better understanding of the roles and expertise each party has to offer. However, the researcher was aware that such a paradigm shift as outlined by Perri 6 et al (2002) and Riddell and Tett (2004), could take time to implement and extend after the completion of the research.

After exploring the timing of when a key worker service may be implemented, there is a need to explore what resources the key worker may utilise in order to promote an effective beneficial alliance. One such channel of support is through the exploration of internal resources, for example: the parents reported by Carson (1993), spouses as seen by Moore et al (1991), siblings as introduced by Orsillo, McCaffrey and Fisher (1993) to children as highlighted by Sachs (1991). Such variance in the uptake of carers' post-hospitalisation is an area, as emphasised by Lees (1988) to consider in order promoting a more effective key worker model of support. In developing this consideration, the researcher acknowledged how such changes in family roles not only affect the view that the family member has of him or herself but also how they may view others.

Alternatively, the key worker may explore various different external resources in order to facilitate the family needs. One such area explored was in relation to the area the researcher works in, that is community rehabilitation for people with a TBI. Unfortunately within Ireland, services are few and far between and there are many families living with a loved one with a TBI who have no contact or even awareness of such services. This concept is supported by Spivack (1994) who comments on how current services for families of those with a TBI are largely fragmented, inaccessible and insufficient. Moreover, such fragmentation of services can also contribute, as outlined by Gordon, Parker and Loughran

(1996) and Sloper and Turner (1992) to families experiencing confusion and higher stress levels due to the need for numerous contacts and demands placed on them from different workers. Such lack of a single point of contact can as emphasised by Barton and Clarke (2006) exacerbate the stress levels of the family due to the constant need to reiterate and explain their situation to multiple professionals on an ongoing basis. Therefore, such fragmentation of services could portray, as outlined by Sloper (1998) a piecemeal and service-led service rather than a needs-led service. However, DeJong (1999) argues how such an inference is predominantly based on anecdotal information and individual case study families and not on empirical research. When exploring literature surrounding the key worker in Ireland, support for the assignment of a key worker can be seen within the EPSEN Act (2004) and the Disability Act (2005), all of which highlight the need to provide the assigning of a single point of contact i.e. a “key worker” to families to support and assist in the care planning of their loved one.

Finally, to strengthen our understanding of the role of the key worker, consideration was given to the duties of the role. The first duty explored focussed on the planning of meetings. Within this duty, the key worker would be required to plan regular meetings with the family in order to assist with the co-ordination of support, whilst also collaborating with the diverse multi-disciplinary team of professionals and services. The importance of such regular meetings is supported in studies carried out by Greco and Sloper (2004), where findings reflect how families benefit from regular meetings, obtaining relevant information and assistance with correspondence issues and this assists in reducing their levels of stress. In developing this concept further, within a later study conducted by Greco et al (2005) families expressed the need for key workers to be more proactive in the consistency about frequency of contact with families. However, one would need to consider the implications of cultural and religious beliefs noted by Kenny and McGilloway (2007), and how such beliefs and cultures could have an impact on the participatory level of families within the partnership. Within this study, regarding services for children with learning disabilities in Ireland, Kenny and McGilloway (2007) cite:

“Ireland tends to be characterised traditionally, by strong societal and particularly religious norms, which may lead to a misplaced stoicism and lower levels of parental help seeking”.pp227

The second duty explored focussed on the key worker offering guidance and education surrounding the specific disability. Such dissemination of information may, as highlighted by Wesolowski and Zencious (1994), be channelled through handouts and articles on known TBI services within the local community. Within Ireland, the two main service providers of Community TBI rehabilitation, ABI Ireland and Headway both have TBI service providers' information and TBI leaflets which are distributed within the community health professionals and to families upon being referred to the service. All of these information leaflets can also be viewed on both websites. (www.abiireland.ie and www.headway.ie. [Accessed February 24th 2015]

There is also a need, as outlined by Sloper (1998) to assign a specialist within the assigned multi-disciplinary team of professionals who has knowledge of the specific area of disability. Sloper (1998) notes how such designation of a specialist will benefit the partnership alliance in different ways. Initially, the promotion of trust may be strengthened due to the heightened levels of knowledge. Furthermore, by the key worker having specific knowledge, appropriate facilitation of referrals and access to information and services may be enhanced. However, thought needs to be given to concerns emphasised by Greco et al (2005) that expectations may be raised that may not be able to be facilitated due to availability and financial implications and resources. In developing the key worker role further, consideration was given to how such a key worker may promote dependency as opposed to independency amongst families. However, in contrast Greco et al (2005) continue to argue how alternatively such key worker duties can also assist with reducing stress levels experienced by families.

In order to develop the effectiveness of the key worker role, areas of consideration as outlined by Greco et al (2005) will be introduced. The first area considered identified the need for a clear key worker's role definition. This concept is further supported by Barton and Clarke (2006) who emphasise how a clear definition of the role can promote better understanding, which is a vital component in the development of the key worker role.

To address such a need, the role of the key worker was clearly defined at the early invitation stage of the research. This definition was periodically reviewed by all participants to enhance guidance and understanding. The second area considered was the need for supervision and

training. Within such a consideration, thoughts were given to the cost implications, especially within the current economic climate. However Greco and Sloper (2004) would argue how if training is not addressed and invested, it can result in an under-developed service with an insufficient level of awareness of best practice. To address this concern, the researcher felt that through the research and continuous academic studies, she would continue to learn and grow within the field of TBI. The researcher also felt that with the support of her supervisor and indeed the families and professionals that she worked with, a greater understanding and appreciation into the needs of families who live with a loved one with a TBI would be obtained.

Section 1.4 How the Key Worker can educate families and professionals post TBI

Introduction

Family members have a wide range of needs in different phases (acute, discharge to transition out into community stage) during the recovery of the TBI patient. (Coco et al, 2011).

When considering the aspect of rehabilitation, Barnes (1999) notes how rehabilitation after TBI is considered to be different from most other medical and surgical specialities, due to it being based on the principles of education. To address the need of education, Barnes (1999) suggests the individual with the TBI and their family to be involved and provided with education on the complete rehabilitative process to support meaning. This practice of educating and including the family on all aspect of the rehabilitative process is supported by National Clinical Guidelines for Rehabilitation following acquired brain injury published by the British Society and Rehabilitation Medicine (BSRM) 2003.

Providing TBI education for families occur at different stages of rehabilitation.

- **Acute stage on TBI:**

Initially, educational intervention should occur at the time the TBI diagnosis is established (Clinical Practice Guidelines, 2009). However, studies conducted by (Lefebvre and Levert, 2006; Lefebvre et al, 2005) reflect a lack of education being offered to relatives, that is, inadequate information about brain injury and the patient's prognosis. In a study conducted by Lefebvre et al (2008), findings reported how families felt that they were not educated on potential problems and therefore were not prepared for when they met the patient for the first time after the injury. In support of early acute education for the family, a study conducted by Lam and Beaulieu (2004) recorded family members felt better able to cope with the trauma once they received information and understood the injury.

Further reviews conducted by Coco et al (2011) centred on 22 articles, 20 on the family perspective and two on the nursing views of interventions surrounding support for TBI patients' family members in neurosurgical nursing. Results indicated how family members require education on brain injury symptoms at the early diagnosis stage through to practical implications of the brain injury in relation to daily activities. (physical problems -weakness, headaches, and cognitive problems – memory (Arango_lasprilla et al, 2010, McCabe et al, 2007) to Speech production and comprehension difficulties (Rotondi et al, 2007).

Follow-on Practical education:

Coco et al (2011) argue that education should not stop once a patient is discharged from hospital but should continue on into the community setting and address the educational needs of the family towards practical support on everyday activities going forward. A study conducted by Rotondi et al (2007) reported how families received too little training for the future and experienced uncertainty and fear because the TBI patient's condition was difficult for them to understand.

Key worker:

The role of the key worker of supporting education for the family members is recommended by the (BSRM, 2003) to continue take place throughout the different rehabilitative stages. The researcher's methodology, as a key worker was to adopt a phased inclusive method of gradually supporting the transition of individuals and their families through the educational process of rehabilitation from the acute stage of recovery out into the discharge stage of community integration. Within Ireland, the two service providers, ABI Ireland and Headway (www.abiireland.ie and www.headway.ie. [Accessed February 24th 2015] key worker's role provides ongoing education support for the family members from the early acute stage out into the community. At the early acute stage the key worker works in collaboration with the existing neurological hospital team, for instance nurses and doctors. Following the patient being discharged from hospital, both service providers, continue to provide ongoing education on the practical implications of the injury towards activities of daily living working in partnership with the designated primary care team. This collaborative educational approach in working practice of the key worker supports the guidelines outlined within the National

Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland (2011). The practice of providing TBI information/education is supported in a study conducted by Bell et al (2008). The study setting was within an Emergency Department to Community setting, and consisted of 366 patients with a mild TBI. The intervention group received phone call support, contact number was given and additional information on TBI and where to get help was offered. The control group received the usual care (patient handout and outpatient treatment if prescribed). Findings reflect that patients who received the additional support and education reported fewer symptoms 6 months post injury than the control group (6.6 differences in adjusted mean symptom score, 95% CI 2.2 to 5.2).

Community Based Rehabilitation Model:

On a broader scope, the researcher identified how the research was to be centred on a Community Based Rehabilitation (CBR) Programme structure and considered how the concept of education could exist within such a community supportive mechanism. The WHO defines CBR as:

“Community-based rehabilitation (CBR) focuses on enhancing the quality of life for people with disabilities and their families; meeting basic needs; and ensuring inclusion and participation. It is a multi-sectoral strategy that empowers persons with disabilities to access and benefit from education, employment, health and social services. CBR is implemented through the combined efforts of people with disabilities, their families and communities, and relevant government and non government health, education, vocational, social other services.”

Re: WHO Report (2010a)

Community-based rehabilitation (CBR) is a strategy approved by WHO (2010a) for general community development in supporting the rehabilitation, poverty reduction, equalisation of opportunities, and social inclusion of people with disabilities (PWD). The CBR matrix (WHO, 2010a) provides a basic framework for the development and implementation of CBR programmes. The matrix highlights the need to address rehabilitation at different aspects of life including the five key components: health, education, livelihood, social, and empowerment. The CBR programme is not meant to implement every component, as it is recognised how not all PWD require assistance in each component of the matrix (Iemmi et al, 2013)

For the purpose of the research, the programme addressed the needs of the primary carers within the research and their loved ones, which were prioritised and addressed. One such component identified and addressed was the need for Education on TBI. The aim supported Iemmi et al (2013) concept that by providing one component, in this case TBI Education to the primary carers, the individual with the TBI and other professionals who participated within the research, for instance the PCC team, that the consequences of the TBI may be reduced through identifying areas of development, for example sourcing assistive devices to achieving a greater awareness and understanding of TBI.

Efficiency of CBR:

Although CBR is currently implemented in over 90 countries, in reality only 2% of PWD are estimated to have access even to basic health and rehabilitation services (Meikle, 2002). To address this need, Hartley (2009) and WHO Report (2011) promote the need of the scaling up of CBR programmes, but also raise the need for stronger evidence base on the efficacy and effectiveness of CBR programmes to be researched. When considering research on the effectiveness of CBR after a TBI, a study conducted by Altman et al (2010) surrounded the effectiveness of 489 individuals who participated in a CBR programme as opposed to individuals (114) who were precipitously discharged. The intervention consisted of postacute brain injury rehabilitation (PABIR) delivered in the home and community by certified professionals staff on an individual basis. The results showed significant differences between the groups when reviewing the Mayo-Portland Adaptability Inventory (MPAI-4). The MPAI-4 was completed on admission by means of professional consensus. Whilst at discharge the MPAI-4 Participation Index was conducted through telephone contact at 3 and 12 month follow-ups.

Another study on the potential benefits of CBR in relation to TBI was conducted by Powell et al (2002), who employed a randomised controlled design in a follow-up study of severely injured individuals who were 3 months to 20 years post injury. The 46 participants who availed of CBR demonstrated significant greater gains in daily living skills and psychological

wellbeing, compared to the group who only received written information at discharge from inpatient rehabilitation.

PCC Teams Education:

Finally, Beasley et al (2007) highlight the need to promote research and education into the area of primary care to promote health outcomes and enhance the field of primary care. By including primary care professionals within research, it supports the right questions being asked, results from research to be used in practice, and a scholarly and evidence-based approach to primary clinical care to become the norm. (Beasley et al, 2007, and van Weel and Rosser, 2004). Through inclusion of primary care teams within educational research, Maeseneer et al (2003) outline how the integration of multiple methods of comprehension can be ascertained, “self-reflective” practice encouraged, to bridge the gap between evidence and practice. This form of continuous professional development (CPD) is in line with the National Policy and Strategy for Provision of Neuro-Rehabilitation Services in Ireland (2011). The practice facilitates one of the perquisites suggested for effective neuro-rehabilitative services of providing appropriate education and training to healthcare professionals towards informing of service users’ needs with appropriate actions. (The HSE document *Education and Development of Health and Social Care Professionals in the Health Services 2009-2014*, HSE, 2009b).

Section 1.5 Primary Care Team Model

Introduction

Over the past few years, many nations, for instance: New Zealand, UK, Canada to Ireland have identified the need for better health care due to a combination of reasons, for example: burgeoning medical technology, ageing population and increased patient expectations. (WHO, 2000). When relating these reasons to the field of TBI, modern technology has supported an increased survivor rate of TBI. (Marion, 1999) and has created a new population of individuals who are in need of long- term treatment and rehabilitation from their traumatic injuries. (Ireland's National Rehabilitation Strategy, 2011., and the NAI Report, 2010). These reasons combine together to create an escalation in the costs incurred surrounding the provision of brain injuries health and social care. For instance: Walsh et al (2013) and Horgan et al's (2013) studies in Ireland on the experiences and long term needs reported by stroke survivors living in the community, to Thompson et al's (2012) study in the US on the Utilisation and Costs of Health Care after Geriatric Traumatic Brain Injury.

As a result of such identification and recognition, there has been an upsurge in many countries towards developing policies surrounding better health care with the use of primary care models to support a reduction to limit the spiralling costs of secondary and tertiary care. Some examples are: New Zealand (2001) launched a primary care strategy encouraging the population to self-refer on a voluntary basis's with a primary care provider, in Canada (2001), at Saskatchewan, a Commission on Medicine produced a report recommending the integration of the delivery of primary care to the population, to within the United Kingdom a document entitled *Primary care, general practice and the NHS plan* was produced in 2001.

Global developments on primary care health strategy have greatly being impacted by a report conducted by the WHO (2000). The WHO (2000) identified how many countries were falling short of their potential in providing an effective, beneficial health service for the population. As a result of this report, many countries on a global level have taken up the findings and are searching for ways to improve their health service through better equity, efficiency, effectiveness and responsiveness. However, it is important to consider thoughts

by Atun (2004) that highlight even though there appears to be some level of generalisation, there is still no agreement on a global scale of the most optimum way of structuring and delivering a health service that is cost-effective and beneficial to the population. Some agreement on a global level has occurred through the acceptance of the role of PHC as emphasised by WHO (1985), Ham, Robinson, Benzeval (1990) and the NHS (1994) and within Ireland through the Health Strategy (2001). All of these strategies aim to provide a structure for a cost- effective health care system.

Ireland's Health Strategy Legislation

Within Ireland, the overall national objective of the Health Strategy (2001) was to improve better health services for all. It was identified how such an objective would require mobilisation of time and development across various sectors. Such mobilisation would ultimately, once completed, improve the ease of access, improve the quality of services, generate greater response and timing issues to appointments and improve the level of care received by the individual. To aid the development and implementation of the Health Strategy (2001) reform, the HSE and the DoH have undergone annual reports reflecting a strategic framework for the reform of the health service.

In 2012, The Department of Health presented the “Future Health – A Strategic Framework for Reform of the Health Service 2012 –2015” detailing actions to be taken in development of the Health Strategy (2001). The core of the Government's health reform programme is a single-tier health service, supported by Universal Health Insurance (UHI) designed to promote equality and access for Ireland's population. The Irish government continue to work on the implementation of the Health Strategy reform through the development of National Service Plans (2013, 2014 and 2015). Each of the annual National Service Plans sets out the type and volume of services to be delivered by the HSE and is informed by the Department of Health's (DoH) Statement of Strategy (2011) and Future Health, A Strategic Framework for Reform of the Health Service (2012).

Within Ireland's Health system review, McDaid et al (2009) reported how Ireland's primary care sector attention focussed on the level of utilisation and access by those individuals who have nether a medical care nor private health insurance. In 2005, the government

significantly raised income guidelines for medical care entitlements and introduced a new GP visit card for an estimated 230,000 individuals with incomes slightly above the maximum limit to qualify for a medical card. In another move to improve access to primary care services, by the end of 2005 out-of-hours GP cooperatives were available in at least part of 25 of the 26 counties within the country. (McDaid et al, 2009). Another key component of the Government's strategy to tackle inequities in access to treatment has been to establish the National Treatment Purchase Fund (NTPF), which allows for those waiting for more than three months to be treated by private sector in Ireland or the United Kingdom. HSE figures quoted in an article in, *The Journal* (2012), [Accessed March 20th 2015], showed a figure of 178,000 people in Ireland were waiting to see a specialist at an outpatient clinic and more than 300 patients were waiting over four years to be seen by a consultant after being referred by their GP.

PCC Model in Ireland

The Health Strategy (2001) within Ireland is currently in the process of developing the implementation of an inter-agency team-based approach to primary care provision.

(Curry, 2011). The members of the primary care is purposed to include GPs, PHNs, health care assistants, home helps, physiotherapists, OTs, social workers and administrative personnel. Furthermore, to cater for the more enrolled population, the strategy also aims to include the inclusion of other care professionals consisting of S&Ls, community pharmacists, dieticians, CWOs, dentists, chiropodists and psychologists.

One of the key areas of reform in the Health Care Strategy (2001) was service provision in primary care. The Primary Care Strategy (2001) aim was to integrate more the primary, secondary and continuing care services. Central to reform was the development over a 10-year period of 400- 600 multidisciplinary primary care teams across the country. Each primary care team would service a population between 3,000 and 7,000 people, depending on the location (urban or rural area). The strategy envisaged that 50-60 of these teams would be placed by the end of 2005. (McDaid et al, 2009). To-date 423 primary care teams were reported to be providing services for the population. (Irish Medical Times article, “ Some 423 PCTs are ‘in place’ countrywide” 2014) [Accessed March 18th 2015]

When relating the development of multi-disciplinary PCT's towards TBI, the National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland (2011), outline the need to develop and invest in the existing community based neuro-rehabilitation teams in Ireland is raised in order to meet the LITI criteria for rehabilitation. The LITI criteria outline how rehabilitation should be meet, Local, Individualised, Timely, Integrated.

PCC Model

In order to provide a systematic review of the primary care system and possible diverse focus on reliance, consideration was given towards current health care system, potential reliance on medical specialists versus the probable development of a health care system that could rely on general practitioners and primary health care.

Primary care means working with the health problems at all levels of complexity. Anderson and McFarlane (2000) maintain the main difference between primary health care and primary care is that primary health care is fully participatory and involves the community in all aspects of health and its subsequent action. The model enables the PCC to be the first point of contact for each individual when accessing health and personal social services. When considering the term “primary care”, it is often synonymously used in conjunction with “general practice”. While general practice is a key element to the role of the PCC, the PCC has a wider, generalised focus on overall health and personal social services which is delivered by different professions. The PCC play a vital role not just in the health treating illness side, but also towards supporting and empowering the individual and their families within the process of providing and maintaining an effective care package. The functions of the PCC are vast, encompassing many different areas being addressed. They include a range of services for example, Discharge team from hospitals, GPs, PHN, general nurses, social workers, practice nurses, midwives, community mental health nurses, dieticians, dentists, community welfare officers (CWO), physiotherapists, occupational therapists (OT), home helps, health care assistants, speech and language therapists (S&Ls), chiropodists, community pharmacists, psychologists and others. Currently the PCCs in existence within Ireland are made up of a combination of these disciplines, often working in isolation.

Definitions (Specialist v Primary Health Care)

The term specialist care is defined by services that are delivered by narrow professionals.

Within a NHS news archive article on November 6th, 2013, *NHS England launches major exercise to shape the future of specialised services*, a specialist is defined as:

“Specialised services are those services which are provided from relatively few specialist centres. Conditions treated range from long-term conditions, such as renal (kidney services), mental health care in secure settings and neonatal services, to rarer conditions such as uncommon cancers, burn care, medical genetics, specialised services for children and cardiac surgery”

Ref: . <http://www.england.nhs.uk/2013/11/06/spec-serv/> [Accessed February 24th 2015]

Within the DOH, UK (2002) Specialised services national definition sets:

“Specialised services are defined in law as those services with a planning population of more than one million people. This means that a specialised service would not be provided by every hospital in England; generally, it would be provided by less than 50 hospitals”.

Re: DOH (2002). Specialised Services National Definitions Set.

When considering TBI specialist rehabilitative care, the NAI (2010) Report in Ireland defines:

“A specialised rehabilitation service may be broadly defined as “a service for patients with severe complex disabilities whose rehabilitation needs are beyond the scope of their local rehabilitation service”.

Re: NAI Report, pp 34 Chapter 3.

Another definition on specialised rehabilitation care for brain injury is DOH (2009), Specialised Services National Definition set:

“Specialised rehabilitation services support patients with complex disability whose rehabilitation needs are beyond the scope of their local rehabilitation services”.

Re: Specialised Services. National Definitions Set. (2009). Specialised rehabilitation services for brain injury and complex disability [adult].

Specialised care are usually based in a hospital setting or in an ambulatory setting and are not considered to be delivered by primary care. When considering the definition of primary health care, the term is fraught with difficulties. Furthermore, definitions for the primary health care, can be termed on the basis of concept, level of service, the content of such service, the processes involved and finally to the team membership. An attempt to define primary health care by Parker, Walsh and Coon (1976) in America generated no less than 92 definitions. Similarly, attempts by Boerma, Van der Zee and Fleming (1997) and Wienke, Groenewegen and van der Zee (1998) to define primary health care indicated a variation amongst countries.

Surrounding the exploration of the definition of primary care, many differences arose. Within the Irish Health Care Strategy (2001), primary care is defined as:

“Primary care: is an approach to care that includes a range of services designed to keep people well, from promotion of health and screening for disease to assessment, diagnosis, treatment and rehabilitation as well as personal social services. The services provide first-level contact that is fully accessible by self-referral and have a strong emphasis on working with communities and individuals to improve their health and social well being.”

Ref: Health Care Strategy 2001, pp.15

In recent years there has been a shift in paradigm towards acknowledging how the model of PCC supports a better health population through improving equity, efficiency, effectiveness and responsiveness to health systems. However, the WHO (2004) states how there has been no systematic reviews on primary care versus specialist-orientated systems or on the case for primary health care being firmly established. Also when exploring research within Ireland, it was important to note how the implementation of the PCC into the Irish health care system is still at its infancy stage and therefore no research exists to explore the effectiveness of the PCC model.

When consideration was given towards the current literature on the effectiveness of incorporating a primary care model into the health system, different literature exists which generally categorise the exploration of the effectiveness of the PCC model into four different areas: Population health and aggregated health expenditure, equity and access, quality and

efficiency of care, cost effectiveness and patient satisfaction. Some of these areas will now be briefly explored below.

Population health and aggregated health expenditure

When consideration was given surrounding the effectiveness of the primary care team models in relation to the population health and aggregated health expenditure, Macink, Starfield and Shi (2003) conducted a study across 18 wealthy Organisation for Economic Co-operation and Development (OECD) countries over a 30- year period. Their research found that the strength of the country's primary care model was greatly associated with the population health outcomes such as all-cause mortality, premature to cause-specific mortality. Therefore indicating that stronger primary care meant better health outcomes. Furthermore, the PCC characteristic such as geographic, longitudinal, coordination and community orientation was also seen as significantly important to the effectiveness of the PCC and the improvement in the health of the population. Such findings are reinforced by Starfield (1992) which involved researching into 11 developed countries which also highlighted the effectiveness of implementing a PCC model aimed towards producing better population health outcomes at a lower cost along with greater patient satisfaction levels. Beasley et al (2007) state that within the last two decades several researchers have shown the strength of the primary care component of health system to be positively related to common indicators of population health status. They go onto suggest how these benefits are greatest seen in relation to the causes of death that are especially amenable to primary care interventions, including stroke mortality to years of potential life lost. These findings are consistent and found in international comparative studies by Macinko, Starfield, and Shi (2003), Starfield, Shi and Macinko (2005), and Baicker and Chandra (2004). Their research findings demonstrate the positive results towards the contribution of primary care systems to health outcomes. These findings are supported by historical research conducted by Shea et al (1992) who found that the absence of a primary care model was considered to be the most important determinate in poor health. Such findings were considered relevant and supported the inclusion of the primary care model in enhancing better health outcomes for each of the case study families within the research.

Cost effectiveness

Upon reviewing the literature surrounding the cost effectiveness of the PCC model, Mills and Drummond (1987) confirm the cost effectiveness of PCC setting compared to other health programmes. Cochrane and Zachariah (1983) support this concept by noting within their World Bank findings how primary care activities, for instance: infant and child health, nutrition programmes to immunisation and oral hydration programmes were found to be more cost-effective when compared with hospitals.

In exploring literature on the shifting from specialist lead to PCC settings without adverse affects on outcomes, Aaraas, Soraasdekkam and Kristiansen (1997) in Norway from their research found general practitioner-led hospitals provided care at a lower cost when compared with alternative modes of care. They went onto note how this was the case as a result of averting hospital costs. In the UK, different studies like Baker et al (1986) and Treasure and Davies (1990) showed how GP hospitals reduced costs as a result of reducing referrals and hospital admissions to hospitals that are staffed by specialists. Furthermore, Ward, Huddy and Hargreaves (1996) explored the cost-effectiveness of GPs providing care compared to hospital specialists found how the GP setting was more cost-effective due to reduction in referrals to secondary services and lower prescription levels.

When considering the cost-effectiveness of the PCC model, previous studies conducted on an international level by Starfield and Shi (2002) and Macinko, Starfield and Shi (2003) show that countries with well-developed primary care systems have lower overall health costs, better health outcomes and higher levels of satisfaction.

When considering an economic evaluation of the PCC model, Nolte and Pitchford (2014) report titled “*What is the Evidence of Economic Impact of Integrated Care?*” reviews the economic impacts of integrated care approaches. 19 reviews were identified as eligible for inclusion. The report analysed the reviews using three economic outcomes: utilisation, cost-effectiveness and cost or expenditure. Findings reflect, in general, a cost-effectiveness of utilising the integrative approach adopted within the PCC model. However, limitations are

considered surrounding the report. The WHO report is based on reviews only. The reviews utilised do not explicitly define “integrative care” as a topic of review, and the reviews studied a wide range of interventions and care approaches. Another study by Wren et al (2014) prepared for the Irish Heart Foundation, in conjunction with the Economic and Social Research Institute (ERSI) and the Royal College of Surgeons (RCSI) in Ireland focussed on “Towards Earlier Discharge, Better Outcomes and Lower Cost Rehabilitation in Ireland. The study found a cost saving of €12 million nationally in support of early discharge from reduced hospital length of stay. However the study highlighted the need for further development and investment in primary care towards the hiring of additional community therapists to support individuals once discharged from hospital.

Universal Health Care

Virtually all of Europe has either publicly sponsored or regulated universal health care or publicly provider universal healthcare. The public plans in some countries provide “basic or sick” coverage only. Within these cases, the individual can purchase private insurance to facilitate the additional coverage. An example of countries with universal health care are: Austria (Hofmarcher and Rack, 2006), Denmark (Vrangbaek, 2013) Finland (Vuorenskoski, 2008), Germany (Busse and Riesberg, 2004), Italy (Lo Scalzo et al 2009), Netherlands (Willemijin et al, 2010), Norway (Johnsen, 2006), UK (Harrison, 2013) and Ireland (White Paper on UHI, DOH, 2014). Universal health care can vary from country to country. The WHO (2000) Report measured the fairness of financial contributions to health systems across different countries. The measurement was based on the fraction of household’s capacity to spend on health care. Findings reflected Ireland was ranked 6th on the list, with Colombia recording as the top-rated country in this category, followed by Luxembourg, Belgium, Djibouti, Denmark, Ireland, Germany, Norway, Japan and Finland. Colombia achieved top rank because it reflected how an individual with a low income might pay the equivalent of one dollar per year for health care, while a high- income individual pays 7.6 dollars. (WHO, 2000). Countries judged to have the least fair financing of health systems include Sierra Leone, Myanmar, Brazil, China, Viet Nam, Nepal, Russian Federation, Peru and Cambodia (WHO, 2000). The least fair financing ranking, for instance Brazil, a middle-income nation, was ranked low within this table due to its population being required to make high out-of-pocket payments for health care. (WHO, 2000)

In conclusion to the exploration of literature surrounding the effectiveness of the PCC model, the literature was predominantly from the United States and European countries for example: UK, Netherlands and Nordic countries to low income countries in Africa. Literature from the transition countries (Russia and China), middle-income countries and Latin America was found to be lacking. There is a scarcity of studies on the advantages and shortfalls of the PCC model, with comparative studies on the PCC and the specialist system mainly coming from the United States. The cost-effectiveness studies mainly reviewed specific interventions and not the actual management of the PCC model. The extent to which the above literature can be generalised is debatable.

Section 1.6 Conclusion

When considering the first section of the literature review, TBI, it was highlighted how as medical science improves, the survival population following a TBI will grow. It is estimated that by the year 2021, Ireland will have a population of 869,143 persons living with a neurological condition. (HSE (2007), Strategic Review of Neurology and Neurophysiology Services in Ireland). Within the National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland (2011), the importance of continuum of rehabilitative care and the need for development and staff intake to support the growing population of individuals within Ireland who suffer from a neuro-disability is highlighted. Literature on the needs of the family post-TBI, reflected, as emphasised by Bekker (2000), the paramount importance of professionals placing equal significance on exploring both the needs and impact of TBI on the individual and their family. The Key working literature reviewed noted how families voiced, as emphasised by Lees (1988) the need for on-going support through a single point of contact after discharge from the hospital out into the community. Literature reviewed also highlighted the need for TBI Education to be offered to families and service providers towards providing a beneficial provision of care. (Kolakowsky-Hayner, Miner and Kreutzer, 2001). Finally, literature on the PCC model outlined the complexities of working with health problems at all levels. The role of the primary care should not be taken in isolation, but seen as an integral part of an overall health system, from the hospital to the specialist care setting.

Aims of the Research:

In support of the concepts proposed by the National Policy and Strategy for the Provision of Neuro-Rehabilitation in Ireland (2011), the research was to be conducted out in the community with the aim of supporting and exploring the continuum of care of families who have experience of a loved one with a TBI. To support the collaborative approach of working with families, the research focussed on working in partnership with six families towards identifying not just the needs of the individual with the TBI, but also the family's own unique needs in order to develop and implement an effective rehabilitation and intervention plan supportive to all. To support the development of the partnership with the family, the key

worker adopted a designated key worker role within the research to act as a single point of contact out in the community. TBI Education was considered for the six families and participating professionals with the aim of creating more of an awareness surrounding TBI. Due to the research being conducted within the community, a decision was made to invite and work in collaboration with the local PCC teams of the families involved in the research. It was the intention that through working within an inter-sectorial, multi-disciplinary capacity the needs of the family could be better met.

CHAPTER TWO - METHODOLOGY

Section 2.0 Introduction to Methodology

The research methodology chapter consists of different sections outlining the exploration, development and implementation of the methodological approach taken in the research.

2.1 The first section is referred to as the *Groundings* section which commences with the groundings towards reviewing the range of different paradigms, metatheories, perspectives, values and epistemologies that inform the various practices of action. Within this section, principles that drive action research will be explored, with particular emphasis on the six comprehensive principles as outlined by Winter (1989). Issues and dilemmas of action research in practice were introduced to aid a greater understanding of the process in practice, ranging from frontline practitioners to the community participation itself.

2.2 The next section, *Practices* represents the diverse approaches to action research and how action researchers can draw from a range of methodologies. Within this section consideration were given to such different approaches and two ideal types identified by Grundy (1982), Boutilier et al (1997) and Leitch and Day (2000), as follows: practice-based to participatory were presented. After reviewing each type, the researcher presents the rationale towards the decision surrounding the utilisation of the participatory type conducted within a community action research model.

2.3 The third section, *Skills* addresses the skills required surrounding the competencies from the participants during the initiation and conduct of the research. Skills considered surrounded the practice of co-operative enquiry, and self-reflection in its entirety.

2.4 The fourth section focuses on representing the *Flow of Action Research*. Within this section, the implementation of action research into practice takes place, incorporating the cyclical or spiral approach to action and reflection as suggested by Lewin (1946).

2.5 The fifth section refers to different methods of data collection, mainly *Qualitative and Quantitative* research methods. However, the researcher was aware of concerns raised by Sale, Lohfield and Brazil (2002) surrounding how such inclusion of these methods within the

healthcare setting can be problematic. To address these concerns, the researcher reviewed literature on each method separately. The final section is a review of arguments for using either qualitative or quantitative methods or the mixed method approach.

2.6 Section six refers to the *Ethical and Practical Issues* of moral principles or values which governed the conduct of the individual or group. The researcher acknowledged the responsibility to the participants involved in the research that at no time, the function or the information collected was to be brought into disrepute. In order to adhere to such needs, different ethical and practical considerations were reviewed, documented and taken on board for the research.

2.7 In section seven, there is an introduction to *Activity Theory* (AT) which is the theoretical framework used in the research. Within this section, the researcher considered the background to activity theory, assumptions in theory to design and implementation within the research.

2.8 The final methodology section, section eight represents different considerations of the use of the *Case Study* format for the research. Two different categories and selection methods of case studies, as proposed by Yin (1984) were considered, along with variations in sources of data.

Section 2.1 Groundings in Action Research

Introduction

The researcher adopted the action research methodology due to the appreciation of how research is firmly located through the practice of self-reflection. Such practice was achieved within the research as emphasised by Parkin (2009) through the participants making observations and communicating with others in order to make informal evaluations and judgements about what they do.

Initially, different research paradigms were explored to identify how they could impact on the development of the action research approach.

The first paradigm considered was the *positivist paradigm* which lies within an objectivist epistemology stance commonly known as positivism. Creswell (2009) describes how the positivist paradigm maintains a belief and practice that knowledge is only an observable fact, with no credence being given to non-observable entities such as feelings and values. An example of such practice within the area of TBI rehabilitation can be seen within the completion of a neuropsychological assessment, where findings, often statistical in nature, are taken and generalised to produce a report.

During the last 50 years, a new research paradigm has emerged within the social sciences tackling the constraints imposed through positivism. The new research paradigm, referred to by Koshy, Waterman and Koshy (2010) as the *interpretive paradigm*, supports the belief that reality is constructed by subjective perception, which is influenced by culture and history. The paradigm retains ideals of researcher objectivity with the researcher acting as a passive expert and interpreter of the collected data.

Through reviewing the perspectives and methodologies associated with both paradigms, there are some researchers, for example; Morley (1991) and Lather (1986) who feel that neither paradigm houses sufficient epistemological structures under which to place action research.

They outline how there is a need for a paradigm of praxis to be developed, expressing how the term praxis, a term used by Aristotle, relates to the art of acting upon conditions one is faced with in order to change them. Furthermore, the praxis deals with the ethical and political lives of people on an ongoing basis, through deriving knowledge from practice and practice from knowledge. Such a concept is the cornerstone of action research and is supported by Reason and Bradbury (2001) who cite:

“A participatory, democratic process concerned with developing practical knowing in the pursuit of worthwhile human purposes, grounded in a participatory worldview which we believe is emerging at this historical moment. It seeks to bring together action and reflection, theory and practice, in participation with others, in the pursuit of practical solutions to issues of pressing concern to people, and more generally the flourishing of individual’s persons and their communities”.

Reason and Bradbury (2001).pp. 1

Principles of Action Research

Consideration was given to what gives Action Research its unique flavour and what drives such an approach. In addressing this question, consideration was given to how principles which guide action research are imposed. Such principles can be seen by Winter (1989) who outlines a comprehensive overview of six principles; reflective critique, dialectical critique, collaborative resource, risk, plural structure to theory practice and transformation. For the purpose of the thesis, some of these principles will now be briefly outlined:

- **Reflective Critique**

Within the reflective critique, the research commences with taking account of the current situation. Notes, transcripts or official documents are reviewed which could make implicit claims to be authoritative or imply that the information is factual and true. However, when considering truth, the researcher was geared by thoughts raised by O’Brien (1998) and Doyle (2007) that emphasise how truth within a social setting is relative to each individual. Doyle (2007) suggests when considering the reflective critique within action research, the individual reflects on issues and processes and makes explicit interpretations, biases, assumptions and

concerns upon which judgements are made. Within the utilisation of participants' knowledge and personal development, Meyer (2000) and Brydon-Miller, Greenwood and Maguire (2003) emphasis how the strength of action research lies in its focus on generating solutions to practical problems and its ability to empower practitioners. In relation this practice to the research, practitioners learnt through actively getting involved in the research and subsequently partaking in the development or implementation of activities.

Another consideration surrounds the theory of action and the reflectivity of consciousness relating to the act of understanding. Difficulties arise when consideration is given as outlined by Water-Adams (2006) to how understanding is gained; the concept of how it comes from within the practice; to the theory of how outside interpretation inevitably imposes meaning on a situation. Concerns are raised by Altricher, Posch and Somekh (1993) who suggest how such differing rationalities may lead to conflict, categorises two variances: the technical and the reflective. Technical rationality suggests that the solution to the practical problem is general and can be solved outside of the situation. However, reflective rationality solutions to problems are complex and demand specific solutions which can only be addressed within the practitioner's environment. In relation to transferability, the approach within the research adopted, as outlined by Waters-Adams (2006) and Hamilton (1981) whereby solutions cannot be generalised and should be considered as a tool towards a wider search of understanding. The researcher adopted what was proposed by Elliott (1991), of not promoting individuals reflecting in isolation from each other. Practitioners involved in the research collectively reflected on their actions to ensure that the action research would not become a form of technical rationality aimed at improving just their own personal skills.

- **Collaborative Resource**

Collaborative resource involves the merging of various different resources, for instance specialised adaptive equipment to the use of meeting rooms, and professions, for instance members of the primary care team. Such sharing of resources is seen by Adler, Shani and Styhre (2004), Burns (1999) and Kemmis and McTaggart (1988) as beneficial in the creation of a new theoretical development. They go onto outline how the collaborative process is the practice where each participant's ideas are of equal significance and act as potential resources

for the process. Such collaboration of resources creates an interpretive category of analysis, negotiated amongst the participants. The aim of such a principle is to avoid sole input and gives rise and acceptance to the variances and contradictions that can exist between many different viewpoints. Water-Adams (2006) further emphasise how truths and reflections are dependent upon the practitioners intentions, values and beliefs surrounding the situation. Within the research, participants were requested to be truthful and honest in their reflections and work in collaboration with others to gain an overall holistic view of the presented situation. In support of such a collaborative concept, Elliott (1991) emphasises how action research is “emancipatory” in nature and how it is paramount for groups of people to explore challenges and constraints collaboratively to address the desired need and action.

- **Plural Structure**

Ahmed (2009) maintains how action research supports a multiplicity of views, comments and critiques, all of which lead to multiple possible actions and interpretations. This principle supported the reporting of the research through taking all of the different explicit accounts of the options presented, noting the different commentaries and contradictions. It also supported the collaborative nature of the research through the promotion of an open discussion form amongst all collaborators rather than a final conclusion of fact. In developing this principle, the plural structure within an action research can present with different levels of commitment, as a result of the multiplicity of individuals involved. One such issue surrounds the need for all participants to maintain a level of commitment. Such commitment is necessary for the rigorous examination and critique of their practice. (Carr and Kemmis, 1986)

Issues and Dilemmas of Action Research in Practice

When deciding on adopting the action research approach, different issues and dilemmas were considered. One issue surrounded how the researcher considered herself a novice action researcher and felt she would benefit from clear guidelines towards the designing of the research. Such feelings are reflected by Baskerville and Wood-Harper (1996) who emphasise how there is a lack of publications that present with detailed guidelines for practitioners and

researchers to follow. In addressing such a need for guidelines, the research incorporated Lau (1997) proposed framework of guidelines towards the development of the action research.

They were as follows:

1. The research was to adopt a community action research approach with the focus on community collaboration.
2. The traditions and beliefs were explored within the community and consideration was given towards how such assumptions could impact on the research.
3. The research process was clearly outlined, with details of the participants and the process, along with the role of the researcher clearly identified. Ethical and professional problems may ensue if the researcher does not clearly define their role. This could result, as emphasised by Baskerville (1999) in the participants of the research expecting a consulting-type performance, whereby creating an ethical breach regarding informed consent.
4. The style of presentation adopted was clearly outlined, incorporating all of the tools and methods utilised within the research.

When considering the practical implications of action research surrounding the collaborative process, different dilemmas may present themselves. Boutilier et al (1997) outline dilemmas can evolve from the impact of political issues to different individual perspectives, for example frontline practitioners, managers, researchers, to community members. Each of these participant areas was considered for possible dilemmas and issues in order that the researcher may be proactive as opposed to reactive if presented. For the purpose of the thesis, two participant areas, frontline practitioners and community members will be presented.

Frontline Practitioners

The term “frontline workers” describe health care workers that provide routine and essential services in a medical practice. (Menehan, 2012). They are derived from a multi-disciplinary group of health and social professionals who work together to deliver accessible health and social services to the community. (Health Strategy, 2001. Revised, 2015). The group can

consist of Social workers, PHNs, Physiotherapists, OTs, GPs, S & L Therapists and other network of services including dietetics, psychology and home helps. Frontline practitioners bring their own unique situations to the group and can pose, as introduced by Boutilier et al (1997) two dilemmas. The first dilemma surrounds an individual's career prospect, and how he or she may be in a position where they need to assert how efficiently they work. This can then lead to the individual taking on more work and becoming overworked and having little or no time to participate in any research. However, if the project has originated internally, the individual may feel politically under pressure to perform, even if they feel little personal commitment to participate within the project. The second dilemma can occur when the frontline practitioner is allocated to the project for a specific duration of time. As a result of specific times being allocated, the research may move, as referred to by Boutilier et al (1997) in fits and starts. Alternatively, should the practitioner complete the necessary work outside of their designated time, this can cause them to become stressed through trying to maintain their own individual workload as well as keeping up to speed on the project. These dilemmas can be further enhanced by the unpredictability of the timeframe of action research within the community. Another potential problem outlined by Avison et al (1999) stems from the researcher and the practitioner working together in the sharing of a mutual ethical framework. Such a dilemma could occur whereby the research may lead to some individuals losing their jobs. Within this case, conflict may occur where such an action is acceptable for the practitioner or vice versa by the researcher.

Community Members

Since the research took place within a community, the researcher looked at how the method of action research could be hindered when entering the community. Two main dilemmas surrounding the nature and substance of the research were highlighted. When considering the nature of the research, one dilemma surrounded the potential level of influence the community organisations, structures and internal dynamics as well as the different mandates of the professionals could have the research. This can be seen, whereby an organisation may only be equipped or only willing to solely address a pre-identified and/or internal issue. As emphasised by Boutilier et al (1997), such structure can create limitations towards enhancing

participation, assessing the issue within a broader holistic context, to utilising the process of addressing issues as an ongoing learning process.

Adding to the complexity of the collaborative process within the community was the possible dilemma that residents may create an “insider/outsider” status. Stringer (2007) emphasises the primary goal of community based research is to democratise research by breaking down the traditional boundaries between “researcher” and subject” and involve community members fully in the research process. As the boundaries between academic researchers and the community members are broken down, Kerstetter (2012) outlines how the issue of trust emerges as critical to creating and sustaining successful partnerships. To address the issue of trust, Wallerstein and Duran (2008) highlight the need for the researcher to reflect on how a perceived “insider or outsider” status could affect the research process and its outcomes. Dwyer and Buckle (2009) suggest how an insider researcher may be able to engage research participants more easily and use their shared experiences to gather a richer set of data. However, Kanuha (2000) raises concerns surrounding how the researcher may have difficulty with separating their personal experiences from those of research participants, confront questions about potential bias in their research (Serrant-Green, 2002) and face issues of confidentiality when interviewing members of their community about sensitive subjects (Serrant-Green, 2002). In relation to an outsider researcher, Chawla-Duggan (2007) and Gasman and Payton-Stewart (2006) suggest how outsider researchers are frequently valued for their objectivity and emotional distance from a situation, but may find it difficult to gain access to research participants.

In addressing possible dilemmas surrounding the nature of the initial involvement of the research, questions were raised as to why professionals were being invited to participate in the research. In answering this question, it was voiced how the professionals were asked to participate as a result of the request from the family to contribute and support in a problem-solving process. The next possible dilemma surrounded the substance of the research and the participants. Commitment levels surrounding time, resources or research skills as emphasised by McKernan (1996) can also impact on the process, especially when dealing with a long research process.

This can be seen in the commitment levels of a community participants who may have no time restrictions to that of a college researcher who may be time restricted by the duration of the grant given. In addressing such dilemmas, each individual involved in the research was asked to represent the views of the broader community, as opposed to their own individualised perspective. However, consideration was given to how such generalisation could cause concern for the individual who may not feel that they can accurately represent the broader community. It was also acknowledged that in order to fully generalise the research findings, further research would need to take place on a wider geographical area. The research would need to incorporate all sectors of the community, from unaffiliated, under organised to unpopular segments of the wider community to be involved in the process.

Section 2.2 Practices in Action Research

To help identify the most suitable form of action research to pursue, different forms were considered. Different labels that relate relatively to the approach of action research were identified:

- Participatory action research (Chevalier and Buckles, 2008 and 2013 and Reason and Bradbury, 2008);
- Participatory research (McLean and Porpora, 2001 and Macaulay et al, 1998);
- Action research (Koshy, Waterman and Koshy, 2010 and Parkin, 2009);
- Community action research (Hennessey et al, 2005 and Vender, 2001);
- Action science (Friedman, 2001 and Argyris, 1995);
- Collaborative action research (Riel, 2010 and Kemmis and McTaggart, 2005); and
- Participatory evaluation (Suarez-Balcazar and Orellana-Damecela, 1999., Selener, 1997., and Fetterman, 1996).

When reviewing each of the different approaches towards the research, the researcher considered two “ideal types” or models of research typology identified by Grundy (1982), Boutilier et al (1997) and Leitch and Day (2000) as follows; the practice-based, and the participatory model.

Practice-Based Model

In considering the practice-based model of research, there exists recognition of the knowledge and experience of participants in relation to their own practice. Often this type of research is utilised within an educational setting, addressing the teaching practice with a view to improving one’s self- practice through reflection and insight. This practice of self-reflection can often result in changes being geared more at the individual practice level, as opposed to an overall organisational level. In support of this concept, Elliott’s (1991) has revised the self-reflective spiral of cycles proposed by Lewin (1952) with the aim of improving the quality of action within a situation, for example:

“action initiates reflection”

Elliott (1991) pp. 23

Participatory Model

Within the “participatory research” there exist four characteristics outlined by the Institute of Health Promotion Research and British Columbia Consortium for Health Promotion Research (1995): community participation, education, research and social action. When considering the process of identification and ownership, the project maintains a collective control within the community, rather than with external experts. Such practice is fundamental, as raised by Whitehead (1996) to the participatory research approach by individuals creating improvements in the present and future context through the evaluating their past. In developing this practice, Evans (1994) outlines, in order to complete such an evaluation, the individual needs to carry out actions through a variety of means including, documenting minutes of conversations, case studies to reflective writing and journals as recommended by Holly (1989). Each member of the team is valued within the resolution to the problem at hand. Furthermore, the role of the researcher is taken as an additional resource to the group and the decision-making responsibilities are with the complete group and not one member.

After reviewing each of the above types, the researcher decided to pursue the participatory approach. The approach complemented the research question by the acknowledgment of how the research was to be driven by the participation of a team of individuals within the community. The approach also supported how the research recognised each participant to be a valued equal member towards the resolution of the problem at hand. As the nature of the research was based within the community, the researcher decided to utilise, more specifically, the community action research approach.

Community Action Research

Different factors contributed to the decision to adopt the community action research approach.

- The first one stemmed from thoughts raised by Hughes (2008) who maintains that in order to understand health; professionals need to see themselves as inter-dependent components within the human element system and how in order to understand health, professionals need to look at the person within a holistic manner. The research supported the holistic manner approach as put forward by Hughes (2008), due to the health care setting as well as the investigation being adopted into the current supportive (if any) territory community services available for families that have experienced of a loved one with a TBI who participated within the process.
- The second factor surrounded how the research was based within the community, and supported an equal collaborative approach from all participants. This holistic approach as emphasised by Hughes (2008), is congruent with the participative paradigm of action research.

Implementation of Community Action Approach

Different considerations were addressed concerning the implementation of the community action approach. The first surrounded the need for participants to have an interest in taking part in the research. In addressing this consideration, each member of the group was actively involved within the local primary care team and had an interest in developing services surrounding TBI. Members involved, GPs associated with each family followed with the appropriate PCC team members, for example, the local public health nurse, community occupational therapist to the physiotherapist. Where appropriate, members from hospitals, for example head ward nurse and in-house social welfare officer were also included surrounding the development of the discharge plan.

Due to the multiplicity of participants within the research, the researcher considered, as highlighted by Hancock (2007), the commitment levels of all participants. Hancock (2007) argues the level of commitment by participants within a research provides the long-term and committed engagement that ultimately assists and sustains the ongoing development of the projects aims. A study exploring levels of commitment was conducted by Ireland and Thomalla (2011), examined the role of collective action in assisting rural communities to cope with and adapt to environmental risks in Nepalgunj, Nepal, Krabi Province, and Thailand. The study found that as a result of long-term commitment offered by local Non Government Organisations (NGOs), it provided secure employment to the local facilitators and enabled the program to develop and improve methods over time.

Consideration was also sought in relation to how the community action approach could support the learning process. Thoughts raised by Reason and Bradbury (2001) maintain how the approach supports the production of practical knowledge that was to be useful for all participants within their everyday lives. Individuals involved were required to support transformative learning and have experience within the area of the desired action. To address this concern, those who became involved, took on their role within their daily professional capacity. To accommodate ease of logistics, each participant either resided or worked within the local community. The researcher feels that since the participants worked or lived in the locality and completed the research tasks during the working day, it aided to support commitment.

After considering all of the different areas, the decision to utilise the community action research approach was ultimately supported by the researcher's aim of fostering collaboration amongst all participants of the research within the community. Lastly, the practice of collaboration within the community also addressed and supported the development of relationships which ultimately supported each team member towards transformative learning and change.

Section 2.3 Skills required for Action Research

Initially, there was a need as outlined by Robey (1997) to be explicit about the research, in clarifying the research aims, theory and method from the outset. This was required to help implement a structure that, as outlined by Avison et al (1999) would effectively manage any alterations and interventions, monitor the outcomes of the findings to supporting the implementation of the learning process itself.

Co-operative Inquiry

To promote collaborative learning, the skill of co-operative inquiry was practiced within the research. This form of inquiry was adopted to help deepen the understanding of the lives of those affected and promote creative ways through looking at things collaboratively. The aim was, as emphasised by Reason (2002b), to help the development of skills towards learning how to promote and implement change. When reflecting on literature surrounding the co-operative inquiry practice (Heron and Reason, 1985; Reason, 1988c), reported findings on a group of medical practitioners who got together to review their practice to develop a theory of holistic medicine. Another piece of research conducted by Heron and Reason (1981) focussed on findings from a group of counsellors who adopted such an approach towards refining over several weekends a description of the experiences and practices of the self-directed client.

When considering the practical methodology of the co-operative inquiry cycle within the research, the researcher reflected on the four phases of reflection and action proposed by Heron and Reason (2001):

Phase 1:

The group of co-researchers come together to explore an agreed area of human activity. Within this phase, the group consisted of the researcher, the GP, Primary Care Team (PHN, OT), the family and the individual with the TBI. All of the team focussed on identifying the needs of the family in question. This was achieved through open discussion amongst the group on what were the needs, how to go about addressing these needs, prioritising these needs, to establishing which action was to be addressed first. A set of procedures were devised, outlining how such collection of data was to be recorded and feedback given. Within this method, letters, meetings, file notes, telephone calls and texts were used to keep each other updated on what was happening.

Phase 2:

In phase two, the co-researchers became involved in the actions. Therefore, the participants became co-subjects and recorded and reflected on their agreed outcomes, actions and experiences. This was achieved through ongoing communication amongst the team on what was happening and how it was making them feel. The researcher kept a reflective personal journal of her actions and how she felt at that time. This was used as a reflective tool to identify personal perceptions and feelings and identify how the learning could be incorporated into the next cycle of actions.

Phase 3:

Within this phase, the co-subjects (all participants) become fully immersed in and engaged with their actions and experiences. During this stage, participants (co-subjects) became more at ease with talking about their experiences and reflection of their own actions and were able to talk more openly. Through this intense phase, it allowed participants to become more aware and deepen their understanding of the needs of the families involved. This resulted as time had evolved to allow participants to witness first-hand the difficulties that the current system provides. It also allowed time for families to see first-hand through the co-operative inquiry the difficulties faced by the professional within the current working health system. Ultimately this phase promoted a greater understanding for all involved.

Phase 4:

This fourth phase occurred after an agreed set time following phase two and three. The co-researchers reassembled to share their experiences and data collected to-date. The original ideas were reflected upon, and changes recorded. Through this reflection, changes in ideas or plans were either altered or rejected in light of the findings, and occasionally more questions were posed. At this stage, the group either chose to move forward to the next cycle of action, refocus on the original action and address it differently or focus on a completely new cycle of action.

Overall throughout this cycle of reflection and action, the cycle was repeated several times. The level of action for each cycle depended on the outcomes of each reflection. Through repeating cycles of action, the intention was to enhance the validity of the procedures. During the research, each family unit had its own set of co-researchers and co-subjects. Each group went through the four phases of co-operative inquiry for each action reflecting on each cycle of action, experiences and data collected. At the end of the research, each Group's set of actions were reflected upon and collated together to validate the findings across the board.

Validity of Co-operative Inquiry

When considering the validity procedure of the co-operative inquiry, participants examine their own experiences and actions carefully within a collaborative setting. However, the researcher acknowledged how throughout this practice, people may not answer or be true to themselves. In addressing such a possibility, participants were encouraged to practice critical subjectivity within the co-operative inquiry process, through recognising how their own personal meanings, experiences and beliefs could impact on the objectivity of the actions taken. This practice is supported by Reason (1994a, 1999a) who highlights how participants within a group could be considered as a vessel for co-operative inquiry.

To support the critical subjectivity, the list of skills and procedures suggested by Heron (1996a) were adopted: *being present and open*, *bracketing and reframing*, *radical practical and congruence*, *non-attachment and meta-intentionality* and *emotional competence*.

They are as follows:

- *Being present and open*. Every participant within the research was to be in the present and open to various different perceptions of the world that they found themselves in.
- *Bracketing and reframing*. Each individual learnt to practise holding their abeyance to their own classifications and constructs as these might automatically impose on perceptions. The skill here is to be prepared to being more open to looking at alternative forms of perception and reframing possible predetermined ideas or beliefs.
- *Radical practice and congruence*. Within this skill, each individual became aware during the action of the event itself in all of its form, motives and defining beliefs. It also involved the individual being aware of the lack of similarities that may occur between different facets of the actions and to adjust actions if so fits.
- *Non-attachment and meta-intentionality*. This skill promoted the individual not investing their own identity into the action and acknowledging how an individual's perception and beliefs could indirectly impact on the action.
- *Emotional competence*. Involved recognition of how an individual's previous experiences could impact on the current action and the consequences of such occurring.

When considering the validity procedures, Reason (1994a, 1999a) emphasises how the co-operate inquiry group, in itself, can be considered as a discipline vessel in which the skills proposed by Heron (1996a) can be developed. Reason (1994a, 1999a) moves further to suggest a range of validity procedures the group can adopt to free the findings from being subjected to various forms of distorted uncritical subjectivity. Such processes can range from research cycling, divergence and convergence, authentic collaboration, challenging consensus

collusion, managing distress, reflection and action to chaos and order. Three of these processes will be briefly introduced because they are most relevant to the research being carried out:

- *Research cycling*

The process promotes going through the four phases of inquiry several times. (Reason 1994a, 1999a). Within the research, the procedure of reflecting on each action, looking at the experience and practice from different angles, promoting different ideas and exploring alternative ways of behaving was adopted. (Reason 1994a, 1999a)

- *Challenging consensus collusion*

This process involves authorising one member of the research team to adopt the role of devil's advocate in order to question the team's reflections on actions, possible limitations, fixation on false assumptions, unaware projections distorting the inquiry process or a lack of rigour in inquiry method and in applying validity procedures. (Reason 1994a, 1999a). Within the research, different members of the research team adopted this role. When reflection was sought on a particular activity surrounding a profession, for instance an OT action, another member of the team outside of the given profession would challenge the findings to ensure objectivity, clarity and validity.

- *Managing distress*

The very process of exploring the human condition may bring up anxiety and trigger some distress amongst the group through the possible feeling of invasion of one's privacy. Therefore the group must be willing to address emotional distress when it arrives in an open manner and allow time to be given to the individual. (Reason 1994a, 1999a) Within the research, distress may be experienced by some members as a result of reflecting on their own experiences of actions and how it may impact on their well-being. To address this, time was always given to allow each member to speak openly about how they felt, which was always followed by time being given to the individual to heal.

Self-Reflective Inquiry

To support the co-operative inquiry practice at a personal level, the researcher adopted the practice of self-reflective inquiry into the research. The aim was to encourage the researcher to pay critical attention to practical values and theories that informed her in her everyday actions. The practice was to also act as a learning tool, as suggested by Bolton (2010), towards her own professional learning through the reflection and analysing of her experiences. This concept is also supported by Hendricks, Mooney and Berry (1996) who outline how the self-reflective inquiry practice can support healthcare professionals in learning due to the complex and ever changing environment.

Upon reviewing the literature on self-reflection, many different models exist, for example, the model of reflection suggested by Gibbs (1988) this involves six distinct stages: Description, Feelings, Evaluation, Analysis, and Conclusion to Action Plan. Rolfe, Freshwater and Jasper (2001) introduce another model of self-inquiry which is based on the development model proposed by Borton's (1970). This model is composed of three questions asked by the practitioner (What? So What? and Now What?). A different model proposed by Marshall (2001) consists of three frameworks of parallel attention disciplines: the inner and outer arcs of attention, engaging in cycles of action and reflection and being both active and receptive. After reviewing the literature, the researcher decided to implement Marshall's (2001) model on self-reflective practice, as it was felt that each framework supported for better understanding to be gained.

Each of Marshall's disciplines will now be briefly introduced, along with how the researcher incorporated them into the practice of self-inquiry during the research.

- *Inquiry through inner and outer arcs of attention*

The researcher paid particular attention to her inner arcs, exploring notification of her own perceptions, how she came about making meaning, framing issues and choosing how she approached and communicated with individuals. The researcher kept a personal journal recording some of the inner arcs of attentions, as it was felt to report everything would be impossible and could become too self-absorbing. When pursuing the outer arcs of attention,

it involved exploring outside of the researcher and engaging with other people in the practice of inquiry in a collaborative process. However, it is important to note how this does not necessarily mean the need to seek joint exploration or affirmation from others. Indeed finding differences in it may be an important factor to consider and explore. Therefore within the research, the researcher sought to include other members within the outer arc of attention. During each contact, the researcher noted and recorded how her attention was affected during the collaborative process. Within this process, notes were taken of what was happening, the content and if a pattern was occurring. The researcher also took notes verbatim of what was being said to reflect on them later. However, the researcher was aware of how her perception is selective and sometimes may not have processed all information correctly, becoming mechanical at times when tired. To counter this concern, the researcher reiterated her notes to the individual to ensure clarity. When taking the above concerns into account, the researcher utilised the outer arcs of attention for the topic and context- related inquiries within the research. Overall, during the researchers reflective process, she endeavoured to move and juggle between inner and outer arcs of attention, seeking to promote a more overall holistic form of reflection.

- *Cycles of action and reflection*

The next attention discipline incorporated into the inquiry process was the promotion of engaging in cycles of action and reflection. Within this discipline, the researcher endeavoured to plan to engage in an action, immerse in the activity and keep notes going along. Afterwards, the researcher took a step back and reflected on the experience, noting perceptions, beliefs and behaviours. This form of action and reflection is supported by Marshall and Reason (1998) as a way of generating its own momentum and enhancing different forms of attention and behavioural experimentation. In self-reflecting, the researcher might judge or question actions taken. When trying something new, the researcher queried was the action a valuable testing or was the researcher trying to avoid the issue or challenge at hand. In addressing these concerns the researcher understood the only way to address these dilemmas was within the process of inquiry.

- *Being both active and receptive*

Another discipline adopted was for the researcher to be aware of how she reacted and dealt with coping strategies when faced with anxieties and uncertainties. The researcher became more aware of her own self-assertion, whilst also reflecting on her wider self through reflection of her interaction, possible interdependency and receptiveness with others. The researcher treated what she did and said as a learning tool, in which to reflect and grow and gain a greater insight into how and why she acted and perceived things in a certain way. Therefore, the researcher found herself practising a direct and open/receptive approach testing both of these dynamic combinations within the given moment.

The possibility of potential conflicts of interest and how the researcher acting as the key worker may become too close with the case study families and present with bias was also considered. To address these concerns, the researcher incorporated triangulation in the recording of the events and actively worked with her supervisor for self-reflection and support. This support consisted of periodic telephone conversations and emails between the researcher and her supervisor. Meetings also took place twice a year with the researcher travelling to Birmingham. During these meetings the supervisor sought to question the researcher's self-reflection to ensure clarity and offered support and guidance throughout the research process.

Overall, the researcher utilised the above self-reflective inquiry practice within the key worker role in acknowledgment of how part of the process involved making judgements on what was the focus which required a skill of knowing when to be open and receptive. The researcher acknowledged, as emphasised by Marshall (2001) how each person's inquiry approach is distinctive, disciplines cannot be cloned or copied. Furthermore, each person involved in the research was required to identify and craft their own qualities and practices. Therefore, the question posed and addressed through the development of the self-inquiry methodology section addressed the researcher's own self-reflection procedure in order to produce quality, rigorous and non-defensive findings.

Section 2.4 The Research Plan

When reflecting on the practical approach to action research, Lewin (1946) outlines how there exists a spiral of steps. Within each step, there is a series of circles which involve planning; action and fact finding surround the result of such action. In relating Lewin's (1946) examination process to the research, a meeting initially took place with each family to establish the current history. Within this examination, areas of need and services required for the family and the individual who had sustained a TBI were identified. Needs were recorded and prioritised. Please refer to *Appendix Two – Family (A) and Individual (B) Identification of Needs*. This record led onto the development of an “overall plan”. Please refer to *Appendix One –Designated Specialist Key Working Model*. The flow chart outlined areas to be addressed, noting who, and what services were involved, with expected dates of execution. Subsequent to the development of the “overall development plan” a priority list was identified, and the decision to implement the first step of action was agreed between the researcher acting as the key worker and the family.

Once the desired objective was decided, the next step as cited by Lewin was to:

“Compose a circle of planning, executing, and reconnaissance or fact finding for the purpose of the evaluation of the results of the second step”. Re: Lewin (1946) pp: 206

This process began to form the circle of action, as it formed the rational bases for planning the third progression step. At this stage, the desired first action was put in place which involved either or both the family and the key worker exploring the services that could facilitate the desired need, for instance for the key worker to make a referral for a service/profession. Professionals who became involved at this stage were invited to become part of the research team.

The researcher acknowledged how through utilising Lewin's approach it presented the team with a sequential form, which could be open to literal interpretations. To accommodate such interpretations, the process of self-reflection was utilised to enable the team to identify and produce a practice that was appropriate for the service users.

Theory into practice

The researcher would now like to present the practicalities of the research by outlining how the theory was put into practice. This will be achieved through presenting the development of the research itself. Initially, research ethics approval was sought and granted from the University of Birmingham in April 2010.

- **Invitation Process – July to October 2010**

In support of good logistics and to create a good first impression, an invitation letter (*See Appendix Three, Four, Five and Six: Invitation Letters and Information leaflet to GP and Family*) outlining the aim of the research, detailing the researcher's academic and professional experience, and the University Ethical Approval for the proposed research was distributed to local GPs within a five mile radius of where the researcher resided in urban Dublin. The researcher made the decision to source the case study families through local GPs to support a single point of referral from within the community. To promote a greater understanding, ethical and consent forms were also included with the invite letter reiterating the aim of the research. To increase the response rate, the letter, suggested by Turocy (2002), was personalised with each GP's name, acknowledging their value towards the success of the pilot. The letter outlined reasons, as emphasised by Dillman (2000) to why respondents were chosen to become involved in the research. The purpose of the letter was to obtain GPs who could nominate at least two families attending their clinic with experience of a loved one with a TBI. Information on the research along with ethical considerations and consent forms were also enclosed for families to review and sign. Please refer to *Appendix Three - Six (Invitation Letters and Consent Forms to General Practitioner and Family)*

- **Sampling approach**

The first batch of invitations was issued to four GPs on the 1st of July 2010. Follow-up calls to the GP's surgeries took place outlining the research and answering any questions they may have. Out of the first batch of invite letters, one GP accepted placement on the research and nominated two families who were willing to participate in the research.

The second batch of invitation letters were distributed to five more GP's, outlining the research on the 13th of July 2010. The process of calling and following up on the letters proceeded. Within this batch, one GP commented on how he may have a family who could avail of the research. However, this later fell through as the family changed their minds and felt it was the wrong time to become involved in research. No forms were signed at this time. No families were obtained within this batch as the GPs advised that they were either too busy, had no families that would fit the criteria of the research or some GPs would not engage with the researcher, either through not accepting calls or responding to the invite letter.

On the 28th of July 2010, a third set of invite letters went out to three GPs with the same details. Follow up occurred through similar means as before. At this stage, two GPs expressed an interest in the research. One GP advised of the possibility of two families that may be interested. Later on it transpired that only one was to take up the invite to participate in the research. Another GP nominated one family who was willing to participate in the research. Therefore at this stage in August 2010, the researcher had four families that had decided to become involved in the research and three GPs.

In order to seek the final two families required for my research, a fourth set of invite letters were sent to nine GPs in the middle of August '2010 along with another invite letter sent to one GP in October 2010. Out of these two batches of invites, one GP nominated two families who were willing to become involved in the research. Therefore, by October 2010 the researcher had six families that had agreed to participate in the research and four GPs.

Further information on the process of the invitation process of the GPs and families to participate in the research can be seen in the Appendix Seven – Spreadsheet recording

General Practitioners Invitations. This Appendix outlines the procedure flow within a spreadsheet, noting when the letters were issued, the follow-up calls and what was advised.

- **Meeting Families (September & November 2010)**

Once the GPs had nominated the six families, the researcher sought consent from the families to participate in the research. Discussions took place with the relevant GPs and it was agreed for the GP to make the initial contact with families and obtain consent to hand over the contact details. Once these were obtained and transferred over to the researcher, initial contact was made with five primary carers at the beginning of September 2010 and one at the beginning of November 2010. The first phone call involved introducing and reconfirming details of the researcher and the aim of the research. A meeting was arranged with each family at a time and place of their convenience within Dublin. These meetings took place in different locations depending on the location and needs of the families. Some of the meetings took place in the family home while others took place in the hospital as the family member was currently an in-patient.

- **The Flow of the Interview Process**

The flow of the interview adopted the layout outlined by Lofland and Lofland (1995), whereby the interview began with a general introduction about the researcher, the aim of the research, followed by acknowledging the value of the recipient's participation. The focus of the introduction was to create a comfortable open environment, whilst building on the rapport between the interviewer and interviewee. Questions were asked to establish pre and post TBI historical background and current needs of the primary carer, utilising different interviewing techniques. One such technique adopted was "active listening" used to confirm with the interviewee that close attention was being paid to what they were saying. Another technique, in support of the researcher's exploration of the family responses, was the use of prompts and probes as suggested by Robson (2002). Once the questions were addressed, the interview moved to the closure stage, whereby the interviewee was thanked for their participation. At this stage the next step of the research was outlined. Consideration was given to the

possibility of the need for a “cooling off” period or the possibility of the interviewee continuing to talk after the cessation of the interview. This was required for four out of the six family initial meetings. The aims of the initial interview were to meet and greet and create a supportive collaborative alliance between the researcher and the family. Followed, with obtaining data on the current situation and needs of the family. Finally, the needs outlined were prioritised and an action plan developed. Subsequently the action plan was commenced and the first desired action initiated.

Interviews

At the initial design stage of the interview, different data recording methods were considered, for example, audio-recording to taking notes. Initially, a dictaphone was considered, noting how such a method could free up the interviewer to concentrate, listen and respond to the interviewee. However, consideration was given to concerns raised by Knowler (2007) on how interviewees may feel uncomfortable and unwilling to reveal their true thoughts and opinions should the interview be taped? The next method explored was note taking. Consideration was given to how the interviewee may become inhibited by the interviewer’s act of note taking during the process and become disheartened to whether they are being listened to. Furthermore, the researcher also considered concerns expressed by Hancock (2002) surrounding the possibility of researcher bias occurring during the transcribing process, possibly down to a lack of experience and time on both parties. After discussing these options with the families and later on with the other participants, it was decided to use note taking as all participants expressed how they would feel uncomfortable being taped. Furthermore, to address Hancock (2002) concerns surrounding researcher bias, notes were recapped and confirmed with the interviewee and were immediately typed up following cessation of the interview. (*Refer to Appendix Eight – File Note from Mary (Case Study 4)*).

Alternative forms of interviews, for example the semi-structured to the unstructured interview were explored to ascertain their suitability for the research. Within the *unstructured interview*, the researcher uses at most *aide memoire* as a checklist of prompts surrounding certain topics that he/she wishes to discuss. The question format may present as a singular question, where the interviewer asks the question and allows the interviewee to respond

freely. Alternatively, within the *semi-structured interview* the interviewer has a set of questions or an idea of a specific topic that they may wish to explore. Within the research, questions were asked to establish pre and post TBI historical and current background information for instance: nature of TBI, Date of Birth, and what was the family situation pre and post TBI. *Please refer to Appendix Two Identification of Needs (A & B)*. Ultimately, the decision was made to utilise the semi-structured interview due to, as emphasised by Hogskola (2005) and Barker, Pistrang and Elliott (2002), the collection method supports the researcher in gaining access to phenomenological data surrounding the respondent's perceptions of themselves and the world in which they live. However, consideration was given to thoughts raised by Barker et al (2002) surrounding concerns of potential validity issues, whereby respondents may deceive themselves or others. To address such concerns, the researcher used this as an explorative tool, to address any contradictions that may arise between the data collection tools used.

- **Team members**

Once the initial meeting with each of the six family primary carers took place and the needs identified, the process of inviting and working in collaboration with different professionals and members of the community began. Each family's identified needs formed an individual action plan which required the service of various different multi-disciplinary teams of professionals to take part in the research. For the families who were still within the acute hospitalisation stage, the multi-disciplinary team consisted of in-house social workers, doctors and nurses. However, once discharged, other professionals, for instance members of the local PCC, for example PHNs, Community OTs, to Physiotherapists and staff from community organisations became involved to support and facilitate the action plan.

When exploring the collaborative workings with the multi-disciplinary team, the researcher initially made contact with the desired professional and introduced the aim of the research. Details of the individual case study needs were outlined and the necessary service provision required. Discussions took place, mainly over the phone towards how the professional could facilitate this action. All conversations with team members, for instance professionals and

primary carers were recorded with the researcher recapping the details to ensure clarity and agreement of the notes taken with the individual involved. Please refer for an example to *Appendix Nine - File Note from Public Health Nurse*. These records were then filed within the family's folder under the relative section, for example: Professionals. At all times, as the team grew and the action developed, each team member was verbally updated.

- **Recording Methods**

Each of the six case study family's had an individual folder, whereby records of notes of all conversations, meetings or case conferences were collated into three different sections: Family, Professionals and GPs. In promoting ease of retrieval, contact names and details were presented at the beginning of each folder.

Another form of recorded data utilised was the "flow chart". This allowed the family to visualise the flow of the agreed actions in relation to each other. This too was reviewed regularly and adjusted accordingly. Please refer to *Appendix One- Designated Specialist Key Working Model*.

Finally, the researcher supported the feedback process to the GPs, by issuing a report on each family in question in November 2010. This was to provide GPs who were under time restraints in their involvement of the research, with feedback on the needs identified by the primary carer, the services sought and needs still to be addressed.

Section 2.5 Qualitative and Quantitative Research

Due to the nature of the research, the focus was predominately on the most common distinctions between qualitative and quantitative research methods within a healthcare setting. The use of a combination approach of qualitative and quantitative methods is supported by studies conducted by Tashakkori and Teddlie (1998), Morgan (1998) and Droitcour (1997).

Introduction to Quantitative Research

Nenty (2009) introduces quantitative research as a theory validation procedure, which promotes the research process to be cyclic in nature, commencing and ending in theory, at all times validating and refining the theory. On a practical level, Muijs (2011) suggests how quantitative research surrounds the collection of numbers and counting and measuring of data within an objective hard data format. Such collection, as emphasised by Neill (2006) may involve the use of a structured questionnaire with a limited number of predetermined response options. Neill (2006) also notes how quantitative research can be considered more commonly used to investigate research questions.

When considering different associated style of research questioning that could support the research, the researcher considered styles outlined by Tully (2014); descriptive, comparative to relationship-based research questions.

- Descriptive research question quantifies the variables to be measured. This can be seen in questions like, how much? how often? To what percentage? Descriptive research questions often focus on one variable within one group however, they can include multiple variables and groups if required. Tully (2014).

- Comparative research questions aim to examine the differences between two or more groups on one or more variables. Such questions can often start with “What is the difference?” Tully (2014). This type of questioning considers how comparative questioning can support the research, in examining the differences between two or more groups, for instance; the six case studies.
- Relationship research questions are interested in the causal relationships, associations, trends and/or interactions amongst two or more variables on one or more groups. This type of question may commence with “What is the relationship between or amongst?” This type of questioning was deemed to support research that was interested in the relationship, association or trend between two or more dependent and independent variables within two or more groups. (Tully, 2014).

Types of Quantitative Research

Once the research questioning design was considered, the focus moved to identifying the different classifications of quantitative research. Williams (2007) identified three broad classifications of quantitative research: experimental, casual comparative and descriptive. Two of these will be briefly presented below as the researcher felt they housed more relevance to the research:

- *Experimental Design* also considered as longitudinal, true or repeated-measures studies is when every effort is made to identify and impose control over all variables except one. (Williams, 2007). An independent variable is manipulated to determine the effects on the dependent variables, for example Araz et al 2013 research into the effects of a new treatment plan on lung injury.
- In *Casual Comparative* research the independent variables are examined to determine how affected they may be by the dependent variables and involves considering the cause and effect relationship between the variables. (Williams, 2007). Mertens (2015) suggest when conducting a casual comparative research, the researcher needs to: identify a research problem, select a defined group and a comparison group, and

collect data on relevant independent and dependent variables, and on relevant background characteristics to finally analysing and interpreting data with special focus on competing explanations. An example can be seen within research conducted by Sullivan and Artiles (2011) on examining differences in special education placements by race and ethnicity.

Validity in Quantitative Research

When considering the validity of quantitative research, Burke Johnson and Christensen (2013) outline four major types of validity: statistical conclusion, internal, construct, and external validity. Each of this will now be briefly outlined:

- *Statistical conclusion validity* refers to the ability to make an accurate assessment on the strength and relationship on the independent and dependent variables. (Burke Johnson and Christensen, 2013).
- *Internal validity* is defined as the "approximate validity with which we infer that a relationship between two variables is causal" (Cook and Campbell, 1979).
- *Construct validity* represents a collection of forms of validity (i.e. content validity, convergent and divergent validity) utilised to assess the measurement procedure within a given construct. (Messick, 1980).
- *External validity* surrounds the degree to which the results of a study can be generalised across populations of persons, settings, times, outcomes, and treatment variations. (Burke Johnson and Christensen, 2013).

Introduction to Qualitative Research

Qualitative research as emphasised by Moser et al (2014) is primarily exploratory in nature and supports the researcher in gaining a closer understanding of human behaviour and the underlying reasons, opinions, and motivations associated with the behaviour.

Glenn (2010) suggests the design provides the researcher with insights into the identified problem and assists with the development of ideas or hypothesis for potential quantitative research. The design, as emphasised by Shank (2002) also supports through the inquiry process, the researcher in achieving a greater understanding of the individual's experiences.

Types of Qualitative Research

In reviewing the practical process of implementing qualitative research, there exists a variety of methodology approaches, with different disciplinary origins and tools. Two commonly used approaches: action research and mixed methods were considered for the purpose of the research. The action research approach was considered and adopted to support the collaborative nature of the research process within the community. The approach is introduced and discussed within sections 2.1, 2.2 and 2.3.

Mixed Method Approach

The next method considered was the mixed method approach. This method was considered due to the utilisation of both quantitative and qualitative data collection methods within the research. It was also considered due to the approach being commonly utilised and accepted within the healthcare research setting. (Sale et al 2002).

The mixed method approach can be utilised when a dual set of information is required, for instance: studying the implementation process as well as the outcomes of integrated care for people with diabetes. (Busetto et al, 2014). The mixing of methods can occur within one

study or across different studies. However, such a strategy of mixing methods involves, as emphasised by Creswell (2003) the research being opened and warranted throughout the process. This process requires, in terms of sequencing, each method to run simultaneously with a clear priority amongst the methods, for instance equal or one method precedence. Finally, Creswell (2003) highlights how there needs to be some form of justification for utilising a mixed-method approach, outlining the nature and timing of such integration, be it, full or partial during the data collection, analysis, or interpretation process.

Validity in Qualitative Research

In considering validity Guba (1981) outlines four criteria for the researcher to consider in developing validity and trustworthiness of a qualitative research:

1. credibility (in preference to internal validity);
2. transferability (in preference to external validity/generalisability);
3. dependability (in preference to reliability);
4. confirmability (in preference to objectivity).

For the purpose of the thesis, the first two criteria areas will now be briefly introduced:

Credibility:

Shenton (2004) outlines a list of provisions that can assist the researcher within the area of credibility. For the purpose of this research, some of the list will be briefly introduced:

- Adoption of established research methods successfully utilised within previous studies.
- Development of an early familiarity with the culture of participants. Marshall and Rossman (1980) support this concept by recommending when studying human behaviour; the researcher needs to understand the framework in which the participants interpret their thoughts, feelings and actions.
- The use of triangulation of different data collection methods, for instance observation and/or individual interviews which form the major data collection tools for qualitative

research. Guba (1981) and Brewer and Hunter (1989) suggest that through the use of triangulation of different data collect methods, the practice will compensate for each individual methods limitations and support the respective benefits.

Transferability

Merriam (1998) suggests how external validity concerns the extent in which the research findings can apply to other situation. In order to assess the extent of the research transferability, similar projects employing the same methods are required to be conducted in different environments to enable a more inclusive overall picture to be gained. (Shenton, 2004, Gomm et al, 2000).

Deciding which approach to use

When deciding on which to use, the researcher utilised four of Hammersley (1991) possible argument structures: *data, research setting, meaning versus behaviour, and personal/professional element, and action* to aid in her decision. Due to the relevance towards the researcher's decision, data and research setting comparisons of two of these structures will be presented within the thesis.

The first comparison was how the *data* differs within each approach. When considering a quantitative approach, a researcher may seek to generate statistical data surrounding a percentage of a certain phenomenon. However, the qualitative researcher may place greater importance on the understanding of a certain phenomenon, in order to obtain a greater insight into the actions of a human being. It could be argued that the quantitative researcher is more precise due to the objectivity of the numerical data collected. However, in contradiction, people change and the social situation is far too complex for numerical description. At the heart of this argument surrounds the “knowing” part. Qualitative researchers would question how a person can be sure about what they claim to know from quantitative data. With this

argument, quantified evidence can be powerful and hide a great deal about the participants, especially the subjectivity of those individuals' understandings of the phenomenon.

When exploring the comparisons of the *research setting*, qualitative researchers have long criticised laboratory based research as “artificial”, noting how people react differently in different contexts. Furthermore, criticisms exist surrounding how the research may be influenced by the researcher and findings jeopardised when compared with research conducted in a “natural” setting. This argument is explored by Hammersley who cites:

“In my view this distinction between natural and artificial settings is spurious. What happens in a school class or in a court of law, for example, is no more natural [or artificial] than what goes on in a social psychological laboratory”

Hammersley (1991) pp 231

When addressing these criticisms, surrounding the artificiality of structured interviews within a qualitative approach, interviews are not required to be structured. The main focus is on how the research act interferes with the phenomenon being explored. Moreover, concerns may exist surrounding whether the findings are valid and represent what they believe is a true reflection from the participants or are the participants just reacting to the researcher. Within qualitative research, the researcher seeks to minimise the impact of the interventions through practising triangulation in order to generate objective knowledge. Furthermore, qualitative researchers endeavour to “build” theory from the ground up through the exploration and incorporation of experience and or practice. The qualitative researcher acknowledges the importance of the place in which the context takes place and therefore, concretises why the research should be rooted there accordingly. However, in developing this concept further, consideration needs to be given to generalisation and how the research findings can be translated from one place to another. Such consideration is explored further within the generalisation section of the methodology.

Conclusion

After reviewing literature surrounding different approaches, the researcher decided to utilise the mixed-method approach due to different reasons. The first reason focussed on how the

utilising of both approaches supported the concept proposed by Haase and Myers (1988) of how both the quantitative and qualitative approach share a unified goal, of understanding the world in which people live.

Secondly, the two paradigms were considered compatible due to the sharing of tenets of theory and knowledge, and the value placed on the inquiry process. Both approaches shared a similar level of commitment towards obtaining a greater understanding and strove towards improving the human condition. The use of the mixed-method approach also supported the research practice of sharing understanding through the disseminating of knowledge for practical use. This concept was in support of Reichardt and Rallis (1994) who emphasised how the combining of qualitative and quantitative approaches promotes the sharing of a level of commitment for rigor, conscientiousness and critique within the research process.

Thirdly, since the research was centred on a healthcare setting, the mixed-method approach was considered appropriate to accommodate possible complexities. In developing this third point, Baum (1995) outlines how research within the public health sector involves many complexities. Whilst, Steckler et al (1992) argue issues within social interventions, such as health and education, require the incorporation of both the qualitative and quantitative approach to be utilised to address such complexities within any given research.

On a practical level, the mixed-method approach of incorporating a combination of qualitative and quantitative research methods was utilised within each case study framework. Theorists such as Mitchell (1986) and Reason and Rowan (1981) support such combination of these methods by highlighting how the strengths of one method can counterbalance the flaws or weaknesses of the other. The quantitative data involved the collection of statistical data surrounding the frequency of contact amongst the participant along with the use of a structured questionnaire used to obtain background information of each family unit. The qualitative data involved the recording of interviews, observations and communication that occurred throughout the collaborative process. For the purposes of the research, the researcher utilised the quantitative data collection approach first, followed by the qualitative approach of collecting data.

Section 2.6 Ethical and Practical Issues

Initially, ethical approval was sought and obtained by the University of Birmingham before commencement of the research in April 2010.

When completing the research, different ethical principles outlined by the revised edition of the British Psychological Society in Ethical Principles for Research with Human Subjects (1993) and the Market Research Society (MRS) Qualitative Guidelines (1998), were considered:

- A consent form granting permission was sought from all participants to complete in the research. (*Please refer to Appendix Three to Six - Invitation letters*). Identity of all involved within the research was confidential. Therefore, no real names of people or places were recorded in the research or findings, only fictitious names were used.
- All participants were informed about the aim of the research (*Please refer to Appendix Three – Information Sheet*). Each participant was presented with the research findings on the 28th of February 2014.
- All information/data collected was kept confidential at all times and was kept under lock and key and password protected.

When considering the practical issues of the research, the researcher addressed the following areas:

- In the event of a family deciding to opt out of the research: consent was sought at the initial invitation phase from the GP of another family to allow the process to recommence accordingly.
- To ensure to incorporate a follow-up care plan as outlined by the Declaration of Helsinki (2002). To address this ethical need, the researcher continuously updated all participants of the development of each case study to allow the support to continue once the research ceased.
- To consider the possibility of a power struggle Stone and Priestly (1995) suggest a reformulation of traditional disability research to create more equal status of control and details of core principles, for example, adopting an epistemological stance of the social model of disability. Therefore the research was to ultimately benefit the participants practically and remove possible disability barriers. To facilitate such a paradigm, the researcher adopted practical questions raised by French and Swain (1997), questioning whether there is equal ownership over the decision-making process, and whether the research addresses the concerns of the participants.

Section 2.7 Activity Theory – Theoretical Framework

Introduction

The Activity Theory (AT) originated from the classical German philosophers, Kant (1788) and Hegel (1812), who explored the development of ideas within an active and constructive role context in humans. Kuutti (1996) remarked on how such a philosophy was fuelled more by the contemporary beliefs of Marx and Engels to Vygotsky and Leont'ev. The researcher adopted the AT framework, not as a methodology but as a philosophy towards learning. This concept is supported by Kuutti (1996) who cites how this framework should be seen:

“as a philosophical framework for studying differences forms of human praxis as developmental processes, both individual and social levels interlinked at the same time”

Ref: Kuutti (1996), pp. 532

AT posits that conscious learning emerges from an activity and not as a precursor to it, providing an alternative view of human thinking and activity. The theory focuses on the interaction of the human activity and the consciousness within the relevant environmental context. The theory is a powerful socio-cultural and socio-historical tool, through which, as emphasised by Jonassen and Rohrer-Murphy (1999) and Bødker (1991a), human activity can be analysed. However, at this stage it is important to state how an activity cannot be understood or analysed outside of the context in which it occurs. Therefore, when analysing the human activity, the researcher examined not only the activity itself, but also those engaging in the activity, noting their goals/intentions, the result of the object, the rules and norms that circumscribed the activity to finally the community itself in which the activity took place.

Assumptions of Activity Theory

Jonassen and Rohrer-Murphy (1999) present different underlining assumptions of activity theory from the minds in the context, human consciousness, participant's intentionality and object-orientation, community as a context, historical-culture dimensions and tool mediation to collaboration. For the purpose of this thesis, the researcher will briefly introduce and relate two assumptions to the research.

Intentionality

When considering intentionality, the researcher needs to first of all acknowledge how humans interact within environments and learn in order to achieve a goal. Activity Theory, as proposed by Linnard (1995) focuses on how actions are performed with a conscious intent. Initially, intentions are planned before they materialise into actions. Humans conceive the intention/activity and plan how they will perform and achieve the goal through activities. Within the Activity Theory, intentions are created through contradictions individuals experience within their environments, for example: what they perceive they know to what they actually know.

When relating this concept to the research, actions surrounding identified needs were devised and intentional activities aimed towards assisting the family within the community were developed, initially between the key worker and the primary carer. This can be seen within the development of the family's individual plan. Different individuals were assigned tasks to complete based on their profession and knowledge. Within the research an example of an intervention was the need of an OT assessment within the home to accommodate cognitive functioning. The action plan consisted of the key worker requesting a referral form from the occupational therapy department. Once the form was completed by the family, the key worker forwarded it onto the OT Department for processing. The OT's intention within the action plan was to fulfil the assessment of the family and identify and implement necessary adaptations to support the family within the home.

Collaboration

Regarding collaboration, the majority of activities involved the participation of a group of individuals. This form of social interaction and development is in support of Leont'ev (1981) who cites:

“The human individual’s activity is a system of social relations. It does not exist without those social relations”.

Leont'ev (1981) pp46 -47

Collaboration within the AT system takes into consideration the individuals who partake in an activity; and how they concurrently become members of alternative activity teams through different objects, tools, and social relations. Such concurrent membership of activity teams is referred by Jonassen and Rohrer-Murphy (1997) as a form of “horizontalness” within the activity theory dynamics. This concept is further emphasised by Engeström (1987) who describes the activity as a human process of collaboration.

When reflecting on the collaborative process within the AT framework of the research, each member initially formed part of their own team and then became, through collaboration part of a wider team. Within the research, primary carers initially formed part of their family team. Following participation within the research; the primary carer became part of the case-management team. Other members of the research team consisted of professional teams which relating to their profession, for instances: physiotherapists, OTs, S & L therapists. In turn, each of these professions came together to form part of another collective team, referred to as the primary care team. Once an action involving the participation of a profession, for instance, an OT was identified within the research activity system, the collective PCT team and the professional team (OTs) then became part of the case-management team working together with other professionals and families alike.

Rationale behind the utilisation of the Activity Theory approach

The attention towards incorporating the AT framework into the research was based on thoughts raised by Jonassen and Rohrer-Murphy (1999), who cite how

“The activity theory is a socio-cultural, socio-historical lens through which designers can analyse human activity systems”.

Jonassen and Rohrer-Murphy (1999), pp. 61

The incorporation of the AT supported the participatory action approach (PAR), through the inclusion of each participant, the collective process of identifying the family needs to addressing these needs within an activity system. Furthermore, the AT concept addressed the interaction between the human and activity on a consciousness level within its relevant environmental context. The researcher acknowledged how the learning that was to emerge from the research was to take place during and following the activity and not as a precursor to it. Such a paradigm of learning is supported within AT approach, as the objectives and aims of the research were not predetermined but would evolve over time. In developing the practice of learning, the research strove to replicate the activity structures, tools and signs systems, socio-cultural, and community expectations for the participants in order to promote a continuum of learning after the completion of the research.

Another beneficial factor of AT framework, as emphasised by Nonaka and Takeuchi (1995) surrounds the perception of how the key for innovation is knowledge. In progressing Nonaka and Takeuchi’s concept further, the researcher considered how innovation was a process of creating and defining problems, which results in new knowledge being established throughout the research. The process of knowledge involved tacit knowledge, stemming from the knowledge and experiences of each participant. Nonaka and Takeuchi (1995) develop this concept by defining two dimensions for knowledge creation: epistemological and ontological dimensions. The epistemological dimension relates to the conversion of knowledge from tacit level to explicit level and from explicit level to tacit level. The ontological dimension relates to the conversion of knowledge from individuals to groups and then onto organisations. These two dimensions are further developed by Nonaka and Takeuchi (1995) by defining four active learning processes, namely: socialisation,

externalisation, combination and internalisation. For the purpose of the research, each dimension was considered below.

Socialisation

Socialisation begins with the building up of a “field” of interaction to accommodate the sharing of members’ experiences and mental models. In the research, socialisation involved formal discussions, initially, with the GPs, followed with the families involved in the case studies. The aim at this stage was for the socialisation to promote the practice of sharing and developing a network of experience and knowledge, in order to address the needs of the family. Issues were raised, and each member discussed and shared input, and experiences towards addressing the identified needs.

Externalisation

The next active learning process is externalisation. During this stage, tacit knowledge is articulated into explicit concepts. Within the research, externalisation occurred when the case study team articulated meaningful dialogue and/or promoted collective reflection. In a formal setting, it occurred through telephone conferences and occasional meetings. All forms of externalisation helped to improve on the initial ideas generated during the socialisation process.

Combination

During the combination stage of active learning, different bodies of explicit knowledge are reconfigured through sorting, adding, combining and categorising into a database to form new knowledge. Within the research, combining knowledge promoted shared learning and understanding of all participants. The information expressed by the team members was captured and recorded during the socialisation and externalisation process stage.

Internalisation: (Individual learning)

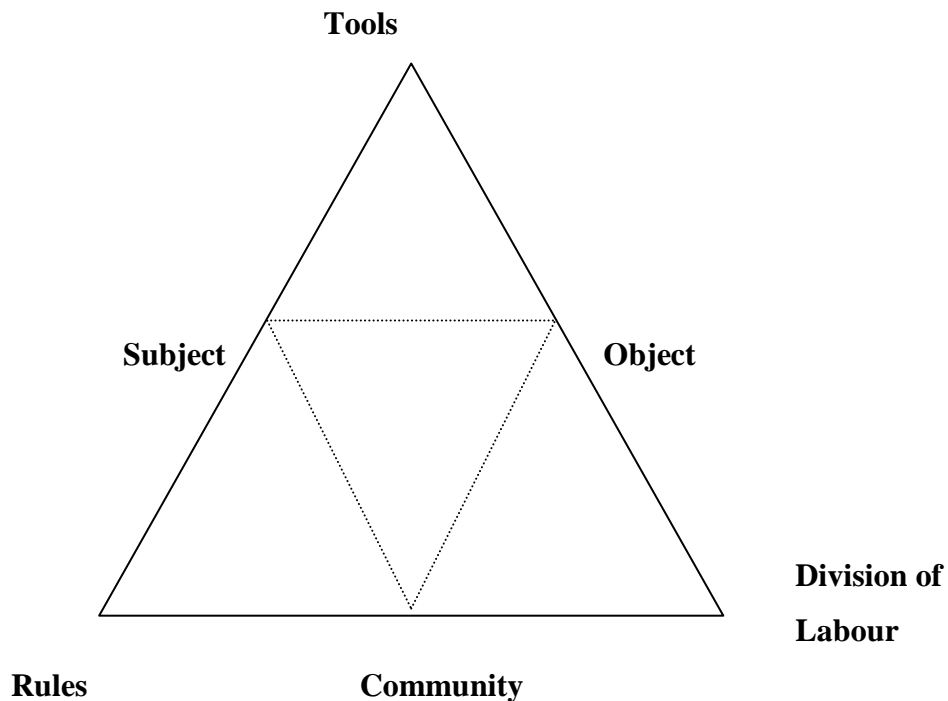
Internalisation is during the process of embodying explicit knowledge into tacit knowledge, closely related to “learning by doing”. Within the research, during the socialisation, externalisation and combination forms of active learning, experiences were internalised into the tacit knowledge of the individual based in the form of shared mental models or technical know-how. Such knowledge then became a valuable asset. This process of learning was seen within the research when information surrounding TBI and other professional services were circulated around the team for review. Furthermore, this form of active learning was also where information documented from self-reflection on actions was reviewed and shared amongst the team.

Components of an Activity System:

To strengthen the understanding of Activity Theory further, each component of an activity system will be presented with reference to the research.

At a singular level, a unit of analysis can be described as an activity. A group of activities are then organised, as outlined by Engeström (1987) into an activity system. Please refer to triangle below:

Figure 2 - Activity system



The primary focus of the activity system (top level) is to produce some object as a result of an activity. Such a production of an activity involves, as outlined by Nardi (1996) a subject, identification of the object of the activity, tools required within the activity, actions and operations that affect the outcome.

The *subject* of any activity refers to the individual or a group that partakes in an activity. In the case of the research, the subjects were formed across different individuals.

- The first one was the researcher who was conducting the research and adopted the role of the key worker, assisting the primary carers throughout the research project.
- The next set of subjects consisted of local GPs who were invited to partake in the research. For logistical purposes, the GPs selected practiced within the local urban area of Dublin where the researcher resided. The GPs became subjects within the activity of identifying six case study families to participate within the research.

- The six families, who became involved in the research following a referral from their GP, also became subjects through the process of identifying their needs, initially with the key worker and then through the development of the activity system itself.
- Finally, the last subjects consisted of members of the local primary care teams, hospital staff and community services. Within these subjects, various different services were required to address the different objects of the actions. For instance; Physiotherapists and OTs were required to process referral forms for their own individual therapies, hospital staff was required to provide discharge plans, whilst PHNs were required to provide nursing care within the home for the family.

The subject acts upon the next part, the object.

The *object* of the activity refers to the intentional, motivational, physical or mental product that is sought. Within the research, the object of the action varied at different stages. Initially, it was to complete an interview to identify the needs of the family. The object evolved onto the designing and developing of a flow through chart, outlining the identified needs of the family. The last object was to ensure that each action was coordinated and developed, for instance: the completion and submittal of a referral form for therapy.

The *tools* refer to anything used within the transformation process, from physical for instance: computers, to mental for instance: alternative models or heuristics. Tools utilised within the research consisted of many, from computers to record spreadsheets and minutes of meetings to specific forms for instances: referral forms. It was important to consider how different tools could alter the activity and in turn be altered by the activity. In the research, an example of a tool that altered the activity system was the Family (A) Identification of Needs Spreadsheet, (Appendix Two, A & B). The tool was initially, to act as a record of the identified needs of the primary carer. However, the spreadsheet (tool) altered the activity through the tool becoming the activity system itself, outlining what needed to be done and

when. The importance and impact the recording spreadsheet tool had on the research is supported by a citation by Jonassen and Rohrer-Murphy (1999), who cite how:

“We even think of activity theory itself as a mediating tool for research and development”.

Jonassen & Rohrer-Murphy . pp.63

Overall, when considering activity theory as a system, each activity is driven by a goal-directed hierarchy of actions. Please refer to Figure 3 below. Each action is used to accomplish the desired object (consisting of tasks, actions and operations). The Activity, itself is a conscious performance of actions which involve a chain of actions, for example; completing a needs assessments of a family. While actions are a chain of operations, for example record updating etc. Therefore actions are completed by an individual, while an activity is completed by a group of individuals. Initially, operations performed are actions, due to the conscious effort required to perform the task. With practice and repetition, all activities alter to actions and eventually into operations, as they become more habitual and automatic, requiring less conscious effort. Alternatively, the reverse can occur, with the operations becoming disrupted and revert back to actions. Therefore, the relationship amongst the activities, actions and operations is changeable.

Figure 3 - Hierarchical nature of activities, actions and operations



Jonassen and Rohrer-Murphy (1999) propose meaning to the activity system factors by citing:

“The Community consists of the interdependent aggregate who share a set of social meanings. Rules inherently guide the actions or activities acceptable by the community, so the signs, symbols, tools, models, and methods that the community uses will mediate the process. The division of labour prescribes the task specialisation by individual members of groups within the community or organisation”.

Jonassen and Rohrer-Murphy (1999) pp.64

In conclusion, the incorporating of Activity Theory Framework into the research was to act as an essential tool towards gaining a greater understanding of possible conflicts, friction, contradictions and inconsistencies both between and within the components of an activity system for each of the six case studies. Furthermore, the theoretical framework allowed the researcher and the participants to conceptualise what innovations worked and did not work, what impeded change, at what level and in relation to which factors. Essentially, the framework supported the participants of the research in providing a tool to study the reconfiguration of practice resulting from the introduction of the innovations within each case study.

Section 2.8 Case Study Approach

Introduction

The researcher adopted the case study approach to illustrate a comprehensive examination of each of the case studies and merge each study's findings together in all its complexity. This approach is supported by Zonabend (1992) who proposes the case study should be completed in its entirety through warranting special attention towards the observation, reconstruction and analysis process. Such level of completeness was used to promote the case study as a "proof of concept" towards how a collaborative process of a multi-disciplinary team could support families of those who have experience of a loved one with a TBI out in the community. The case study approach supported the multi-dimensional approach by promoting, as suggested by Said (1991) and Feagin, Orum and Sjoberg (1991), the listening of all parties along with the ethical need of ensuring accuracy and validity of data collected. (Stake, 1995 and Yin, 1984).

Definition of a case study

The case study method aims to support the researcher in closely examining data within a specific context. In general, the case study method selects a small geographical area or a very limited number of individuals to study, and promotes the exploration of a real-life phenomenon through the detailed analysis of a number of events or conditions as well as their relationships. (Yin, 1981). After the researcher discussed the sample size of case studies with her supervisor, the decision was made to invite six case study families to participate in the research who were to reside close to where the researcher lived. Six families were identified as the number of families the researcher felt she could best support throughout the project. This decision took into account how the researcher was working within a full-time capacity and was due to perform the research outside of her normal working day activities.

McNiff and Whitehead (2010) maintain how case studies are commonly utilised for reflecting studies of singularities (an individual, “I”) with the cooperation of other singularities (other people, you and your research participants). These singularities move forward and enter into a cooperative or a collaborative relationship, which creates a collective sense (a group, “we”). When considering this process, it is paramount that the researcher does not consider “we” or the group as a homogenous group, or just a simple collection of individuals, but to consider the term “we” as a collection of individuals, who share a common purpose and commitment to a certain value(s). Within the research, the case studies consisted of a group of individuals, for example: the researcher, the family and professionals who worked towards providing beneficial supportive services to the families who have experience of a loved one with a TBI. It is important to emphasise even though participants of the research presented with a commitment towards a similar cause, the aim was not to create a sense of overall consensus. This concept was taken to facilitate concerns raised by Said (1991) who proposed how such a promotion of overall consensus could eliminate critique and promote the possibility of descending into fundamentalism. To support this concept, findings of the research showed how individuals involved in the case studies were actively listened to and a sense of openness was promoted to provide an overall holistic environment.

Duration of a case study

The duration of the case study can be short to long term with an in-depth examination of a specific event for a singular or multiple case study formats. Such examinations could be utilised to provide a systematic way of observing events, collecting data, analysing information and reporting results over a period of time. For instance, an example of a short-term case study could surround researching participants’ benefits of a week’s training course within an organisation. Whereby, an example of a longitudinal examination could be researching into the development of children’s language. Within this type of longitude examination, observations are taken and recorded over time to ascertain the level of language development. Within the research, data was recorded for each of the six case studies over a six month period.

Considerations taken

Consideration was given to the practicalities of applying the case study format. Two distinctive topics were considered. The first one was governed by the research question. Shavelson and Towne (2002) emphasise the importance of identifying whether the research question is a descriptive question (what happened?) or an explanatory question (how or why did something happen?) With these types of questions, Yin (2004) maintains how the case study method is best suited to research that addresses descriptive or explanatory questions and aims to apply and produce an in-depth understanding of a specific phenomenon.

The next topic surrounded whether the researcher wished to highlight a specific, in-depth situation and gain a greater understanding of the phenomenon. It was acknowledged, in support of concerns raised by Bromley (1986), that by utilising the case study method, it would enable the researcher to make direct observations and collect data within the natural setting, as opposed to relying on “derived” data as seen in test results or statistical data maintained by government agencies.

Single or multiple case studies

Once the decision was made to utilise the case study method, decisions needed to be made surrounding whether to do the research as a single-case study or a set of case studies. The term “case study” can refer to either single or multiple-case studies which constitutes two types of case study designs. The single case or multiple-case design was considered taking into account the suitability in relation to the issue in question.

It was acknowledged how a *single-case design* can be utilised, when the event is rare or there are no other cases available for replication. Furthermore, a single-case design as explained by Yin (1994) can be utilised to confirm or challenge a theory, or represent an exclusive or extreme case, whereby the researcher has access to some unique event or phenomenon. For instance, Zaidah (2007) recorded how the social study of the effects of

the collapse of Highland Towers in Kuala Lumpur in the 1990's can be conducted using a single-case design due to the limitation of a single occurrence. However, a consideration of the single-case design surrounds the generalisation of the research findings, especially when the question or event is rare. A way to facilitate such a concern is through the use of triangulation, by incorporating other methods into the research to confirm the validity of the process and the data. Therefore when considering a single-case study, the researcher is enabled to devote careful attention to that one case.

When considering a *multiple-case design*, these designs can be utilised to record real-life events through the incorporation of numerous sources of evidence. In developing the multiple-case designs, replication rather than sampling logic combined with noting deliberate or contrasting comparison is presented which adds to strengthening the researcher's findings. This concept is developed by Yin (1994) who emphasises how generalisation of results, be it within single-case or multiple case designs are based on theory rather than on population.

In order to gain as much insight and understanding of the research phenomenon, the researcher decided to go with a multiple-case study of six families to represent confirmatory cases which would replicate the phenomenon and not represent universal generalisation. This concept is supported by Yin (2004) who outlines the motive for the utilisation of multiple-cases studies should not be to represent some universe but to follow the rational framework of the inquiry. The six families presented with variations for example: length of time post-injury, gender and age. None of the six families was considered to be "controls" for each other, as it was not the intention to explore the case studies as a "control group". The researcher wanted to explore the real-life events without any interference.

Category of Case Study

The next area to consider surrounded the category of the case study to be utilised. Two different categories proposed by Yin's (1984), the exploratory and the explanatory case studies were considered within the research.

The first category, *exploratory case study* aims to explore any phenomenon within the collected data, which serves as a point of interest to the researcher. For example, conducting research on an individual's reading process the researcher may ask, "Does the individual use any strategies when reading a text? And, "if so, how often? These types of questions are utilised to support further development and examination of the phenomenon being observed. Prior fieldwork and small-scale data collection may occur before establishing the research question or hypotheses in order to create and prepare a framework of the pending study. Yin (1984), McDonough and McDonough (1997) support the initial running of a pilot study, considered as an exploratory case study and how such early work is a crucial component in determining the protocol to be used.

The second category suggested by Yin (1984) is the *explanatory case study* format. The explanatory case study examines the data closely both at the surface and at a deeper level, to explain the phenomena within the data collected and presented. For instance, Zaidah (2003) queries how a researcher may ask the reason as to why a student uses inferencing strategy in reading. Following this question and collection of data, the researcher may then form a theory and progress as emphasised by McDonough and McDonough (1997) towards testing the theory.

The decision was taken to adopt the *explanatory case study* format initially as it supported the basis for the research question. That is "How the role of the key worker can support families in the community who have experience of a loved one with a TBI". This format supported Yin and Moore (1987) concept of the need to acknowledge the complexities and the multivariate of cases that could be involved in research. The *exploratory case study* format would then be utilised to present the findings on "What" the role of the key worker was in providing support for the families involved in the research.

Unit of analysis

The unit of analysis can, as proposed by Sjoberg et al (1991) be an individual, community, an organisation a nation state to a civilisation. For the purpose of the research, the unit of analysis was six families who have experience of a loved one with a TBI. The intention was to select appropriate cases and focus on two issues, *how* and *what* the role of the key worker could and would do out in the community to support families. These two issues were adopted as the researcher felt these issues were fundamental to presenting and understanding the real-life experiences of the cases being examined.

Advantages of the case study approach

When considering the advantages of utilising the case study format, Yin (1984) suggests how the data collected and examined is often conducted within a real-life situation, that is, the situation or environment in which the activity occurs at a micro level. Through utilising the approach, the researcher gains insight and understanding of the observed subject within the environment the event is taking place. This practice is unlike, as emphasised by Zaidah (2003), some experiments which isolate a phenomenon within its context and focus solely on a limited number of variables. Within the research, the approach enabled the researcher to explore and present the complexities of the situation which may not be captured fully within other forms, for example: experimental or survey type of research.

Disadvantages of the case study approach

After considering the above advantages, there exist criticisms surrounding the case study approach. Yin (1984) introduced two types of arguments against case study research. The first argument surrounds the lack of rigour. Yin cites:

“too many times, the case study investigator has been sloppy, and has allowed equivocal or biased views to influence the direction of the findings and conclusions”.

Yin (1984) pp 21

The next argument surrounds the difficulty in the generalisation and transferability of case study findings. This concern is emphasised by Tellis (1997) who questions whether single-case studies are capable of generating and providing a generalised conclusion.

For the purpose of this research, the researcher did not intend to present with an overall generalisation due to the logistics of the research. Further research would be required on a larger logistically nationwide level to establish transferability and generalisation of the findings. However, the researcher intended to present a form of analytic generalisation towards the findings through the comparison of a developed theory, coupled with some statistical information to strengthen the overall findings.

Case Study Protocol

The researcher adopted Yin (1994) guidelines on outlining the need to develop a case study protocol. The protocol is composed of two subheadings: *Determine the Required Skills* and *Develop and Review the Protocol*.

Required skills, as suggested by Yin (1994), are that the researcher needs to pose good questioning skills, good insight and ability to interpret the responses, have excellent listening skills, be flexible and be able to adapt to situations as they occur. Finally, as outlined by Feagin, Orum and Sioberg (1991), the researcher is required to have the ability to function as “senior” investigator, thereby presenting with good leadership skills.

In adopting the protocol put forward by Yin (1994) within the research, different areas were *developed and reviewed* within the case study format.

Background

Initial identification of previous research surrounding TBI and support for the family within the community was reviewed. The main question was defined:

The phenomenon being explored is to seek how the role of the key worker can support families in the community who have experience of a loved one with a TBI and identify what that role will involve?

Design

It was identified to use multiple-case design, at a holistic level due to the multiplicity and complexities of the participants involved in the agreed six case studies. The object of the study explored the role of the key worker within each case study, noting how and what such role may involve.

Case Selection

Initial invites were sent out to GPs within a five mile radius of where the researcher resided in urban Dublin, requesting assignment of possible suitable families who had experience of a loved one with a TBI and who would be interested in participating in the research. Families were to live within the researcher's locality to support logistical issues. The individual with the TBI was to be between the age of 16 years and 65 years of age. Six families were sought from GPs.

Data Collection

All communications, for instance: meetings, telephone calls to texts were recorded on the same day that the event took place. The researcher maintained an individual file for each case

study family containing all recorded information. The six case study family files were locked and stored away for safe-keeping in a filing cabinet within the researcher's home. Soft copies of the data were stored on a password protected memory key, which was stored within a locked filing cabinet. Information on the individual with the TBI and their family were collected and recorded, for instance: pre- and post-history on individual with the TBI, date of birth, date of injury, and information on injury to identifying the needs of the individual and the family.

Analysis

The researcher utilised a qualitative data collection method for analysis, recording all events as they occurred. As the research developed, different data elements evolved and were analysed to identify "how and what" the role of the key worker completed towards supporting and addressing the identified needs of the six case study families within the research.

Validity and Reliability

When considering the validity and reliability of the research findings, the researcher considered thoughts raised by Yin (1989) surrounding the construct validity, internal validity, external validity and reliability. As presented earlier, both exploratory and explanatory designs were utilised within the research due to the "*What and How*" questions of the phenomenon. In addressing the "What and How" questions of the phenomenon it enabled the researcher to provide construct validity through the exploratory design of the researcher identifying and recording the process of how the role of key worker supported the identified family needs. The internal validity was obtained through the explanatory design of the researcher outlining what role the key worker played within supporting the six case study families (unit of analysis) identified needs within the research project. To strengthen the construct validity, and support Tellis (1997) multiple sources of evidence were incorporated into the data, for instance, interviews or documents. When considering the external validity, the theoretical relationship was to support the generation of the external validity and would not be sought from generalisation. Finally when considering *reliability*, the research

supported the concept proposed by Tellis (1997) surrounding reliability through the devising and providing of a formal case study protocol.

Reporting

Upon completion of the findings, each member of the case studies had access to reviewing the research findings and noting any issues that may have arisen.

Please refer to the case study protocol of procedure outlined into three stages in *Appendix Ten - Case Study Protocol*. In support of Yin's (1994) good case study format practice, the protocol was reviewed on an ongoing base, in conjunction with the development of each case study.

CHAPTER THREE – FINDINGS (FAMILY)

Section 3.0 Introduction to Research Findings

(Chapters 3 and 4)

Within the findings chapters of the research, the data will reflect how the role of the key worker supported the six case studies out in the community through data recorded on the identification of needs process for the six case studies. The presentation of findings is very long and for this reason it is split over Chapter 3 (focussing upon data related to families) and Chapter 4 (focussing upon data related to professionals).

Chapter 3 reports on data identified surrounding the primary carer's needs of the six case studies. Initially, data was obtained utilising Stambrook et al (1994) family crisis stages on life-cycle and role changes to explore and identify the impact resulting from the experience of a loved one with a TBI. Once this grounding information was collated, the research moved onto completing the process of identifying the needs of each of the six primary carers in all its complexities. To promote a greater understanding, data was presented in the form of written detailed case studies, tables and graphs.

Chapter 4 reports on findings in relation to the professional role, as well as reviewing the findings through an Activity Theory framework.

The first section of Chapter 4 focussed on presenting findings on how the role the key worker supported each of the families during the research. In order to explore the role of the key worker, the research initially obtained data on background information from each of the case studies surrounding the level of time post-TBI without any key worker support. This information was to explore the variance in times as suggested by Lees (1988) in which the role of the key worker could be implemented. The next area of findings focused on presenting the identified roles of the key worker as requested by each of the six primary carers. These needs were to form the development of each activity system for the family within the research.

The second section of Chapter 4 presented data on findings generated by the involvement of the multi-disciplinary team. Within each case study, different professionals assisted within the development of the research. Data on the different categories of professionals who were involved in the development of each case study was recorded. Findings presented only reflect the professional functional involvement along with the researcher's own personal reflection on the collaborative process. The data does not contain individual professional citations, as all of the professionals involved did not wish to be cited within the research.

The third section of Chapter 4 surrounded the analyses of the research through the Activity Theory framework. To complete this analysis, the researcher reviewed Engestrom (1987) proposed model of components on each activity to present findings on what was learnt.

Section 3.1 - Introduction to Family Needs

Due to the vast amount of data recorded and the complexity of the needs, the findings concerning the needs of each family member were presented through different areas.

The first section concentrates on reporting the experience of each family member at different family crisis stages throughout their loved one's recovery. To present these findings, the researcher utilised Stambrook et al (1994) listing of family crisis stages, namely: in-patient, out-patient, and discharge to other stage. Findings were initially correlated within a table format for recording purposes. To promote a greater understanding of the data, the researcher presented an in-depth review of the findings for each family crisis stage experienced within the case studies.

The second section presents findings on the data collected in relation to the six case studies family life-cycle and role changes post-TBI. Information was presented in a table format, utilising Stambrook et al (1994) FLC which recorded the different cycle each of the families was in at the time of the TBI. The findings then went onto present the different roles the families were required to adopt in order to deal with the needs of their loved one. These findings were initially presented in a table format. Each role change was then presented in-depth to enhance the understanding of the impact and change each family experienced resulting from the TBI.

The final section presents the recorded family needs identified during the research. The identified needs support findings from a study conducted by Serio, Kreutzer and Witol (1997). Initially, findings were presented collectively in a table format, and then individually in-depth to enhance the understanding of the different identified family needs.

Family Crisis Stages

Families are confronted with different stages of family crises and therefore altered family needs throughout the recovery process. For the purpose of the research, such interrelated stages were presented using Stambrook et al (1994) family crisis stages, namely; the in-patient stage, the discharge from hospital stage and the discharge from out-patient stage. The findings were presented initially in a table format to give a visual understanding of what stage of the recovery process each family was at. The researcher then went into further depth for each stage and presented the findings for each of the families who participated in the research. The researcher adopted this approach in recognition of April (1997) and Lezak (1995) who raised the importance of the need for professionals to obtain such groundwork exploration and understanding, in order to support the family more efficiently throughout each stage. Below is a table of the different family crisis stages (Stambrook et al, 1994) in relation to the six case studies that participated within the research.

Table 1 – Family Crisis Stages

Case Studies	Time since injury	In-patient stage	Out-patient stage	Discharge stage	Other
The Long Family – CS1	6 years				√
The Timmons Family – CS2	27 years				√
The Coyle Family – CS 3	6 years				√
The McCroon Family – CS 4	3 months	√		√	
The Carling Family – CS 5	2½ years	√	√	√	
The Sterling Family – CS 6	1 year				√

In-patient stage

Greer, Knack and Roberts (1992) record how often families only focus on the needs of their loved one and nobody else during the in-patient stage. Their research also recorded families feeling that they were in a time warp and that their whole lives were turned upside down, with their primary focus being on just getting their loved one through each day. Within the research there were two families at this in-patient stage. The key worker came in contact with the first family; the McCroon Family (CS4) six weeks after the individual had sustained his injury, and had only recently come out of a coma. The circumstances of the second family (CS5), the Carling Family were different. The individual was still under the care of the hospital, two and a half years after he had sustained his injury.

McCroon Family (CS4)

During this stage, the mother reported concern and bewilderment surrounding how their loved one was actually doing. Such findings support April (1997) and Kreutzer et al (1990b) concept of how families don't focus on the possibility of future care, but just focus on the present, living day by day. In following the findings from the McCroon Family, records show how the mother was happy with how her son had awoken from his coma and felt as a result of him being awake he would make a complete recovery as outlined by Jackson and Haverkamp (1991).

Carling Family (CS5)

In relation to the Carling Family, the reason for the length of time in hospital was down to a lack of facilities or funding being available to support this individual and cater for his needs. Such a situation in itself caused the family great distress as they could not move forward in his rehabilitation. The mother, Kathy cited:

"I feel we are in a time warp for the past two and a half years. Visiting the hospital every day for sometimes up to six hours a day".

Ref: Kathy Carling

However as time went on, both mothers of the McCroon and Carling families started to indicate how realisation of the extent of their loved one's injury started to become apparent and how their loved one was somewhat "different" then before. It was recorded by hospital staff in relation to Danny from the Carling family that due to the duration of hospitalisation care, Danny's difficulties were permanent and how such changes could be life-long. However, the researcher would query as to whether the full realisation of Danny's injuries are fully understood by the family as their son has remained in the hospital care setting and the family have known nothing else since the time of his injury.

Frustration became evident as the carers began to feel that they were being ignored by some medical professionals. Mary and Kathy (both mothers in the case studies) reported feeling left out in the recovery process for their loved one. They recounted how they had asked to speak to the medical team but were either left waiting or saw somebody different each time who wouldn't answer their queries. In saying this, families also recorded how when the medical professional did speak with them, medical terms were used which they did not understand. Mary McCroon cited:

"How am I supposed to understand this language, I am not a doctor. I need somebody to explain how my son is in easy language".

Ref: Mary McCroon

Such findings are in support of Martin (1998) who emphasises how families may become stressed and frustrated to the response of the medical professional when questions are posed to them.

Discharge from Out-patients stage

Findings on this stage refer to the Carling family, whereby the possibility arose for the family to take their son home for a short while. From the onset of the research, the mother stressed the desire to take their son home for family events and weekends and voiced how she was looking into adapting their house to accommodate such visits. The process of discharging her son for a short while involved a lot of professionals, both internally in the hospital and

externally within the community working together to support the family and the individual with the TBI.

The family did manage to take their son out for a family event twice for two hours. This was the first time the family had to fully support their son away from the hospital and they stressed that they could easily manage. Following the first outing, the family expressed a sense of a “honeymoon” period, as outlined by Kay and Lezak (1990), reporting all went well. However, during the second outing difficulties and realisation began to manifest into the extent of their son’s injury. Certain emotional deficits began to emerge which the family reported afterwards had not been recognised before. Initially, the family’s sole focus was on the physical difficulties of their son. The mother reported dealing with her son’s emotional deficits as being very stressful, as outlined by April (1997) and how she did not know how to deal with these. Upon being advised of these feelings from the family, professional counselling and guidance were offered to the family as supported by Prigatano (1999). However, the mother refused to attend any of the sessions, citing:

“I am just fine, I am his mother, and I can’t do that on him. It’s my duty”.

Ref: Kathy Carling

When the next outing was being arranged and discussions began to emerge surrounding overnight access; the family began to identify barriers to such discharge, noting that the house was not ready yet or that they had no transport for their son on that day. Therefore, the outing did not transpire.

Total Discharge stage

The total discharge stage is when, as emphasised by April (1997) the patient has finished receiving therapy from the hospital and is discharged from the out-patients service. As a result, families are forced to deal with the long-term rehabilitative needs of their loved one. Within this stage, the findings relate to two case study experiences, the Carling and Sterling families.

During this stage Stambrook et al (1994), comment on how families may experience a feeling of isolation and uncertainty towards the future. In exploring this possibility, findings from the mother of the McCroon family report how the family felt totally let down and unsupported by the medical profession, feeling isolated and scared. The mother reported a sense of fear for the future and questioned who, if anybody was going to help her through it. However, the key worker became aware, as seen with the Carling family, of how families may also be reluctant to voice their feelings for fear of betraying their loved one. Furthermore, in both families, the primary carers were mothers. Both of the mothers would only discuss and focus on their sons at the early stages and were reluctant to disclose or discuss their own feelings and fears.

Another crisis at this stage reported by both mothers surrounded financial concerns. Both mothers had stopped working in order to care for their son in different ways. Mary from the McCroon family initially left her job in order to visit her son in hospital. After his discharge, Mary reported being afraid to leave her son unattended and felt that she had to go everywhere with him for fear he may fall ill. Kathy, the mother of the Carling family, spent all of her time at the hospital. It was at this stage for both cases, that the role of the key worker took on the activity of sourcing suitable financial social welfare payments to aid both families. This action was completed in support of Kreutzer et al (1990b) who emphasises how families may experience financial distress and for the need of rehabilitative professionals to complete a full needs assessment to identify areas of support for the family. It was the researchers experience within the research that this source of support was only briefly introduced prior to the key workers intervention for the McCroon family. However, it is important to note how both families were involved in different hospitals.

Other treatment

Stambrook's et al (1994) last stage explored was "others treatment" referred within the research to families that were out of the hospital, medical and professional environment and in some cases were many years post-injury.

The table below outlines the case studies families involved in this stage, recording the length of time post-injury away from any medical or professional intervention.

Table 2 – Length of time post-injury

Case Studies	Length post-injury
Sterling Family (CS6)	1 year
Long Family (CS1)	6 years
Coyle Family (CS3)	6 years
Timmons Family (CS2)	27 years

Even though each of these families were at a different length of time post-injury, findings recorded indicated how these families still experienced difficulties which, as emphasised by Stambrook et al (1994) may present themselves when their loved one was discharged from out-patients. Such findings may highlight how these difficulties do not decrease over time.

Findings recorded how each of the four families found it difficult to deal with their loved one's difficulties surrounding emotional and behavioural deficits. The wife of the Timmons family cited:

“My husband embarrasses me when out in public; he acts like a child demanding things. It is like having another child to look after, only worse”.

Ref: Molly Timmons

Also findings recorded indicated how three out of the four families were still experiencing financial distress as the primary carers had become the main earner for the family.

In the cases of the families; Long, Coyle and Timmons due to the length of time post- injury, the realisation of the long-term, lifelong deficits of their loved one were evident. This realisation had in some ways rendered the primary carer as deflated, with a sense of acceptance of how things will never change.

As a result of these feelings, two wives and a mother of one of these families reported how their own life had stopped the day their loved one sustained their injury and that their life revolved around that person. In the case of the Timmons family, due to the length of time post-injury, which was 27 years, the wife reported feeling resentful of her husband, noting:

“My life stopped 27 years ago when my husband, Jack sustained his TBI. I feel that I lost my husband, partner and the father of our children. It was not fair”.

Finally, out of the four families within this section, two wives and two mothers reported how they felt isolated from the outside world and how they felt nobody understood the impact on the family following the injury. Each of the family members went on to report how even though the medical professionals were great during the hospital stage, there was no follow-up or support offered from any medical professional or service provider over the years.

Family Reactions

In order to gain an understanding of the case studies involved in the research, the researcher, as a professional acknowledged how each family had their own unique reaction to dealing with the trauma of their loved one following a TBI. Within the research it was important to note how each of the families were at different stages of recovery and periods post-injury. The table below brings together both of these considerations, reporting on the case studies length post-injury and their reactions towards coping with their loved one following a TBI.

Table 3 – Length post-injury and family reactions

Case Study	Time since injury	Experienced Strain	Harmful coping strategies	Frustration/Anger	Sense of depression
Long Family (CS1)	6 years	√	√	√	√
Timmons Family (CS2)	27 years	√		√	√
Coyle Family (CS3)	6 years	√		√	
McCroon (CS4)	3 months	√	√	√	√
Carling Family (CS5)	2½ years	√		√	
Sterling Family (CS6)	1 year	√		√	√

Reported experiencing strain

The primary carers of each of the six families reported high levels of strain at the early acute stage of the injury. Each primary carer reported the strain being down to a lack of uncertainty surrounding their loved one's medical situation and trying to manage their daily lives surrounding visiting the hospital. Out of the six family's primary carers within the research, four were spouses (wives) and two were mothers. The four spouses reported higher levels of strain than the mothers, noting how they felt very alone and how they had to take over the complete family role whereby it was divided with their spouse pre-injury. The two mothers did report levels of strain, but noted how they felt in some ways that they had reverted back into the parental role of looking after their sons. This notable increase in spouses experiencing strain is reflected in a study conducted by Panting and Merry (1972), where higher levels of strain were reported to be experienced by spouses.

In relation to the research, whereby the primary carers were the mothers, findings recorded a decrease in level of strain over time, whereas the spouses reported how their levels of strain only increased as the years went on. In relation to these increased levels, Molly from the Timmons family who was caring for her husband for 27 years post-injury reported how her strain levels increased as she had to take on total responsibility for the children and work through any issues as the years went on. She went on to note:

"My children have now all grown up and have families of their own now. I am still left here to look after my husband. You know what; it just doesn't get any easier even after 27years on. In fact I feel sometimes it's getting worse".

Ref: Molly Timmons

Harmful coping strategies

Veronica, the wife, from the Long family, and Mary, the mother from the McCroon family both reported using alcohol as a coping strategy to help them get through the difficult times. Both women reported drinking in isolation at night-time, as they found this time the worse.

The two women noted how during this time they felt so alone and helpless towards what they felt as a never-ending situation. Veronica Long cited:

"I get so tired yet wound up and feel so lonely in the night time. Everybody is gone and I am alone with my husband. I use the odd drink to wind myself down".

Ref: Veronica Long

While Mary the mother within the McCroon family cited:

I can't bear to see my son the way he is. At night- time when things are quiet I have a few glasses of wine to help me get ready for the next and the next and the next day".

Ref: Mary McCroon

Frustration/Anger

In the case of carers feeling angry and frustrated, each of the six families reported both of these feelings. The frustration was reported to be mainly down to two areas, the first one centred on the lack of communication at the early stage of their loved one's recovery in the hospital. Each of the six families' primary carers reported feeling frustrated as a result of not knowing what was going on. They also reported a sense of helplessness as a result of waiting to see if their loved one would regain consciousness and if so, what deficits may exist.

The second area of frustration, predominately recorded, was focussed around the post-hospital discharge stage. Each of the six families' primary carers reported that once their loved one was discharged from the hospital, they felt totally alone. Findings also recorded how some had tried, many times, to engage support from the various different professionals to no avail.

This sense of frustration and anger was more evident in the Carling and Timmons families. Kathy, the mother in the Carling family reported how her frustration evolved from feeling that her son would receive better rehabilitation if he was out of the hospital and in a proper rehabilitative unit by reporting:

"I get so angry when I see my son being just left there with no physiotherapy for days on end. Isn't it their job to provide my son with the best rehabilitation? I have asked loads of people about this, but nothing has happened".

Ref: Kathy Carling

During the identification of needs process within the research between Molly and the key worker, Molly Timmons (CS2), reported frustration surrounding a feeling of "What is the point?" in trying to obtain services for her husband. Molly reported feeling like this due to her previous attempts of trying to obtain different community rehabilitative services. Each time, Molly had being denied support and was advised this was down to a shortage of staff, finances or that she was not applicable to avail of such services. The supportive services, Molly had previously applied for surrounded community physiotherapy, occupational therapy, and financial welfare support. In this case, Molly cited:

"I am fed up trying to get any sort of support from anybody. It makes me so angry. Nobody seems to care. I don't know how some of these people got their jobs. They don't even ring me back".

Ref: Molly Timmons

With regard to the reported anger, again each of the six families' primary carers reported this feeling. Reporting their anger over the system and how they felt it let them down in their time of need. Another source of anger was in relation to the medical professionals at different intervals. Four out of the six primary carers reported feeling angry over the feeling of not being listened to from the medical professionals at the early acute stage. Their anger increased once their loved one was discharged due to the lack of support from knowledgeable professionals surrounding the area of TBI. Carers from the Long, Timmons, Coyle and Sterling families reported how they could not find anybody who was familiar with the needs of people with an TBI. This was seen, for instance in a citation from Veronica Long who reported:

"Nobody knows anything about TBI and the implications on the family. Nobody seems to understand. Why is that the case?".

Ref: Veronica Long

Furthermore, findings from each family carer reported anger over how when they sought assistance and support from different routes, for example, social welfare, their calls were quite often not returned. Findings within the research also reported the carer's anger over the amount of paperwork that was required to be completed when seeking services and how many times the service was then refused. As a result of such lack of communication and action, wives from the Long and Timmons families reported that they had just given up looking for help. This is seen in a citation from Molly Timmons:

"Why should I bother going to the trouble of filling out forms, photocopying items and repeating myself many times, if they can't be bothered to reply to my requests. It's just not worth all of the hassle and to be honest I feel that people just don't care?".

Ref: Molly Timmons

However, in contrast, the primary carers of the McCroon and Carling families reported how their anger was not directed at the medical professionals following post-injury as both reported receiving great support from their GPs. In both of these case studies, the same GP applied.

When reporting findings of anger from the family towards their loved one with the TBI, two carers, who were the spouse of the individual with the injury in both cases, reported a feeling of anger towards their husbands as a result of their TBI. These cases referred to Claire Sterling, the wife of Joe and Molly Timmons, the wife of Jack. Both reported even though they felt guilty of their anger towards their husbands, in some way blamed them for their loss of their partner, husband and for their own loss of personal time. This is seen in a citation from Claire Sterling, who cites:

I'm married, but don't have a husband. I feel as if I have another child".

Ref: Claire Sterling

Finally, for one case only, Maura Coyle the mother of Colm, reported how she felt her levels of anger had decreased over time. Initially, Maura reported that at the early stages of her son's discharge from hospital, her anger levels were high as she attempted to obtain community rehabilitative services for her son. Maura reported that once her son began to receive the necessary support, her anger decreased. However, she went on to note how the

support her son was receiving was from a family member who was a social worker and not from the HSE setting and cited:

"If I was to be waiting from help from them, the HSE, my family would be left waiting and my son would not be as good as he is now".

Ref: Maura Coyle

Sense of Depression

Findings for this experience support research conducted by Mauss-Clum and Ryan (1981), whereby it was predominately the spouses who reported a sense of depression over the situation their family was going through. This was reported by three spouses and one mother from the Long, Timmons, Sterling and McCroon families. An example of such findings from the spouses can be seen from a quote from Claire, the wife of Joe Sterling where she cited:

"The whole situation gets me down; I just don't know what to do or where to turn. I feel so tired all of the time and I just can't see any light at the end of the tunnel".

Ref: Claire Sterling

In the case of the McCroon family, it was the mother who reported a sense of depression at feeling lost and scared over handling her son acquiring a TBI. Mary cited:

"I can't bear to see my son the way he is. I feel so helpless. I don't know what to do".

Ref: Mary McCroon

Finally when exploring how the family reacted to having a loved one with a TBI, consideration was only briefly explored within this research towards the siblings. Stambrook et al (1994) reported how the reactions of the siblings may correlate to the reactions of their parents when confronted with dealing with a trauma. Within the case of this research, the key worker did not deal directly with siblings but was indirectly advised of difficulties through the spouses and parents. In all six case studies, the primary carers reported how the siblings felt lost and in some way left out as they were unaware of how to deal with the trauma of their parent or brother. In relation to the Long, Timmons and Sterling families, the siblings

advised their mother of feeling angry and sometimes embarrassed towards their father's inappropriate behaviour and asked questions regarding why their father was behaving in an aggressive manner. While in the Coyle, McCroon and Carling families, the carers advised that their siblings reported feeling unsure of how they should behave around their brother. However, when taking these recordings into effect, it is worth noting how the research was mainly driven towards the needs of the main primary carer within the family, which was either the mother or the spouse of each of the six case study families. It is also important to note how all the siblings in the study were over 18 years of age and were not minors.

Section: 3.2 - Family Life Cycle (FLC) and Role Changes

When considering the FLC, Stambrook et al (1994) outline how the stage in which the family is within the FLC has relevance to the impact a TBI imposes on a family. To support this concept, the FLC model was recorded to enable the key worker to view symptoms and dysfunctions within each family system towards how the nature of the injury impacted on their normal functioning over time. Findings are presented on the six participating families within the research, utilising the list of possible major development challenges that may be faced by families over time as suggested by Stambrook et al (1994).

Table 4 – Incorporating Stambrook et al (1994) major development challenges

Case Study	Time since injury	Family with young children	Family with adolescents	Launching children and moving on.	Between families: young unattached adults	Joining families through marriage	Family in later life
Long Family (CS1)	6years			√			√
Timmons Family (CS2)	27years	√	√	√	√		√
Coyle Family (CS3)	6years		√		√		
McCroon Family (CS4)	3months		√		√		
Carling Family (CS5)	2½years				√		
Sterling Family (CS6)	1 year		√				

Family role changes

In presenting findings surrounding the effects of a TBI within Stambrook et al (1994) model, the occurrence of a TBI can impact on the FLC outside of the normal development. The findings below outline how the families involved in the research were required to adopt different roles at different stages.

Table 5 – Family Life Cycle and Family Role Changes.

Case Study	Years post-injury	Husband-Wife relationship	Parent-Child relationship	Siblings' role change
Long Family (CS1)	6 years	√		√
Timmons Family (CS2)	27 years	√		√
Coyle Family (CS3)	6 years		√	
McCroon Family (CS4)	3 months		√	√
Carling Family (CS5)	2½ years		√	
Sterling Family (CS6)	1 year	√		√

When exploring the role changes within families following a loved one experiencing a TBI, each of the primary carers reported mainly two significant changes. Out of the six families, three case studies involved the wife taking on the role of a surrogate mother. Within this role, families reported how the relationship had shifted from one of equal status to one of surrogacy. Within the research, the role of the wife in the case of three families altered to assuming total control over the husband. As a result of such a role change as noted by Bekker (2000), Degeneffe (2001), and Willer, Flaherty and Coalier (2001) the functionality of the family unit altered. One such report conducted by Kreutzer et al (1990b) noted how the wives of survivors of TBI experienced a dramatic life change both in their financial and family management roles. Such change was reported in the research with each wife noting, how as a result of them becoming the main caregiver, the responsibility added to their levels of stress experienced. Citations from the wives are as follows:

Veronica the wife of Mike Long cited:

"I lost my husband and gained another child. I find the whole situation very overwhelming and stressful".

Ref: Veronica Long

Molly the wife of Jack Timmons cited:

"I now have to deal and look after everybody. I had to rear my four children up myself as well as look after my husband. I had and have no partner, just myself. The stress and strain of doing everything has worn me down over the years".

Ref: Molly Timmons

Finally Claire, the wife of Joe Sterling cited:

"I used to have a husband there to help me with decisions and rear our daughter. Now there is only me and I have to worry about everything and deal with everything".

Ref: Claire Sterling

The remaining three case studies involve the parent-child relationship, where the mothers reinstated the parental role of caring for their sons. It is worth noting how such role change could be considered as no role change but in each case of the research, each mother had to return to fulfilling the parental role which had ceased before the time of injury. Within each of these three case studies, each mother reported feeling that it was their responsibility and in some cases, their right as a mother to reinstate their role of the mother figure and take on the responsibility of caring for their son. This was seen in a citation by Maura, the mother of Colm Coyle who cited:

"I am his mother. I know him best. I have reared him and brought him through everything. It is only right that I should continue to help him in his hour of need".

Ref: Maura Coyle

Within the families of McCroon and Carling, the mothers cited:

"I love my son. He means everything to me. I will never let him down".

Ref: Mary McCroon

"I am his mother. There is nothing more to say".

Ref: Kathy Carling

There were no mothers within the research who had to take on the role of care giving for their daughter. However, each of the mothers reported their uncertainty towards the future and what would happen to their son should they die. Such findings are seen by the following citations from each of the three mothers:

"My motherly role had eased as he had left the family home. Now he is back and so is my role. I am worried, what will happen to my son when I am gone".

Ref: Maura Coyle

"What will happen to my son later on? I won't be around for ever. He is so young".

Ref: Mary McCroon

"I will do everything I can for my son but am scared as to what will happen when I am not around. Who will look after him?".

Ref: Kathy Carling

Such worries from mothers reported in the research are emphasised by Degeneffe (2001) who raises concerns over how parents may be faced with an extended parenthood if their sons were only in their early twenties at the time of their TBI.

Finally, the last role reported indirectly by the primary caregivers within the research surrounded the impact of the TBI on their siblings. In four of the case studies, the carers noted how their children had to adopt different roles.

In relation to the Long and Sterling families, the wives reported how their children had to provide support in order to provide them with respite. In the case of the Long family, the daughters were in their twenties and had families of their own and within the Sterling family, the daughter was 17 years of age.

Such need was more evident for the Sterling family, whereby Claire was forced to return to work to generate an income, which in turn impacted on their daughter. In this case Claire reported:

"I had to return to work for money. The bills were mounting up. Therefore my daughter had to change and become more responsible and take on the caring of her father. In some ways I feel that my daughter had to grow up too fast".

Ref: Claire Sterling

Whilst in the case of the Timmons family, Molly the wife, reported how their children who were only young at the time of their father's injury never experienced having a father figure afterward the injury and in some way missed out on their childhood, citing:

"My kids never really had a father due to their age at the time of their father's injury. As they got older and continue to do so, they need to take over the responsibility of their father in order that I can take some sort of a break. I sometimes feel that they lost out on their childhood and indeed on having a Dad".

Ref: Molly Timmons

This sense of losing their childhood is suggested by Degeneffe (2001) who notes how siblings may experience a sense of losing their childhood and having to grow up too quickly.

Whilst in relation to the McCroon family, Mary, the mother advised how her other sons now had to take on some of the responsibility of caring for their brother and take him out for outings, citing:

"My other two sons now have to look after my son and bring him out on socials. It is the only way he will go out. I sometimes feel guilty asking them and feel like I am forcing them in some ways to bring their little brother around with them, but it needs to be done. All of my son's friends have gone and left him. He has nobody apart from family".

Ref: Mary McCroon

In further development of the Sterling family, Claire reported how her daughter felt angry and resentful towards her father's aggressive behaviour when in a social situation, especially when she brought her friends around to the house. It was reported by the mother how she felt that her daughter was isolating herself away from her friends and how she was not inviting them around to the house any more. She went on to cite:

"My daughter has changed. She is more withdrawn. She won't socialise or bring her friends around anymore to the house. Do you know that my daughter has said to me that she is embarrassed over her Dad's behaviour?"

Ref: Claire Sterling

This feeling of resentment is emphasised by Degeneffe (2001) who notes how the siblings might feel anger and resentment towards their parents as a result of their behaviour and how such anger may also be as a result of them feeling a loss of their childhood.

Section 3.3 – Case studies: Identifying the six primary carers needs

In relation to the study, “family needs” refer to each family’s unique experiences as a result of care giving for a loved one with a TBI. To present findings on the individual primary carers within the research, each family profile will now be presented. The case study begins with a profile of the primary carer, outlining the current identification of needs and the forthcoming activities in addressing such need. The profile moves onto introducing the individual with the TBI, outlining the current situation and identification of needs as requested by the primary carer. For the purpose of the research, the key worker role was adopted by the researcher.

Case Study 1: Veronica & Mike

Profile of Family 1

Wife name Veronica (a pseudonym) and husband name Mike (a pseudonym) were contacted by the researcher on the 24th of August '2010. The primary carer is the wife (Veronica) of a gentleman (Mike) of 63 years of age who sustained a TBI six years ago in 2004 following an assault.

Profile of Veronica

Veronica is a 62-year old married woman who has supported her husband as a carer since the time of his injury in 2004. At the time of Mike's injury, both Veronica and Mike were working full-time in a local supermarket. Following Mike's injury in 2004, Veronica had to reduce her working time to ten hours per week to allow her to apply for the carer's allowance and support her husband. These ten hours consist of Veronica working on a Friday morning and a Saturday morning in a local supermarket. Veronica and Mike have two grown-up daughters who live outside of the family home. Veronica is considered the main carer for Mike and apart from working part-time she has no other form of support or social outlet.

The first initial meeting with the family was to introduce the research and it took place on the 31st of August '10. After the introductions and aims of the research were presented and the family were happy to participate in the research, a consent form was reviewed outlining the ethical considerations for the wife to sign acceptance and agreement of.

Current Situation

Following the above, the current situation of the wife and her husband was established and recorded. Please refer to *Appendix Two – Family(A) & Individual (B) Identification of Needs Spreadsheet*. Initially, details surrounding the address, date of birth for the individual with the TBI and medical information (if available) were disclosed and noted accordingly.

Veronica's individual needs

Veronica identified her initial needs in which she required the support of the key worker in addressing as follows:

1. The seeking of some form of respite.
2. The development of a self-care plan.
3. Management of stress and fatigue
4. A feeling of a sense of isolation.

The above were then prioritised by the wife and the following initial action plan was devised:

Action Plan:

1. When considering the respite need, the wife suggested that she would seek the assistance and support from a family member once a month to allow her "time out".
2. Veronica asked if the key worker could contact the local PHN in relation to obtaining the respite grant form.

Actions one and two are to support number 1 and 2 identified needs.

3. Veronica voiced an interest in local community part-time courses and how through attending some course she would have the opportunity to socialise and not feel so isolated. Veronica requested for the key worker to support her in exploring local community courses.
4. Once courses are identified, an action plan is to be initiated for the application to and attendance at the desired courses.

Action three and four are to support number 2, 3 and 4 identified needs.

Profile of Mike

The below information was obtained from the primary carer and not from the individual with the TBI.

Pre-Injury History

Mike worked full-time in a local supermarket for the past twenty years as an Assistant Manager. At the time of the injury, Mike was 58 years of age. Veronica reported that Mike was an active individual attending two local clubs and was actively involved with his two daughters and grandchildren.

Post-Injury History

Mike spent six months in hospital recovering from his injury, followed by a couple of months spent in a rehabilitative unit in a different hospital. During this stage Mike received in-patient speech and language and physiotherapy sessions. Following discharge from the rehabilitative unit, Mike returned to the family home without any out-patient appointments or form of community support for either himself or his family. Veronica and Mike both noted how this time was very isolating and scary for them as they were both unprepared for the difficulties that were to lie ahead.

Mike's Current Situation

In 2006, Mike attended a rehabilitative training programme within his local area of two years. Since leaving this programme, Mike attends different services catering towards some of his needs. One identified area surrounded his visual needs, whereby he attends a visually impaired service twice a week. Another service he attends every second week, caters for social integration through the attending of a group run by an organisation called [REDACTED] who provide social support for people with TBI within the community. Some time back, Mike used to attend a local book club in his community library. Finally, Mike continues to attend a "Men's Social Club twice a week, once on a Thursday evening and the other on a Sunday morning.

Physically

Mike is actively mobile; however he can lose balance due to a vestibular disorder condition. He can experience tremors in both of his arms and hands and suffers from temporal lobe

nocturnal epilepsy which he is receiving medication for. Mike also presents with extreme mixed aphasia, with both receptive and expressive language difficulties. As a result of his injury, Mike also has a left side hearing impairment as well as left side peripheral vision deficits.

Emotionally/Behaviourally

Mike is very perseverant in his way of thinking and can seem to be very aggressive. Lately his aggression has increased and is causing immense strain on the wife and the family.

Cognitively

Mike is unaware of how he becomes aggressive and has little insight into the difficulties he presents. Mike also presents with reduced speed of processing, attention, sequencing/problem solving and short-term memory difficulties.

Mike's Needs

Veronica identified her husband's needs in which she required the support of the key worker (the researcher) in addressing as follows:

- A service to cater for his speech difficulties focussing on aphasia.
- The referral to the SALT surrounding further speech therapy.
- Exploration of further social outlets for the husband to attend to expand on his weekly schedule of activities.

Action Plan

After identifying the husband's needs, the initial action plan below was derived and it was noted who was to take responsibility for which action.

1. The key worker to source S & L supportive services.
2. The key worker to process a referral to the S & L community service.

Actions one and two are to support number 1 and 2 identified needs.

3. For Veronica and the key worker to explore into the local book club and alternative social outlets/community services to extend the husband's weekly schedule.

4. The key worker to contact and gain an update on Mike's participation from the visually impaired service (NCBI).

Actions three and four are to support number 3 identified need.

Case Study 2: Molly & Jack

Profile of Family 2

Molly, the wife (a pseudonym) of husband's name Jack (a pseudonym) was contacted by the researcher on the 13th of September '2010. This case study concerns the wife of a gentleman of 62yrs who sustained a TBI 27 years ago as a result of a road traffic accident.

Profile of Molly

Molly a 61-year old married women supports her husband as a carer since the time of her husband's injury in 1983. At the time of Jack's injury, he was working full-time in a local bottle factory. Molly was a stay at home mother of three young children, aging from 4, 3 and 2-years of age and was pregnant on their fourth child. Molly is not in receipt of any social welfare payment, except for the pension scheme which she only received recently. For the first ten years following her husband's injury, Molly remained at home and was the sole carer for her husband and her four children. During this time, the family lived off the husband's Invalidity Allowance from the state. In 1993, Molly returned to education and completed a diploma in counselling and gained employment in a local service offering counselling to women in need. From the time of her husband's injury in 1983 to to-date, Molly has never received any form of assistance or support surrounding the rehabilitative needs of her husband. Molly has advised that she had tried to seek assistance over the years and was rejected due to some technicalities within the scheme and has lost all hope and interest in seeking assistance for the belief that nobody will help her. Molly's children are all living outside of the family home and have no relationship with their father. Since retiring, Molly spends a lot of her time offering support in the local community centre, offering support to those in the area. She actively partakes in developing programmes for the elderly and for the local children of her area.

On the 15th of September '2010 the researcher met with Molly and Jack within the family home. After the introductions and aims of the research were presented and the family were

happy to participate in the research, a consent form was reviewed outlining the ethical considerations for the wife to sign acceptance and agreement of.

Current Situation:

Following the above, the current situation of the wife and her husband was established and recorded. Please refer to *Appendix Two – Family (A) & Individual (B) Identification of Needs Spreadsheet*. Initially, details surrounding the address, date of birth for the individual with the TBI and medical information (if available) were disclosed and noted accordingly.

Molly's (Wife's) needs:

Molly identified her initial needs in which she required the support of the key worker in addressing as follows:

1. The seeking of some form of respite.
2. The development of a self-care plan.
3. Management of stress and fatigue
4. A feeling of a sense of isolation.

The above were then prioritised by the wife and the following initial action plan was devised:

Action Plan:

1. In addressing seeking respite, and promote “time out” Molly requested for the key worker to explore and seek assistance from the Local Public Health Nurse.

Actions One and Two are to support number 1 and 2 identified needs.

2. Molly noted an interest in doing some courses which she saw within her local community centre, possibly in the area of Angels and relaxation. Molly advised that she would explore this further.

3. Once courses are identified, an action plan was initiated for the application and attendance of the desired courses.

Action two and three are to support number 2 and 3 identified needs.

4. Molly requested the assistance of the key worker in identifying support groups for her to attend within the area of Traumatic Brain Injury.

Action four are to support number 4 identified needs.

Profile of Jack

The below information was obtained from the primary carer and not from the individual with the TBI.

Pre-Injury History:

Jack worked full-time as a manual labour in the local bottle factory and had worked there since 12 years of age. At the time of his injury Jack was 36-years of age. Molly reported that Jack used to drink excessively before the injury and spent little time at home with the family.

Post-Injury History:

Following discharge from the hospital, Jack was placed within a psychiatric care facility for a short period of time to assess his needs and cater towards his rehabilitation. During his time at the centre, Jack was assessed by an Occupational therapist, however no service or support was offered following the assessment. Molly advised how she was dissatisfied with the suitability of this service towards catering for Jack's TBI rehabilitation. Jack left this institution on his own accord within a short period of time and returned to the family home. The family were unable to provide me with dates surrounding this transition. Jack remained at home without any form of support for the following five years.

The Husband's Current Situation:

It was identified that Jack (a pseudonym) attends a community supported sheltered workshop for the past 22 years. Jack attends there five days a week. He is picked up Monday to Friday at 8.30am and is returned near the home at around 5pm. During the time within the centre, Jack completes piece work, working on placing letters in envelopes to placing stickers on

badges. Jack continues to work with an assigned key worker for the past 22 years. Jack receives a payment of €20 a week for his piece work. Within the centre there is no training or support for people with a Traumatic Brain Injury.

Again, Molly has voiced concerns over how suitable the service is, as it does not cater for people with a TBI. It is more centred on people with Mental Health Issues. However, Molly voiced even though she realises the service is not beneficial for Jack; it does give Jack some structure to his week and gives her some form of respite on a daily basis. Molly went on to note how she would be reluctant to let his place go, unless Jack was to receive something more suitable.

Apart from Jack's attendance to this centre, he is not involved in anything else and may occasionally go to the local publican house twice a week for an hour.

Physically:

Jack is mobile, however his eye sight has decreased since his injury and he can become disoriented and confused when faced with a new routine. Therefore he will not venture out on his own to anywhere except for the bus to the supported centre or to the local pub. He also suffers from poor circulation in his foot and is attending a private chiropodist every four weeks to cater for his feet care. Jack also has poor balance, especially when it is breezy out and can lose his balance easily. His perceptual vision is also affected and has voiced being scared to cross the road, even at traffic lights for not being able to gauge how fast the car is approaching.

Emotionally/Behaviourally:

Jack will not do anything for himself and totally relies on Molly for all of his daily living needs from getting his clothes ready to the cooking of his meals. Molly raised concerns surrounding Jack's poor hygiene levels and how he would not shower or shave for weeks unless prompted. It was reported that Jack sits in the same chair, sometimes for hours every day upon his return from the centre and will not initiate conversation. He can also become very verbally argumentative with Molly which has caused a lot of strain within the family. Jack also presents with sleep problems, going to bed at 7pm and waking up at 2am every day.

Cognitive:

Jack presents with a lot of pre-frontal executive difficulties. This is shown with difficulties with motivation and initiation. He also presents with sequencing, problem solving (being very perseverant in his way of thinking) to attention difficulties, shown with switching of the TV channels consistently. He also presents with short term memory difficulties and a low level of insight and awareness into his difficulties.

The above are difficulties expressed by Molly and observed by myself during the initial meeting. Jack has never received any formal professional neuropsychological assessment to assess and confirm the above diagnosis.

Jack's Needs as identified by Molly

During the meeting, the following initial needs were identified:

1. To explore possible alternative services that provide support and cater for people and families who have experience with a loved one with a TBI.
2. Exploration into cognitive rehabilitation to assess Jack's level of cognition.

Action Plan:

After identifying the husband's needs, the below initial action plan was derived and noted who was to take responsibility for which action.

1. For the key worker to contact Jack's key worker in the sheltered community centre to promote collaboration within research.
2. For the key worker to contact and explore referral to two different TBI services, ABI Ireland and Headway.

Actions one and two support number 1 identified need.

3. For the key worker to develop some form of cognitive rehabilitation exercises to assess cognitive levels, centring on motivation, initiation and sequencing.

Action three is to support number 2 identified needs.

Case Study 3: Maura & son, Colm

Profile of Family 3

Mother's name Maura (a pseudonym) and her son's name Colm (a pseudonym) was contacted by the researcher on the 12th of September '2010. This case study concerns the mother of a son of 28 years of age who sustained TBI 6 years ago as a result of a fall from a house.

Profile of Maura

Maura is a 55 year old married woman who supports her son as a carer since the time of her son's injury in '2004. At the time of Colm's injury, he was working full-time as a roofer within his father's business. Colm is a single male who was residing with his mother at the time of the injury. Maura is a stay at home mother of three children, aging from Colm, 23yrs, another son aged 16yr and daughter aged 14 years of age. Maura is not in receipt of any social welfare payment, and income for the family is based on the husband's income. Maura advised of receiving no assistance or support following her son's discharge from the [REDACTED] hospital for the first three years. During this time Maura fought to receive financial assistance and a rehabilitative service for her son to no avail. Following her ongoing campaign, the [REDACTED] hospital made a referral to a rehabilitative training unit in '2007. Maura reported that at no time before her son commenced on the rehabilitative training programme was she educated or supported for the difficulties that occurred within the family following her son's released home. Subsequently, Maura advised that her niece two years ago completed a Masters in Social Studies and has become the main educator and supporter for Colm and the family, educating him on his rehabilitative needs.

The initial meeting with Maura took place on the 14th of September '2010 in the family home. The husband refused to participate in the meeting or the research. Colm, the son also asked to be excused from participation. After the introductions and aims of the research were presented and Maura was happy to participate in the research, a consent form was reviewed outlining the ethical considerations for the wife to sign acceptance and agreement of.

Current Situation:

Following the above, the current situation of the mother and her son was established and recorded. Please refer to *Appendix Two – Family (A) & Individual (B) Identification of Needs Spreadsheet*. Initially, details surrounding the address, date of birth for the individual with the TBI and medical information (if available) were disclosed and noted accordingly.

Maura's (Mother's) needs:

Maura reported how she would have had needs two years ago, however, now with the support from her niece, who is a social worker, a lot of her son's needs have been addressed. Therefore her only wish was for the research to educate the medical and community professionals surrounding the need to educate and support the families post discharge from hospital.

Overall, Maura reported how she would like to receive support from the key worker regarding:

1. More TBI Education
2. Somebody just to listen to her when she feels she needs to "offload".

The above were then prioritised by the mother and the following initial action plan was devised:

Action Plan:

1. In addressing seeking TBI education, the key worker was to provide Maura with information on TBI for the family to promote more of an understanding of how a TBI can affect the individual and their family.

Actions One supports number 1 identified need.

2. In addressing the need to talk, the key worker was to source a counselling and family support service for Maura and her family from Headway.

Action Two supports number 2 identified needs.

Profile of Colm

The below information was obtained from the primary carer and not from the individual with the TBI.

Pre-Injury History:

Colm worked full-time as a roofer within his father's business. At the time of his injury Colm was 23 years of age. Maura reported that Colm used to socialise and drink excessively before the injury and spent a lot of time travelling with his friends.

Post-Injury History:

Following the accident, Colm attended a neurological hospital initially and was transferred to a rehabilitative unit after three months to receive a complete rehabilitation programme, containing: physiotherapy, occupational therapy to speech and a language therapy. Colm remained in this unit for a further three months, whereby he was then discharged back into the family home without any form of community support. Following discharge, Colm became very withdrawn and depressed and commenced taking illegal substances.

In '2007, Colm was referred to a rehabilitative training service which consisted of a complete community rehabilitative programme. Unfortunately due to Colm's emotional state and distance of the service, Colm ceased to attend. In 2008, the same service offered Colm a

similar service nearer to where he lives. Initially, Colm's attendance and behaviour were good, however, Colm returned to taking illegal substances, his mood became low again and he ceased to attend the service. The service offered him counselling and a neuropsychological assessment was completed. However, Colm became worst and was not in agreement with receiving the support offered and left the service completely.

In around '2007/'2008 Colm's personal court claim began to gain momentum and Colm switched his attention to completing the court case and receiving some compensation for his accident. Unfortunately this court case went on for years and Maura the mother advised that this was due to be finalised in the forthcoming November '2010. Maura voiced how Colm had placed a lot of emphasis on the court case and receiving a large amount of compensation which, he felt, would allow him to regain his life and support his travelling.

The Son's Current Situation:

It was identified that Colm (a pseudonym) is currently not involved in any service and is doing nothing. However, Maura reiterated how Colm is putting everything on hold until the court case is finished in November 2010. Colm remains living at home with his parents.

Physically:

Colm has no physical difficulties as a result of his injury apart from developing vertigo. This now excludes him from returning to his professional trade as a roofer. Colm also suffers from sleep insomnia.

Emotionally/Behaviourally:

Colm went through a period of low mood and was diagnosed with depression. During this time, Colm took part in taking illegal substances which only added to his difficulties and impacted on his ability to take the prescribed medication. Colm's General Practitioner prescribed medication to help Colm come off the alcohol; however Colm ceased to take this medication. It is only within the past two years, Colm has managed to cut down on his alcohol consumption and he no longer takes illegal substances.

Cognitive:

Colm presents with a lot of pre-frontal executive difficulties. Colm would have difficulties with attention at all levels, from focus attention difficulties to sustained/alternating levels of attention. He would also present with higher executive function cognition with decision making and problem solving difficulties. Following on, Colm would also present with a slight form of sexual disinhibition and can be very impulsive. It is only within the past two years that Colm's levels of insight and awareness into his deficits following his injury have been obtained.

The above are difficulties expressed by Maura. Upon asking about reviewing the completed neuropsychological assessment that Colm completed, Maura was unable to locate the report and noted that the above difficulties were the ones noted in the report and through the family's observation.

Colm's Needs as identified by Maura

During the meeting, Maura expressed that Colm's needs were being attended to by his cousin, her niece who is a social worker and that she felt no need for further intervention from the key worker. In this case study, the niece was performing the role of the key worker in facilitating the needs of the family within the community. Therefore there was only one meeting held between the key worker and Maura within the research project.

At the end of the meeting, the researcher reiterated her availability to support the family and Colm in any way for the future, should they feel the need for the intervention.

Case Study 4: Mary and son John

Profile of Family 4

Mother's name Mary (a pseudonym) and sons name John (a pseudonym) was contacted by the researcher on 31st August '2010. This case study concerns the mother and her son of 19 years of age who sustained a TBI in June '2010 as a result of a fall from a building.

Profile of Mary

Mary is a 55 year old separated mother of four boys, ranging from 27yrs, 25yrs, 22yrs and John who was 19 years of age at the time of his injury. Mary is currently unemployed for the past two years after being made redundant in '2008 after 20 years of service within the Civil Service. Subsequently, after Mary was made redundant, Mary went through a difficult emotional stage. Mary overcame this stage of her life with the support of her General Practitioner and through attending counselling and support groups.

Mary's two eldest sons live away from the family home. The two youngest sons' (which includes John) live within the family home. Mary is currently a full-time carer for her son of 22yrs who suffers with Asperger Syndrome. Following John's release from hospital, Mary also took on the role of the sole carer for John as well.

Mary is in receipt of the Job Seeking Allowance from the Social Welfare and does not receive any other form of financial support for her carer's role for either of her two sons.

The key worker began working with Mary and John seventy five days after John sustained his injury. At this early acute stage of John's recovery, he was still hospitalised. The initial meeting with Mary took place on the 2nd of September '2010 within the hospital. After the introductions and aims of the research were presented and the family were happy to participate in the research, a consent form was reviewed outlining the ethical considerations for the mother to sign acceptance and agreement of.

Current Situation:

Following the above, the current situation of the mother and her son was established and recorded. Please refer to *Appendix Two – Family(A) & Individual (B) Identification of Needs Spreadsheet*. Initially, details surrounding the address, date of birth for the individual with the TBI and medical information (if available) were disclosed and noted accordingly.

Mary's (Mother's) needs:

Mary identified her initial needs in which she required the support of the key worker in addressing as follows:

1. To offer support and guidance on her son's rehabilitation plan.
2. To support Mary in developing a self-care plan.
3. To support Mary in managing her stress and fatigue levels
4. To provide information on TBI to help aid the family understanding.
5. To assist Mary in not feeling isolated through identifying supportive services.

The above were then prioritised by Mary and the following initial action plan was devised:

Action Plan:

1. Action one was to address the primary need of the assignment of support and guidance. To address this need, the key worker was to explore the professionals currently working with the family within the hospital and start to work in partnership with them in relation to developing a transitional plan.

2. *Actions one is to support number 1 identified need.*

3. In relation to self care for Mary and addressing fatigue levels, the key worker was to work with Mary in relation to reviewing her timetable for visiting her son and look at allocating time out for her..

Action Two is to support number 2 and 3 identified needs.

4. In relation to Mary's seeking information, the key worker was to provide education for Mary and her family surrounding TBI.

Action Three is to support number 4 identified needs.

5. In relation to seeking supportive groups for Mary, the key worker was to explore possible support groups within the area of Traumatic Brain Injury, for instance: Bri Advocacy, Headway and ABI Ireland

Action four is to support number 5 identified needs.

At the first meeting with the mother, the researcher was introduced to John and his auntie and John's friends who were visiting him at the hospital. The researcher was then asked by Mary to go through the research and promote conversation with John privately.

Profile of John

The below information was obtained from the primary carer and not from the individual with the TBI.

Pre-Injury History:

John had left school early at the age of 16yrs due to difficulties he was experiencing within the environment. John reported that he was bullied a lot at school and found some of the work very difficult. After leaving school, John attended no other form of education. He is actively involved in a rock band, playing the guitar which he hopes to go back into once recovered and maybe look at touring with the band. He has a good social network of friends who regularly visited him in the hospital. John is a vegetarian and during his hospitalisation lost a lot of weight and was considered to be severely underweight. At the time of his injury, John was out socialising with his friends and brothers at a house party.

Post-Injury History:

Following John's fall from a building, John was taken to the neurological unit (), where he was placed into an induced coma for approximately two weeks. John had sustained multiple injuries, from a severe frontal lobe injury, broken collar bone and massive internal injuries. John had also severed his left optic nerve and his left eye required further medical reconstructive intervention. John was then transferred to another hospital to deal with his physical injuries, whereby he received physiotherapy for his left arm and shoulder. Within this hospital he also underwent an operation to remove a cyst from his stomach. During this time John had lost a lot of weight and was being tube feed.

John's Current Situation:

At the time of my initial meeting, John was awaiting to be moved to a rehabilitative unit in a different hospital for a complete range of rehabilitation. The family were working with a social worker within the hospital and had received financial support in relation to hospital needs and costs; however they were unsure of what was going to happen next.

Physically:

John is still at the early stages of recovery and can walk around, however at a very slow pace with the aid of a walking stick. With regard to John's vision, he has lost complete sight in his left eye. The left eye and face will require further reconstructive surgery in the future. John also suffered with right side peripheral visual deficits to the lower quadrant. His left arm and shoulder are gaining strength and movement; however still requires a lot more physiotherapy.

Emotionally/Behaviourally:

John voiced how he moves from very high moods, with a sense that he is invincible and how lucky he was to survive, to a very low mood mainly surrounding his appearance of his facial features and towards the loss/reduction of his vision. Mary voiced also at this time that John is only a young teenager and places a lot of emphasises on how he looks to which John noted how sometimes he feels like a "freak". Mary went onto note how John is becoming very agitated and verbally aggressive towards her and the staff of the hospital, wanting to leave the hospital immediately. Mary feels that John is not fully aware of what happened to him and in some way is in denial.

Cognitive:

John presents with a lot of pre-frontal executive difficulties. Mary voiced how he has experienced short term memory difficulties, word finding and impulsivity. Mary went onto reiterate how John appears to be only focussing on his physical appearance.

The above are difficulties expressed by Mary and some by John and observed by myself during the initial meeting. John at this stage had not completed any formal professional neuropsychological assessment to assess and confirm the above diagnosis. John did complete an ophthalmologist assessment where the above visual deficits were confirmed.

John's Needs as identified by Mary

During the meeting, the following initial needs were identified as needing the assistance of the role of a key worker:

- A link to be made with the social worker within the hospital to aid in the transitional process.
- Start to explore possible supportive services out in the community surrounding, for example: vision deficit support services, Public Health Nurse, Local community rehabilitative team.
- Receive education (when ready) surrounding TBI to aid John's understanding and awareness levels.
- Look into possible counselling services for John.

Action Plan:

After identifying John's needs, the below initial action plan was derived and noted who was to take responsibility for which Action.

1. The key worker to contact John's social worker within the hospital to commence the collaborative process in the transitional plan.

Action one is to support number 1 identified need.

2. The key worker to explore supportive services in the community for John once discharged from hospital.

Action two is to support number 1 and 2 identified needs.

3. The key worker to explore possible counselling routes for John, for instance Headway.

Action three is to support number 4 identified needs.

It was agreed to hold off on the TBI education until a later date.

Case Study 5: Kathy and son Danny

Profile of Family 5

Mother's name Kathy (a pseudonym) and sons name Danny (a pseudonym) was contacted by the researcher on 30th of August '2010. This case study concerns the mother and her son of 23yrs who sustained a TBI in June '2008 as a result of multiple strokes while abroad on a holiday.

Profile of Kathy

Kathy is a 53 year old mother of three children, two sons and one daughter. Danny was 21yrs old at the time of his injury. Kathy is a stay at home mother and currently looks after her grandchild during the day, in between visiting Danny in hospital. The other two children have left the family home. Currently it is only Kathy and her husband who reside within the family home. Kathy's husband works full-time within the construction industry.

Kathy is not in receipt of any social welfare payment. It is Kathy's intention to eventually provide full-time care for Danny within the family home. For the past two years, Kathy has visited the hospital every day to spend time with her son. She spends on average six hours daily within the hospital environment. There is a good social network of support within the family who also visit Danny when they can; however, Kathy refuses to miss a day visiting her son within the hospital. Upon visiting Danny, Kathy would take Danny out in his wheelchair around the grounds of the hospital and would sit with him and listen to a radio.

Since the time of injury, and return back to [REDACTED] Kathy has campaigned publicly and within the Health Service for her son to be moved out of the hospital and into a community rehabilitative unit. Kathy has spent all of her time writing to local newspapers, health professionals and politicians to going on radio shows to campaign for her son. Kathy went onto voice how she cannot sleep until something is done for her son as this is her sole issue within her life at this time.

At the time of beginning to work with Kathy and Danny, Danny was within a hospital unit, on a long-term stay ward for coming up to two years. There was no sign of any discharge plan being organised and there was no form of support being given to the family to aid such a discharge plan.

The initial meeting with Kathy took place on the 1st of September '2010 within the hospital. After the introductions and aims of the research were presented and the family were happy to participate in the research, a consent form was reviewed outlining the ethical considerations for the mother to sign acceptance and agreement of.

Current Situation:

Following the above, the current situation of the mother and her son was established and recorded. Please refer to *Appendix Two – Family (A) & Individual (B) Identification of Needs Spreadsheet*. Initially, details surrounding the address, date of birth for the individual with the TBI and medical information (if available) were disclosed and noted accordingly.

Kathy's (Mother's) needs:

Kathy identified her initial needs in which she required the support of the key worker in addressing as follows:

1. Guidance and how to develop a rehabilitation plan for her son
2. Support in the development of a self-care plan.
3. Support in Kathy managing her stress and fatigue levels.
4. Information on TBI to help aid the family understanding.

The above were then prioritised by the mother and the following initial action plan was devised:

Action Plan:

1. Action one was for the key worker to address the primary need of the assignment of support and guidance for Kathy within the current hospital setting. The key worker was to explore and start to work in partnership with the team of hospital professionals towards developing a transitional plan for Danny.

Actions one is to support number 1 identified need.

2. In relation to self care for Kathy, the first action was for the key worker to explore possible routes of counselling for Kathy and her family to avail of. At this time, Kathy did not want to reduce her time spent with her son.

Action Two is to support number 2 and 3 identified needs.

3. In relation to Kathy's seeking information, an action was noted for the key worker to provide education to Kathy and her family surrounding TBI.

Action Three is to support number 4 identified needs.

Following the development of the above "action plan" a flow chart (see *Appendix One – Designated Specialist key working model*) was devised and presented to aid in the visualisation of how the action research plan will develop.

Following the initial meeting with the mother, the key worker (researcher) was introduced to Danny.

Profile of Danny

The below information was obtained from the primary carer and not from the individual with the TBI.

Pre-Injury History:

Danny completed his national schooling level, to his leaving certificate at the age of 18yrs. Following this, Danny commenced on an apprenticeship course in plumbing. Danny was an active young man who enjoyed socialising with his circle of friends. For Danny's 21st, Danny and his friends went abroad to celebrate with a sun holiday. It was during this time that Danny experienced multiple strokes. He remained over there for a short while until he was medically fit to be airlifted back to Ireland.

Post-Injury History:

Following Danny's return to Ireland, Danny received a full neurological examination. At this time, Danny received an MRI which shown little brain activity to the level of 3. No

explanations for the strokes wherever given to the family. Danny remained in the neurological hospital for approximately three months. He was then transferred to a local hospital, awaiting a bed in the rehabilitative unit within another hospital. After a short while, Danny was transferred to the rehabilitative unit to receive a complete multi-disciplinary team service from intense physiotherapy to speech and language therapy. Danny remained in this unit for approximately five months, upon returning to the local hospital, where he still remains nearly a year and a half later. Danny continues to receive, sporadically physiotherapy, but the family have expressed concern over the length of Danny's stay. Danny has had multiple infections in the past, however, Kathy advised that over the past three to four months, Danny has been ok. Danny needs to be 'peg' fed and doubly incontinent and requires 24hr supervision and support. He requires to be turned in the bed every two hours, whilst also requiring the need of a host to lift him out of the bed and place in a specialised adapted supported wheelchair. Overall, Kathy expressed how the family feels that Danny is not receiving the full necessary support he requires and is afraid that he is regressing and losing any benefits he may have achieved from the rehabilitative unit.

Danny's Current Situation:

At the time of the researcher's initial meeting, Danny remains in the local hospital awaiting the development of a discharge plan to support his transition into a specialised community rehabilitative unit. The family continue to try and receive assistance with the discharge plan, however they continue to be told of a lack of funding within the health service that prevents Danny from moving on.

Physically:

Danny is over two years post injury and requires specialised care. Danny has braces for his legs and arms to try and strengthen and extend the muscles and the family advised that the rehabilitative unit advised that Danny should be receiving physiotherapy at least three times a week. Danny has also lost sight in both of his eyes; however Kathy voiced how she feels that Danny responds to strong light and may be able to follow shadows. Following on, Kathy expressed how she feels that Danny responds to sound and he appears to enjoy listening to his music player. No formal assessment has being completed in the area of hearing or vision. With regard to Danny's communication, Danny can only make sounds. He also has problems with swallowing.

Emotionally/Behaviourally:

Kathy has voiced how she feels that sometimes Danny can be more withdrawn and make no sounds at all and would be concerned as to his emotional well-being.

Cognitive:

Due to Danny's overall presentation it is very hard to assess Danny's cognitive level. No up to date MRI or assessment has being completed to assess whether Danny's brain activity has increased.

The above are difficulties expressed by Kathy and observed by the key worker during the initial meeting. Danny at this stage had not completed any formal professional neuropsychological assessment to assess and confirm the above diagnosis.

Danny's needs as identified by Kathy

During the meeting, the following initial needs were identified:

1. A referral to be made with the social worker within the hospital to aid in the transitional process.
2. To look into a possible referral to an OT surrounding possible home adaption's for the family.
3. To explore the physiotherapy within the hospital Danny is currently residing in.

Action Plan:

After identifying Danny's needs, the below initial action plan was derived for the key worker to action.

1. For the key worker to complete a referral form seeking support of the hospital's social worker within the development of Danny's transitional plan.

Action one is to support number 1 identified need.

2. For the key worker to contact the physiotherapy department within the hospital surrounding the increase in physiotherapy sessions

Action two is to support number 3 identified needs.

It was agreed to hold off on the OT referral (*Need 2*) for the home adaptations as the primary need was to promote a discharge plan to a community rehabilitative unit first for Danny.

Case Study 6: Claire and Joe

Profile of Family 6

Claire, the wife (a pseudonym) of husband's name Joe (a pseudonym) was contacted by the researcher on the 14th of October '2010. This case study concerns the wife of a gentleman of 41yrs who sustained a TBI in '2009 following an explosion in work.

Profile of Claire

Claire is a 40 year old married woman who supports her husband as a carer since the time of her husband's injury in '2009. At the time of Joe's injury, he was working full-time in a local business unit as a security guard. Claire works within a financial business on a full-time basis which she has only recently returned to after taking some time off to support her husband at the early stages of his rehabilitation.

Claire is considered the main carer for Joe and is not in receipt of any social welfare payment. Joe is not in receipt of any social welfare payment and refuses to apply for assistance. Claire and Joe have one daughter who is 17yrs of age and is living at home. The daughter has also taken on the role of supporting her father in conjunction with Claire.

Contact was initially made by phone with Joe on the 14th of October '2010. At this time Joe advised that the family was going away for two weeks and asked if the researcher could write a letter to them to follow up upon their return from their holidays. The follow-up letter was issued out to the family with the researcher's details confirming the discussion with Joe and contact details on the 19th of October '2010.

The first initial meeting with the family took place at the family home on 13th December '2010. After the introductions and aims of the research were presented and the family were happy to participate in the research, a consent form was reviewed outlining the ethical considerations for the wife to sign acceptance and agreement of.

Current Situation:

Following the above, the current situation of the wife and her husband was established and recorded. Please refer to *Appendix Two – Family (A) & Individual (B) Identification of Needs Spreadsheet*. Initially, details surrounding the address, date of birth for the individual with the TBI and medical information (if available) were disclosed and noted accordingly.

Claire's (Wife's) needs:

Claire identified her initial needs in which she required the support of the key worker in addressing as follows:

1. The request for information on TBI to help aid the family understanding.
2. The seeking of a supportive service for Claire to address her feeling of isolation.

The above were then prioritised by the wife and the following initial action plan was devised for the key worker:

Action Plan:

1. In relation to Claire seeking information, an action was noted for the key worker to provide education for Claire and her family surrounding TBI.

Action one supports number 1 identified needs.

2. The key worker to explore possible support groups within the area of Traumatic Brain Injury, for instance Headway, ABI Ireland and Bri Advocacy

Action two supports number 2 identified needs.

Profile of Joe**Pre-Injury History:**

Joe left school at an early age of 15 years of age and subsequently worked in various different labour jobs. Joe reported how he had found school difficult and felt as a result of this he could not read or write well. Joe went onto note how since the injury, his literacy skills have gotten worse. At the time of his injury, Joe was 40 years of age and was working full-time in

a local business unit as a security guard. He also worked three nights a week as a security guard for a local publican house. Claire reported that Joe was an active individual always working and getting involved in local activities. Claire went onto note how Joe had a close relationship with his daughter pre-injury, however since his injury this relationship has become very volatile and strained.

Post-Injury History:

Joe only spent 2-3 weeks in a neurological unit and was discharged home without any form of discharge plan or support for Joe and his family. Claire advised that she had to organise everything from organising outpatient appointments for her husband's burns to his physiotherapist appointments. However, Joe only received six outpatient appointments to attend to his burns, but received no other form of rehabilitation.

Overall, Claire and Joe noted how following discharge from the hospital which happened very quickly, the family received no form of support. They both voiced how they found and continue to find the overall experience very isolating and scary for them as they were both and continue to be unprepared for the difficulties that exist.

Joe's Current Situation:

Since discharge in '2009, Joe continues to receive no form of support or services. He spends his days at home, sitting on the sofa and does not venture out at all, except with his wife and daughter. Joe's only support is his General Practitioner who became involved with me since the invitation to participate in the research was issued.

Physically:

Joe is actively mobile; however due to burns and tissue loss in both legs suffers from constant pain and stiffness in his legs. Joe went onto note how he gets dizzy when he lies down or gets up too quickly. He also presents with slight hearing loss in both ears and has voiced how he experiences constant ringing in his left ear and is prone to ear infections.

Emotionally/Behaviourally:

Joe voiced how his mood is low and how his confidence has decreased surrounding his ability to be independent. Claire and the daughter voiced how Joe gets irritable and has anger outbursts over the least little thing. This in itself has caused huge strain on the family dynamics and has impacted on the family unit socialising within their social scene. Joe is aware of these difficulties and voiced how he would like help with his anger as he gets upset knowing how this impacts on his family.

Cognitively:

Joe has good insight into his difficulties surrounding his anger and went onto voice how he now finds it difficult to sustain attention in a given activity. He also voiced how he finds it difficult to complete the higher executive functioning of problem solving and decision making and has a reduced level of short term memory.

Joe's Needs as identified by both Claire and Joe:

During the meeting, the following initial needs were identified:

1. A referral for physiotherapy surrounding developing strength in his legs.
2. Possibly exploration into his hearing / auditory side of things.
3. Anger Management Training.
4. Explore possible supportive services for Joe surrounding TBI rehabilitation.

Action Plan:

After identifying the husband's needs, the below initial action plan was derived for the key worker.

1. The key worker to source community physiotherapy, Claire also advised that she would explore private physiotherapy for Joe.

Actions One supports number 1 identified needs.

2. The key worker to support Claire in completing a referral for a hearing assessment.

Actions Two support number 2 identified needs.

3. The key worker to explore and implement Anger Management Training for Joe with the support of his family.

Actions Three support number 3 identified needs.

Joe and Claire requested that the key worker concentrate on the above three actions, identified as the primary needs and hold off on referrals for TBI services (*Need 4*) until a later date.

Section 3.4 - Themes across the case studies

Each of the primary carers initial needs were explored and acted upon. Additional needs were then identified, which were developed and expanded within each case study's action plan. Collective findings on the 6 case study primary carer needs are drawn together and presented below in Table 6.

Following the table, each identified need is presented separately in more detail in relation to the research findings.

Table 6 – Findings of exploring family needs.

Case Study	Years post-injury	Education/ Non Medical Language	Emotional Support	Case Management	Professional Guidance	Support Network	Sense of being involved
Long Family (CS1)	6 years	√	√	√	√	√	√
Timmons Family (CS2)	27 years		√	√		√	
Coyle Family (CS3)	6 years	√					
McCroon Family (CS4)	3 months	√	√	√	√	√	√
Carling Family (CS5)	2½ years		√	√	√	√	√
Sterling Family (CS6)	1 year	√	√	√	√	√	√

Education /Non-Medical Language

In relation to reporting on the findings for this section of family need, four out of the six primary carers reported the need for information on TBI surrounding their loved one's brain injury to be offered from the onset. The carers emphasised the need for professionals to use

non-medical language, as each one reported how the medical professionals, especially at the early acute stage of recovery would use medical terminology which they did not understand. An example of such need was emphasised by Mary McCroon who cited:

“How am I supposed to help my son if I can’t understand what the doctors are saying?. How am I supposed to know terms such as “cognitive”? Sure up until recently I never knew anything about the brain”.

Ref: Mary McCroon

The carers from each of the four families indicated a great interest in receiving information surrounding the functioning of the brain and how it could be affected following a TBI. They reported that if they understood more about the brain they could understand and help their loved one’s recovery more. This identified need is in line with findings reported by Mauss-Clum and Ryan (1981) study conducted with a sample of 30 wives during an early hospitalisation stage following a TBI. Within this study, participants noted the need for open and honest non-medical language information being of paramount importance towards supporting them through this stage. However, Camplair et al (1990) gave raise to consideration surrounding research by Mauss-Clum and Ryan’s (1981), surrounding how the study took place at the early acute hospitalisation stage. Therefore, it is important to note how some of the four carers who identified this need were not in the early acute stage of hospitalisation but were in fact many years post-injury and still sought information on TBI to aid in their understanding of their loved one’s TBI. This was seen with the carers from the Long and Coyle Families who were both six years post-injury. Within these case studies, both carers noted how they had never received any information on the functions of the brain or on their loved one’s injury. In the case of the Coyle Family, Maura reported:

“What I know about my son’s injury is mainly down to myself reading everything I could find. Coupled with the support of my niece who is a clinical social worker, I never received any educational training to help me support my son’s rehabilitation”.

Ref: Maura Coyle

Veronica Long reported how she had received very little information surrounding her husband’s injury and how all of the reports presented with medical terminology which she could not understand. She went on to cite:

“Yes, I have loads of medical reports but sure how can I understand all of this, I never went to medical school”.

Ref: Veronica Long

Emotional Support

The second identified need from the carers of the families was the need for professionals, in the case of the research, the key worker to offer emotional support to help them deal with their loved one’s injury. All the carers reported how the need for emotional support was ongoing and not just at the early acute hospitalisation stage. Within the McCroon family, who were at the early acute stage, the mother reported how she needed somebody to give her the emotional support to help deal with the life changing trauma she and her family were going through. Mary went on to cite:

“I just would love to have somebody to listen to me and help me through this maze. I feel that nobody listens to me; nobody is helping me get through this. I am the mother and need to be there for my son and family, but who is there for me?”

Ref: Mary McCroon

This need for emotional support for the carers was evident throughout five of the six case studies. Each family carer noted how during different stages of their loved one’s recovery they needed somebody to be there to listen to them. Each of the five family carers noted how they needed to have somebody they could bounce ideas or questions off to help give them a sense that their loved one was receiving the best care possible. This need of reassurance was noted in research conducted by Mathis (1984), which involved questionnaires being given to 26 families during the early patient intensive care stage. Within this study it was reported how families ranked the need for reassurance that their loved one was receiving the best care possible as high on their needs. Within the research, carers within the Long and the Timmons family reported the need to know that the emotional support was there and ongoing even after many years post-injury. In the case of the Long family, Veronica cited:

“I have learned to deal with my husband’s injury, but even after six years I still feel down and the need for somebody to be there for me, to listen and support me. It never goes away. My husband will always have a TBI”.

Ref: Veronica Long

In the Timmons family, Molly reported how she found it difficult to accept emotional support as she has dealt with her husband’s injury for over 27 years, but that she acknowledged the need for some form of emotional support. In this case Molly cited:

It’s hard for me; I have never received any form of support and tend to just get on with it. But there are days when I know and would love to have somebody that I could talk to. Somebody I can trust and who won’t judge me. I feel sometimes I am betraying my husband and feel guilty asking for support”.

Ref: Molly Timmons

This feeling of guilt by the primary caregiver is previously highlighted within research conducted by Mauss-Clum and Ryan (1981) who recorded how 50% of wives who partook in the research reported a sense of guilt in asking for support surrounding feelings towards their husbands.

However, within the research, one carer within the Coyle family did not report the need for emotional support. In this case Maura reported that she had learned to deal with her son’s injury after six years and that she was receiving emotional support internally from her niece, who was a social worker and how the family did not wish to involve external personnel.

“My son is my business and nobody else. The only people who understand my situation is my family”.

Ref: Maura Coyle

Case Management

Another identified need within the research was the need for case management to be given. Primary carers reported a need for a designated person to be assigned to manage their case file. Within the case of the research, this role was adopted by the role of the key worker. Five out of the six carers reported needing a singular person to help co-ordinate the needs and services of their family and their loved one with the TBI. This is seen by citations from different carers as follows:

"I don't know where to turn or who to contact".

Ref: Claire Sterling

"I don't think each person within my son's case file listens or communicates with each other. I need to repeat myself. Why can't somebody bring the group together and co-ordinate everything? It would be so much easier for me to manage?"

Ref: Mary McCroon

In the case of one carer who did not identify case management as a need for her family, the mother reported how such service was indirectly being supplied internally by her niece. In the case, Maura cited:

"If it wasn't for the help of my niece I don't know where we would be as a family. It is like a mine field out there, if you don't know where or who to go to".

Ref: Maura Coyle

On a different note, during the research many of the professionals that became involved in each of the cases noted a need for one person to take ownership of co-ordinating everything. This was identified as a need as each team involved many different professionals across different sectors, for instance: medical professionals, community primary care teams to supportive community services. This area will be reported within the findings on the role of the key worker, later on in the thesis.

Professional Guidance

Another identified family need was for the key worker to offer professional guidance surrounding attending to their own and their loved ones TBI needs. Four out of the six carers from the Long, McCroon, Carling and Sterling families reported the need for guidance from somebody who was familiar and experienced within the area of TBI. Each of the four families reported how they have experienced a lack of awareness and understanding surrounding the area of TBI in Ireland. Two out of the four carers from the McCroon and the Carling families reported, since the discharge from hospital the only professional TBI support they have gained surrounding the complexities of their loved one's injury was from their own private GP.

"I don't know what I would have done without my GP. My GP knows my family and is the only professional who continues to support me and my family".

Ref: Mary McCroon

Alternatively, the Long and Sterling family carers reported how their GP was not familiar within the field of TBI and the complexities involved, which occasionally caused some issues.

This is seen in a citation from Claire Sterling who cited:

"I know my GP tries to be there for us, but to be honest the GP does not know about TBI and sometimes I feel like he is lost".

Ref: Claire Sterling

Findings within this section also recorded carers noting the lack of other TBI professional support, outside of their GPs. This was seen with two of the carers from the Long and Coyle families whereby it was noted how some medical professionals, for instance; how neurology specialists were very difficult to get in contact with and when you did, there was large waiting lists.

"My GP is great, but really that can't do anything for my husband. It is within the neurological unit of the hospital that needs to attend to my husband as they have the expertise".

Ref: Veronica Long

"I have requested to see the neurological unit for my son, and have ringed up loads of time to no avail. There is such a long waiting list. It is nearly two years since my son's injury. This is absolutely ridiculous".

Ref: Maura Coyle

Support Network

Findings from the carers surrounding the need for a supportive network to be put in place were noted by five out of the six carers: the Long, Timmons, McCroon, Carling and Sterling families. Each of the five carers reported the need and reassurance of such a supportive network being in existence on an ongoing basis.

Mary, the mother of John cited:

"I need to know that there is a group of supportive people around me to help me through my son's rehabilitation. I need to feel that they are there and won't run away after a few weeks".

Ref: Mary McCroon

Veronica, the wife of Mike cited:

"We as families of loved ones with a TBI need to have some form of a supportive network around us on an ongoing basis. Who would I turn to if there was no supportive network and I know from the past six years I will endeavour to need support for many years to come?"

Ref: Veronica Long

Kathy, the mother of Danny cited:

"Support network, what supportive network? There is none. I have to do everything and I can't".

Ref: Kathy Carling

This identified need of a supportive network is emphasised by April (1997), Bekker (2000), Parker (1990) and Ragnarsson (2002) who stress the need for the families of loved ones with a TBI to have an ongoing supportive network to be there when and if required. Within the case of the research, the supportive network referred to professionals whom could provide support during the rehabilitative process, for instance: the key worker, the GP, members of the PCC and voluntary service providers.

One carer, Maura Coyle, reported no need for a supportive network. Maura reported how her family were dealing with her son's needs and that she had no need for any external intervention. She cited:

"I have looked after my son for the past six years with the help of my niece who is a clinical social worker, without the assistance or support of any external professionals or agencies and I certainly don't need to start now. Everything is fine, I can handle it all".

Ref: Maura Coyle

In reporting and acting on these findings from Maura Coyle, the researcher respected the wishes of the mother and did not impose the concept on the family for fear, as highlighted by Tyerman and Booth (2001) of placing the family in the role of needing treatment in order to support their son. The practice was adopted out of concern of the mother rejecting any form of intervention or support as all reported needs centred solely surround her son's injury and nothing else.

In relation to the above finding from Maura, the researcher would raise concerns, as noted by Bekker (2000) towards the possibility of the mother totally focussing all of her energy on her son, and not identifying and therefore neglecting her own needs and indeed the needs of the rest of the family. Unfortunately, this concern was not explored further as the mother did not wish to engage in the research in that depth.

Sense of being involved

When exploring the needs of the family further, five out of the six carers from the case studies (1,3,4,5 and 6), reported the need to be involved within the case management of their loved one. Each of these carers reported how they felt that through participation within their loved one's rehabilitation, they would feel some sort of use. Some of the citations from the carers are as follows:

"I need to be involved in my son's rehabilitation. I need to feel I am doing something to help him".

Ref: Mary McCroon

"Nobody tells me anything about what is going on. How can I help my husband if I don't know what is going on?"

Ref: Claire Sterling

This identification of the carer's need towards being involved in their loved ones rehabilitation or case management is in support of a list developed by the National Institute of Health (1998) which is further supported by Ragnarsson (2002) and Rose (1999) who argue the need for the family to be the pivotal role in the development of the individual with the TBI's case management.

In order to support such a need the research adopted the concept of collaboration as seen by April (1997), Bekker (2000), Parker (1990) and Ragnarsson (2002) by including the family as well as the individual with the TBI within any case management development. However one carer requested a wish not to be involved in her husband's case management. Within this finding, Molly, the wife of Jack Timmons reported how she was the sole carer for her husband for the past 27 years and had no support or help from anybody. She went on to cite:

"I have been the main care provider for my husband for the past 27years; I am tired of the responsibility and want my life back. I don't need to be involved, let somebody else take on the responsibility".

Ref: Molly Timmons

This finding could be down to the length of time the wife had to care solely for her husband, spanning over 27 years. Such longevity of her husband's needs and the level of strain experienced by the wife correlates to findings by Panting and Merry (1972) who reports how spouses of loved ones with a TBI experience higher levels of strain which increases over the years. The researcher respected the wishes of the wife and kept her informed of the husband's progression but did not directly involve her as requested. The door was left open for the wife to become actively involved in her husband's case management should she wish to do so. Throughout the course of the research, the wife did not change her mind but voiced her appreciation for keeping the lines of communication open with her.

Prioritising needs

In recording the prioritising the needs, the following table outlines each carer's ranking of their categorised family needs. Ranking of 1 refers to top priority and works its way downs to number 6, being the lowest priority.

Table 7 – Identification of family needs

Case Study	Years post-injury	TBI Education/ Non Medical Language	Emotional Support	Case Management	Professional Support	Support Network	Sense of being involved
Long Family (CS1)	6 years	1	6	2	4	3	5
Timmons Family (CS2)	27 years	6	5	1	4	2	3
Coyle Family (CS3)	6 years	1	6	2	5	4	3
McCroon Family (CS4)	3 months	1	6	2	4	3	5
Carling Family (CS5)	2½ years	6	3	1	2	4	5
Sterling Family (CS6)	1 year	1	5	2	4	3	6

In developing these findings further, the researcher will present the ranking of the carer's identification of needs, initially collectively in descending order, followed with individual bar charts and fractions on each identified need. The researcher feels the tables and graphs presented below support her decision, as a professional, in identifying the needs of the carers and not to assume that all needs and priorities would be the same for each of the families.

During the initial identification of needs process with the key worker, the primary carer was asked to prioritise their needs from 1 – 6, with 1 being the highest. The table below presents the six identifications of needs from the six carers in relation to their priority level.

The educational need being noted as priority level 1 with a recording of 4 out of 6 carers followed by the remaining five identified needs.

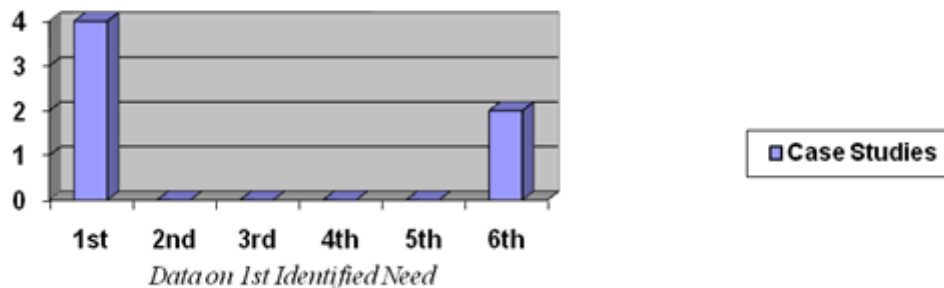
Table 8 – Priority levels of carers needs

<i>Levels of Priority of Need</i>	<i>Identification of Needs from the 6 carers</i>					
	<i>TBI Education/ Non Medical Language</i>	<i>Case Management</i>	<i>Support Network</i>	<i>Professional Support</i>	<i>Sense of being involved</i>	<i>Emotional Support</i>
Priority 1	4 / 6	2 / 6	0	0	0	0
Priority 2	0	4 / 6	1 / 6	1 / 6	0	0
Priority 3	0	0	3 / 6	0	2 / 6	1 / 6
Priority 4	0	0	2 / 6	4 / 6	0	0
Priority 5	0	0	0	1 / 6	3 / 6	2 / 6
Priority 6	2 / 6	0	0	0	1 / 6	3 / 6
Highest % of ranking	$\frac{2}{3}$	$\frac{2}{3}$	$\frac{1}{2}$	$\frac{2}{3}$	$\frac{1}{2}$	$\frac{1}{2}$
	Noted as Priority 1	Noted as Priority 2	Noted as Priority 3	Noted as Priority 4	Noted as Priority 5	Noted as Priority 6

In presenting these findings further. The researcher will now break down each identified need and the relevant associated data, commencing with the first priority ranking of family need, TBI education and the use of non-medical Language.

First Priority of Carer's Family Need with ²/₃ of overall ranking

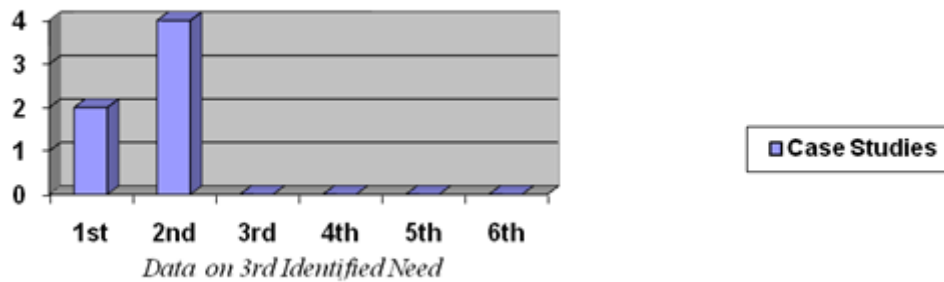
Figure 4 - Education/Non-Medical Language



Within this identification of need, four out of the six carers from the Long, Coyle, McCroon and the Sterling families recorded the need for education on their loved one's injury and the use of non-medical language as being a priority need for them. Four out of the six carers requested a first priority on receiving information on TBI so that they could better understand what was happening to their loved one. The remaining two carers from the Timmons and the Carling families placed this need in sixth place on their priority of need list. In the case of these two carers, Molly Timmons and Maura Coyle, Molly did not want to have anything to do with education surrounding her husband's brain injury, while Maura had obtained education surrounding her son's injury from her niece.

**Second Priority of Family Needs with $\frac{2}{3}$
of overall ranking**

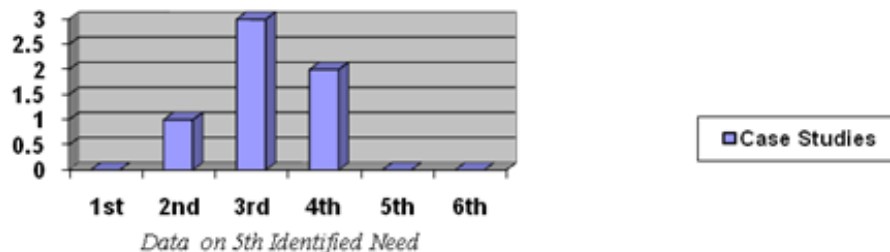
Figure 5 - Case Management



Within the rankings of the identification of the need for case management, two carers from the Timmons and the Carling families placed this need as a first priority need. Whilst the remaining four carers from the Long, Coyle, McCroon and the Sterling families placed it as second on their priority need list. The data indicated that for two-thirds of the carers, once they received some form of education on brain injury, placed their next priority on the case management need. In relation to the other two carers Molly Timmons and Kathy Carling, their sole focus was on obtaining external support for the case management of their loved one.

Third Priority of Family Need with $\frac{1}{2}$ of overall ranking.

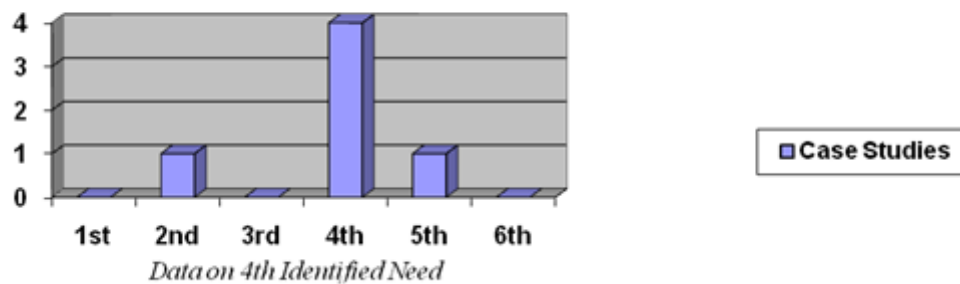
Figure 6 - Support Network



Within the ranking of the identified need for a support network, one carer from the Timmons family placed this need as second on their priority of need list. Three carers, from the Long, McCroon and Sterling families placed it third, whilst the remainder two carers, from the Coyle and Carling families placed it as fourth on their priority listing. With three out of the six carers reporting this need as third on their priority list, data indicated the need for carers to develop a complete supportive network of professionals in order to address the holistic needs of the family.

**Fourth Priority of Family Need with $\frac{2}{3}$
of overall ranking**

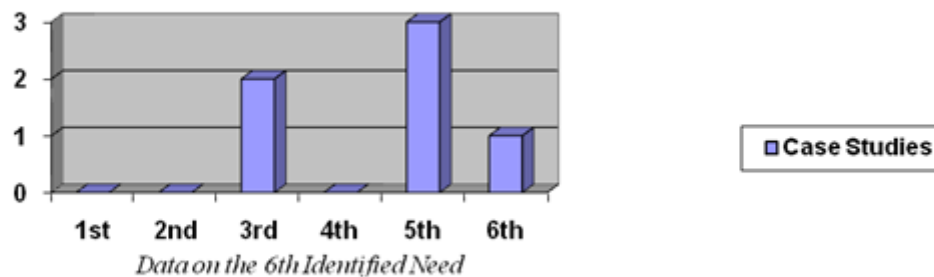
Figure 7 - Professional Support



The majority of the carers ranked professional support as a need on their list. The carer from the Carling family placed it second on their priority of needs list. Four out of the six carers, from the Long, Timmons, McCroon and Sterling families ranked this need as fourth on their priority list. Finally, the carer from the Coyle family placed it in fifth place on their priority of needs list. This fourth priority level supports the third priority of need for a supportive network by indicating the need for professional support to be in existence within the case management team to support the family throughout the rehabilitative process.

Fifth Priority of Family Need with $\frac{1}{2}$ of overall ranking.

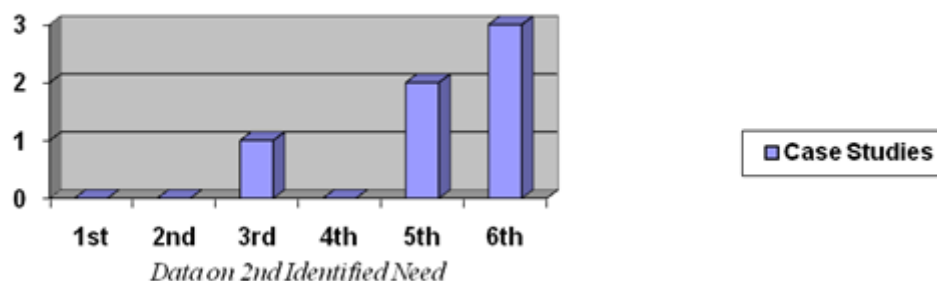
Figure 8 - Sense of being involved



Finally with the last categorised identified need for a sense of being involved, two out of the six carers from the Timmons and Coyle families placed their need in third place. Three carers from the Long, McCroon and Carling families placed this need in fifth place and the last carer from the Sterling family placed it last in sixth place. The fifth priority of need brings together the above four levels of need by supporting and empowering the carer in being involved within the rehabilitative process of their loved one.

Sixth Priority of Family Need with $\frac{2}{3}$ of overall ranking.

Figure 9 - Emotional Support



Within this identification of need surrounding emotional support, carers ranked this low with three carers from the Long, Coyle and McCroon families placing this need as sixth on their

list of needs. The carers from the Sterling and Timmons families placed it at fifth place. Finally, the last carer from the Carling family placed it third on their list of needs. The final priority level indicates how the carers, even though they indicated this need, placed their own emotional needs at the lowest on their priority. However, the researcher felt as a professional, the need to be aware of this need and offer support and guidance when and if requested by the carers.

CHAPTER FOUR – FINDINGS (PROFESSIONALS)

Section 4.1 Key worker roles

It is mainly the family that provides the majority of the care for their loved ones with a TBI. (Allen et al, 1994 and Knight, Devereux and Godfrey, 1998). Furthermore, as explored by Stebbins (1997), families often provide such care often without adequate professional support and intervention. To address this concept, the research explored and will present findings on how the role of a designated specialist key worker could provide support for families in caring for their loved one with a TBI within the community. The researcher acknowledged Degeneffe's (2001) concept of how each family needs were unique, however for the purpose of the research the aim was to try and present commonalities found which are noted and presented below.

The findings will be divided into two sections. The first section will present information on the case studies surrounding the length of time post-TBI, followed with Lees (1988) suggested different stages of implementation of the key worker role for each family. Background information was recorded in order to gain the groundwork for understanding the variances of implementation stages and length in time the families had to cope without support. For the purpose of the research, the implementation stage predominately concentrated on fulfilling the key worker role at the post-hospitalisation stage.

The second part of this section will report on identified roles of the key worker assigned by each case study. The identified roles correspond with Greco et al (2005) key worker roles, as seen with the need for education/information, emotional support, identification and addressing of needs, case management to advocating for the family. The section will begin with Table 10, representing the recorded identified key worker roles for each family. This will then be followed with looking at each role separately in more detail. Findings will be supported with tables and graphs for visual representation as well as quotations from families to support and enhance the data presented.

Background Information (1)

Table 9 below outlines the findings indicating the year's post-TBI of which the family is caring for their loved one. The second part of the table outlines the stage the family was at when the key worker first met them. It is the intention that the information in the table below will give the basic initial grounding and set the scene for the following findings.

Table 9 – Time post-TBI and stage of transition

Case Study	Time since injury	In-patient stage	Out-patient stage	Discharge Stage	Other
Long Family (CS1)	6 years				√
Timmons Family (CS2)	27 years				√
Coyle Family (CS3)	6 years				√
McCroon Family (CS4)	3 months	√			
Carling Family (CS5)	2½ years	√			
Sterling Family (CS6)	1 year				√

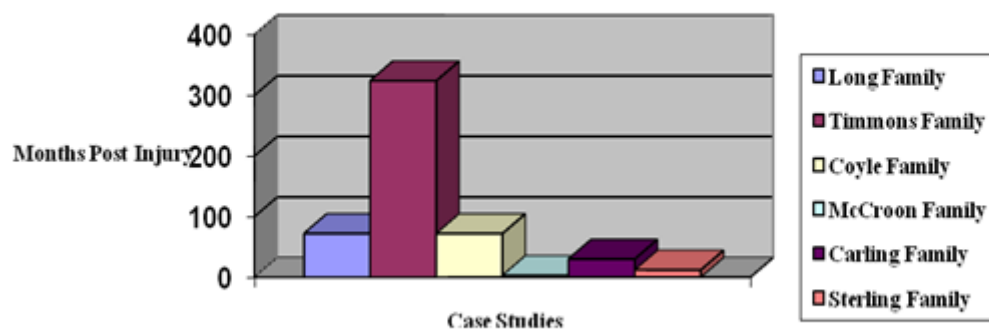
To strengthen the understanding of the findings, the researcher will introduce more information on both factors; the time lapse since injury and the different implementation stages.

Time since injury

The above findings reflect how the range of time post-injury varied from 3 months to 27 years. It is important to note how each family, regardless of the time frame had received no support or allocation of a key worker at any time.

The graph below presents the variance of time since injury. For the purpose of the graph, the researcher presented the time in months post-injury for each family to allow comparisons to be clearly seen.

Figure 10 – Time in months post-injury



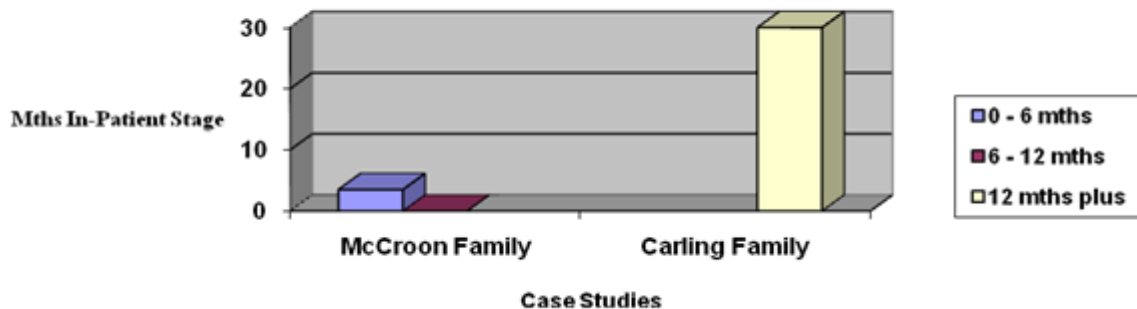
The next area to be present is the findings surrounding the different implementation stages of the key worker within the research. The first one to be presented is the In-patient stage.

In-patient stage

The in-patient stage refers to the initial recovery phase of the individual. It can involve the early acute stage of recovering from a TBI. At this stage the key worker was introduced to two carers from the McCroon and Carling families. Within the case of the McCroon family, the key worker was introduced to the mother of a son who three months previously had sustained a TBI and had only recently come out of a coma. In relation to the Carling family, the key worker was introduced to a mother whose son had sustained a TBI two and a half

years ago but was still within the in-patient stage of recovery due to the seriousness of his injury.

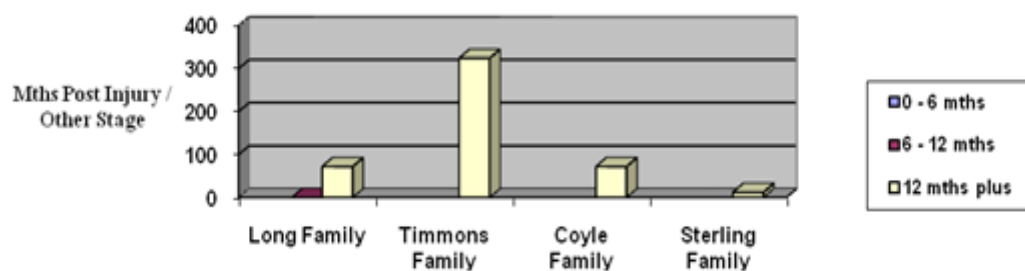
Figure 11 – In-patient implementation stage



Other stage

Lastly is the Other Stage. This stage refers to when the family and their loved one with a TBI are completely out of the rehabilitation services and are not receiving or attending any form of rehabilitative intervention. The length of time lapse since leaving the system ranged from one year to twenty seven years. Within this section the key worker was introduced to carers of four families: Long, Timmons, Coyle and Sterling. Each of these families represented different stages of being out of the medical/professional system. In the case of the Long family, the key worker was introduced to a wife of a husband that had sustained a TBI six years ago. In the case of the Timmons family, the key worker met with the wife that was caring for her husband solely without any assistance for the past twenty seven years. Within the case of the Coyle family, the key worker was introduced to the mother of a son who sustained his injury six years ago. Finally, the last family, the Sterling family involved the wife of a husband who had sustained his injury a year ago.

Figure 12 - Other implementation stage



Identification of key worker roles

Greco et al (2005) note the role of the key worker as offering emotional support, education and information, the identification and addressing of the family needs, case management of these needs, to advocating on behalf of the family. For the purpose of this research, the researcher will incorporate the roles suggested by Greco et al (2005) towards the findings of the research.

Below is a table outlining findings of where the key worker, (in the case of the research, it was the researcher) fulfilled each or any of Greco et al (2005) roles.

Table 10 – The incorporation of Greco et al (2005) key worker roles into the research

Case Study	Education/ Information	Emotional Support	Identification/ Addressing of Needs	Case Management	Advocating on Behalf of the Family (5)
(1)	(2)	(3)	(4)		
Long Family (CS1)	√	√	√	√	√
Timmons Family (CS2)		√	√	√	√
Coyle Family (CS3)	√				
McCroon Family (CS4)	√	√	√	√	√
Carling Family (CS5)		√	√	√	√
Sterling Family (CS6)	√	√	√	√	√

1. Education/Information

Carers of the families requested for the key worker to provide them with information surrounding TBI and the impact it may have on their loved one. They also asked for information surrounding their loved one's behaviour. It is important to note how the role of the key worker varied during the different implementation stages of recovery. A Family Carer's Guide following a TBI was obtained from a local rehabilitative service provider, Headway and given to each family.

Within the in-patient stage, the key worker was introduced to the McCroon family. At this in-patient stage, the mother (Mary) voiced the need for information and education surrounding her son's injury. She reported how this would help reduce stress levels for both

herself and her family as she felt it would help them to be empowered within the decision-making processes that were being asked of them.

For instance, Mary requested the assistance of the key worker to go through the information with her that was required by the medical professional so that she felt that she was making an informed decision for her son. She cited:

“Doctors don’t tell me anything. They just ask questions and go ahead with decisions surrounding my own son. They won’t spend the time to sit with me and explain all of this medical talk. How can I make a decision if I don’t understand what or why they are asking?”

Ref: Mary McCroon

In developing this concept further, Mary went on to record how she could not understand the medical terms used and this was causing her and her family great levels of stress at such a crucial time within the decision making process. This medical practice of the “doctor knows best” supports the theory emphasised by Mubarak (1997) whereby the medical profession may take over the situation and in some ways disempower the family within the decision-making process. This can be seen within a citation from Mary below.

“They act as if they know it all and that I am stupid or something. I may not be a doctor, but I am his mother. I know my son inside out. Why can’t I be part of the decision-making of my son?”

Ref: Mary McCroon

The need for continued education and information was maintained and required throughout the recovery and rehabilitation of John McCroon. The role of the key worker surrounding education/information transcended across each implementation stage the family went through during the research.

The need for education and information was also required to be implemented for three carers from the Long, Coyle and Sterling families. Within each of these cases, the families were out of the medical hospital setting and had no support at all. Each of these three carers noted the need for education surrounding TBI so that they could understand and therefore assist their loved one’s recovery and rehabilitation. Each carer recorded never receiving any formal

training surrounding TBI. For instance, in the case of the Long family, Veronica, the wife reported:

“I don’t know why I was never given education surrounding TBI. How can I help my husband if I haven’t received some form of training?”

Ref: Veronica Long

Whereby the wife of Joe Sterling reported:

“Wouldn’t you think it would be the first thing to take place before discharge? That is educating the family on their loved one’s injury. I don’t need the full medical terminology, just need the basics. I don’t know or ever have come across anything to do with TBI and now I have to deal with it on a daily basis”.

Ref: Claire Sterling

Findings recorded reflect how education and information surrounding TBI and supportive services was ongoing and did not decrease over length of time post-injury. This was reported by carers from the Long and Carling families, who were six years post-injury. In both cases their carers reported that if they had received education that was now being presented at the early stages, they may have been better equipped to support their loved one. They went on to note how the functionality of living and caring for a loved one with a TBI is life-long and how things arise every now and again that they need education and information on. Carers reported how knowing that somebody is there to turn to and question or request such education and information is paramount to them and puts them somewhat at ease. These are seen in the following citations:

“I should have gotten this education and information six years ago. I would have been better equipped than to understand my husband’s injury and deal with it”.

Ref: Veronica Long

“It’s a shame that families don’t receive education and information at the early stage before discharge. I feel it would have helped me and my family big time. It is great to get the education/information now but it would have been better six years ago”.

Ref: Maura Coyle

“It’s early enough days and I know there will be tough times ahead for my family but it’s a comfort to know that I can turn to somebody if and when I should need education or information surrounding my husband’s rehabilitation”.

Ref: Claire Sterling

However, it is important to note how two carers did not request any form of TBI information surrounding their loved one’s injury. In both cases, the wife within the Timmons family and the mother within the Carling family voiced quite strongly how they did not want to know about TBI or the brain. They only voiced an interest in receiving functional information about external issues, for example service providers and possible professionals. Molly of the Timmons family reported:

“It’s too late; I don’t want and need to receive any education on TBI. Sure haven’t I lived with my husband for the past 27 years and managed. It is all information I don’t want to hear”.

Ref: Molly Timmons

Within this citation, the researcher would question whether as a result of the wife solely supporting and educating herself on her husband’s TBI that this has impacted on her susceptibility towards being open to receiving TBI education.

Furthermore in the case of Kathy, the mother of Danny Carling, she reported:

“Why would I need education on the brain? It’s too medical and intense and we are talking about my son, I don’t need or want to hear about my son’s brain so No Thank You”.

Ref: Kathy Carling

Within this citation, the researcher would question whether the mother was refusing education as a form of a protective measure. Also at the initial stage of the research, the mother’s son had been in a hospital setting for over two and a half years and his care was completely attended to by medical professionals. Therefore, the researcher would question whether the mother had become disempowered over time and maybe felt that it was more for the doctors to know about her son’s TBI as opposed to herself.

2. Emotional Support

Within the key worker's role of providing emotional support, five out of the six carers of the Long, Timmons, McCroon, Carling and Sterling families requested and were given emotional support at different stages. Within the McCroon family, the carer requested and received emotional support during the different implementation stages of their son's recovery. Initially the emotional support was given at the early in-patient stage when the family's son had only just come out of a coma and they were unsure as to the effects of the TBI. The emotional support at this stage was mainly provided by the key worker just listening to the family and letting them talk. These meetings took place at a convenient location to the family. At the early stages, the key worker met with them at the hospital. However as the son went through the discharge stage back into the community, meetings took place within the family home. This practice of meeting the family within a suitable convenient location for them is in support of the concept proposed by Dunst, Trivette and Deal (1994) of promoting meetings within a safe empowering environment.

Within this case, the mother cited:

"I need to have somebody to listen to me. Somebody I trust and can feel comfortable with. Having a key worker at this stage is a God send. I now feel stronger and more able to emotionally cope with the situation because of the key worker".

Ref: Mary McCroon

Within the Carling family, the key worker worked with the carer within the in-patient stage initially through to the discharge stage to a nursing home. During this time the mother requested that the key worker could be there for her to support her emotionally through the transition.

The mother, Kathy Carling went on to cite:

"There is such a transition happening with my son moving out of the hospital after two and a half years. I just feel overwhelmed and would value knowing somebody is there for me".

Re: Kathy Carling

In presenting the findings further, in relation to the Long, Timmons and Sterling families, each of their carers had no form of support and was out of the medical/professional system. Each of these carers reported feeling alone and in some ways abandoned by the health system. These carers went on to report how they really would appreciate somebody to talk to about their experiences and difficulties. In reporting on these findings, supporting citations are noted below:

“It has been six years and I have been offered no support whatsoever. What about me? Who listens to me? The family can’t and I wouldn’t do that. I feel each family should have some form of emotional support as it doesn’t get any easier over time, only worse”.

Ref: Veronica Long

This concept of ongoing family emotional support was further supported by the wives of the Timmons and Sterling families.

Molly Timmons cited:

“I don’t understand in this day and age, why families of loved one don’t have any form of emotional support from the health system. How do they expect us to keep on caring for our loved ones without any support? Caring for a loved one is the most emotional rollercoaster experience I have ever experienced”.

Ref: Molly Timmons

Whereby Claire Sterling reported:

“I have cared for my husband over the past year and it has been very emotionally draining. Who can I turn to? I feel that professionals need to care for the carers as well as the individual with the TBI. We need emotional support too”.

Ref: Claire Sterling

3. The Role of Identifying and Addressing the Family Needs

Within this role, the key worker commenced on the “*flow through*” model of the designated specialist TBI key worker with the aim of providing the support and guidance to the family.

The initial meeting with each of the six families' carers adopted the form of a semi-structured interview which took place at a convenient time and location of the families' choice. Two families (McCroon and Carling) were met at the hospital, whilst the remaining four carers (from the Long, Timmons, Coyle and Sterling families) were met at the family home in the evening hours. The practice of ensuring that the meeting took place at a convenient location and time of the family is in support of Dunst, Trivette and Deal (1994) who note the importance of the family being empowered and within a comfortable environment in order to promote a good working alliance amongst the key worker and the family's carer. Furthermore, the allocation of a specialist key worker within the area of TBI supports the concept proposed by Dunst, Trivette and Deal (1994) of supporting a better alliance. Goodinge (1998) notes how the working alliance between the family and the key worker can be enhanced through such professional specialisation and understanding.

Upon reflection of this practice, the key worker was required to be flexible in accommodating the timing and location needs of the family's meetings. To accommodate this need, the key worker was required to organise their day around these meetings, often completing a full day's work and then attending to the family meeting outside. This level of flexibility caused some fatigue issues as it placed strain on the key worker to manage their daily work load and extended the daily hours into the evening. To address this concern, in the future, consideration would need to be given towards supporting the key worker in managing their time to prevent the possibility of burn out.

When reflecting on the initial meeting itself, the key worker addressed the identification of needs between the carer and the individual who had sustained the TBI. In relation to the individual with the TBI, the key worker requested a full medical history of the injury. A detail on the recovery to-date, establishing any services that were offered was ascertained along with any presenting difficulties observed by the family. This information was required to promote an understanding of the recovery of the individual to-date from a medical and family perspective. To accommodate the collection of this information, the key worker asked semi structured questions about emotional, behavioural, physical, and financial to educational needs. Questions were periodically reviewed throughout the research to support the development of the key worker and primary carer alliance in addressing such needs.

After ascertaining the information, the key worker noted same down on the Individual Identification of needs spreadsheet. Please refer to *Appendix Two “Individual (B) Identification of needs spreadsheet)”* for review. Needs and allocation of responsibility for each action were recorded for implementation and monitoring purposes.

In developing the identification of needs further, the key worker ascertained general generic information on the family’s carer, for instance: first name, surname and address to the family cycle and roles. This information supported the obtaining logistical data of the research for the six case studies involved. The logistics supported the key worker in gaining a greater understanding of the impact of the TBI had on the family unit, especially surrounding family life cycles and role changes which ultimately aided in the identification of needs process.

The interview moved forward in addressing the needs of the primary carer. To accommodate this process, the initial meeting was conducted in an informal manor to promote the development of the key worker and primary carer alliance at the carers pace. It was acknowledged how time was required to be allotted to support the primary carer in opening up and trusting the key worker with such delicate personal information. These identification of needs were then recorded, prioritised, action drawn up and delegated noting who was responsible for each action. Once information was received, it was recorded on the “Family Member Sheet”. For example: *Appendix Two “Family (A) Identification of needs spreadsheet”* completed for Mary and John McCroon, Case Study Family 4. Both of these spreadsheets were updated accordingly as each action was completed, and the circle of identification of needs started all over again in order to promote continuous development.

Citations of the carers involved in the research surrounding their identification of need recorded are as follows:

The first citation is from a mother whereby the initial meetings took place in a hospital setting. Meetings then moved to the family home once the son was discharged from hospital.

“I don’t know where to start. There is so much I want to say and ask. It’s all up in the air but I am now more at ease knowing somebody is here to help me sieve through all of this”.

Ref: Mary McCroon

The second citation was also from a mother and all of the meetings took place within the hospital due to the son being in long-term care there.

"It's great that you can meet me here at the hospital. I am so busy now. I am never home as I don't want to miss seeing my son. This way I get to be with my son and get the help I need too".

Ref: Kathy Carling

The last two citations are from wives who have a husband who has sustained a TBI some years back. All of their meetings took place in the evening times at the family home.

"I really appreciate you calling to my house at this hour. I know it's late in the evening but with work and all this is the only time I can get to talk and be listened to. I know my husband has needs but so do I and I appreciate the fact that people know that I matter too".

Ref: Claire Sterling

"I really appreciate you listening to me and helping me identify what my family and indeed I need. I just wouldn't know where to start. It is great to feel that I am important too."

Ref: Veronica Long

Finally within this identification for the need of a designated key worker, there was only one carer who noted not requiring such a service. The mother of Colm Coyle reported how all was in order and how she had received such a service from an internal source, her niece who was a clinical social worker. However, she went on to say how beneficial it would be to other families who did not have a relative within the medical/social worker profession by citing:

"I am lucky enough to have my niece to help me with my family needs, but others are not. Therefore I think that such a role of a key worker should be automatically assigned to every family that experience a loved one with a TBI".

Ref: Maura Coyle

Upon reflection of the identification of needs process, acknowledgment was given towards the importance of key worker including the primary carer in the process as they would have an in depth awareness of the full impact of the TBI on their loved one. The practice of inclusion also supported the empowerment of the carer through listening and including them

in the overall rehabilitative process of their loved one. It was also identified for the need of the key worker to be flexible and patient when providing their service and allow the primary carer time towards feeling comfortable in opening up and discussing their loved one needs. Furthermore, the key worker needs to acknowledge the importance of practicing active listening skills when working with the primary carer to ensure that the ever changing multiple needs of the family unit are being identified and addressed.

Consideration was also given towards thoughts raised by Purves, Riddell and Weedon (2008) on how the key worker's own concerns and preoccupations could impact and might pre-dominate the family needs meetings. With this in mind, the key worker used self- reflection and reviewed the previous minutes before attending the meeting and promoted active listening with the carers to ensure correct interpretation of the carers needs. Furthermore at the end of each meeting, actions of needs were reviewed by all involved in the identification process to ensure clarity.

The researcher acknowledged the need for the key worker to have good time management skills to prevent burn out when working with six families on the research and working full-time. The amount of time spent with families varied. At least an hour was spent with each of the six case study families on a weekly basis's. However, time allocated to each case study family did fluctuate depending on the action that was being attended to, for example a larger portion of time was allocated when attending case management meetings. The time allocated to the research was determined by the Researcher's own work timetable. The majority of meetings with each family took place in the evening or at week-ends. When the researcher was due to attend meetings during the day, she took annual leave from work.

4. Case Management.

Within the research, the key worker explored many different service providers, for instance PCC team's, service providers such as Headway and ABI Ireland to local community service providers, for instance local community centres in order to facilitate the family needs. Within this capacity, each case study evolved into co-ordinating and case managing of a multi-disciplinary team of professionals in order to support each family needs.

Below is a table of the multi-disciplinary teams consisting of hospital staff, HSE staff, social welfare and community PCC teams utilised for each case study within the case management key worker's role.

Table 11 – Multi-disciplinary teams utilised with the case management key worker role

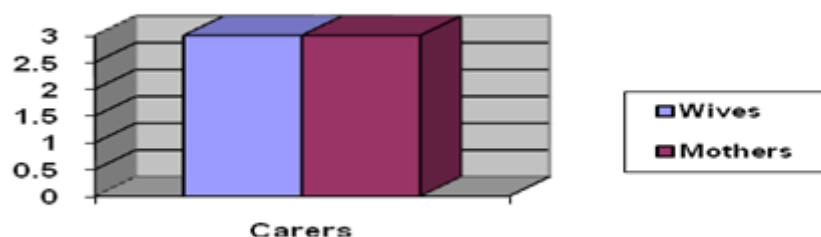
Case Studies	Carer	GP	Primary Care Centre Team					Hospital Staff	HSE Disability Manager	Other
			PHN	OT	Physio	S & L	Social Worker/ Welfare Staff			
Long Family (CS1)	Wife	√	√			√			√	√
Timmons Family (CS2)	Wife	√	√	√	√	√	√	√		√
Coyle Family (CS3)	Mother	√								
McCroon Family (CS4)	Mother	√	√	√	√			√	√	√
Carling Family (CS5)	Mother	√	√					√	√	√
Sterling Family (CS6)	Wife	√	√		√					√

The researcher will now outline in detail the breakdown of the case management duties and who was involved within each case study.

a) Carer

Within this case management role of the key worker, the case studies involved the partnership and collaboration of three wives from the Long, Timmons and Sterling families and three mothers from the Coyle, McCroon and Carling families.

Figure 13 - Carers involvement in Case Management



b) General Practitioner

Within the research, every GP who nominated a family to participate in the research formed part of the case management team. In the case of the research, all of the GPs became involved in the multi-disciplinary team.

c) Primary Care Centre Teams

Not all of the case studies had access or were assigned a PCC team. Out of the six case studies, five involved the identification and referral to appropriate PCC team professionals to aid in the action of the individual and their carer's rehabilitation.

Figure 14 - Primary Care Centre Teams Breakdown



The main source of contact within the PCC was the PHN. Within this role, the key worker made suitable referrals to the PHN and brought them on board to form part of the case management team.

From the referral and assignment of the PHN, referrals were sought when deemed appropriate for other members of the PCC to join the case management team. Within this capacity, two referrals were made to the Community Occupational Therapist for the Timmons and McCroon families. Three referrals were made to the Physiotherapists for the Timmons, McCroon and Sterling families. Two referrals were also made to the Speech and Language department for the Long and Timmons families. Finally, one referral for the Timmons family was made to the Community Social Welfare department. In this case unfortunately the referral was denied due to the age of the gentlemen being under 65 years of age and over adolescent age. This later became apparent as a barrier for all of the case studies as it was reported by a Social Worker that they can only work with children or people over 65 years due to staffing demands.

Citation from Social Worker:

"I am sorry but I spoke with my supervisor and was advised that I can only work with children or individuals over 65 years of age. We haven't as of yet been advised to work with this section of the population. To be honest our case load is too great and we just couldn't facilitate it".

Ref: Timmons Family - Community Social Worker

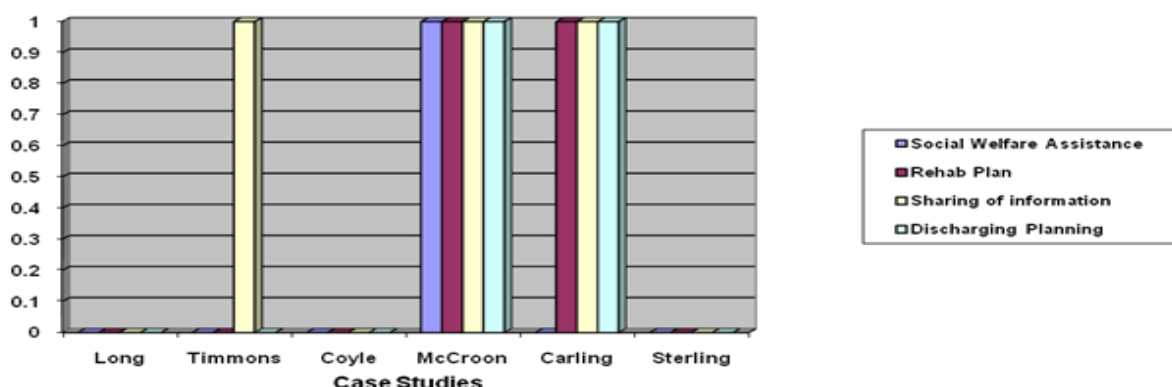
Once these professionals came on board, they formed part of the multidisciplinary team for each family and part of the case management. It was the role of the key worker to collaborate and ensure consistency across the board within this team.

Findings also indicated how families were unaware of appropriate services and how services were fragmented which added to the stress they had to endure. Research conducted by Gordon, Parker and Loughran (1996) and Sloper and Turner (1992) support these findings by recording how families experience confusion and higher levels of stress due to the need for them to communicate with numerous contacts. To counteract such confusion and stress levels, the key worker acted as a single point of contact for all of the members of the multi-disciplinary team and promoted an easy flow of communication across the different members.

d) Hospital Staff

The next section to present findings on within the case management role of the key worker is the collaboration with hospital staff. Within this section the key worker mainly worked with two families, the McCroon and Carling families who were still at the hospitalisation stage. The role involved organising and co-ordinating appropriate services and rehabilitation. Within the hospital setting, the case management role involved the collaboration of the hospital Social Worker, clinical nursing staff and medical teams. The key workers role at this location mainly involved the sourcing of financial allocation of social welfare payments, the setting up of a rehabilitative programme and sharing of information amongst the team to the discharging planning.

Figure 15 - Case Management with Hospital Staff



The case management duties of the key worker mainly involved the need for the family to have somebody to co-ordinate, access and obtain actions in which would enhance and support

their loved one's rehabilitation. During the identification of needs process, each carer reported how they would like for the key worker to assist them with the co-ordination of their loved one's case as they felt very overwhelmed by the whole process and in some cases felt intimidated when communicating with the medical professional. Citations as follows:

"There are so many people looking after my son, I don't know who is who and what they are doing. I wouldn't know where to start to try and organise and co-ordinate everything. It would be just too much for me to handle at this stage".

Ref: Mary McCroon

"I need somebody to try and get things moving for my son. He is here too long and nobody seems to be doing anything. I would be afraid to approach them as I don't think they would listen. Sure they haven't listened to me so far and it is over two and a half years since my son was taken into this hospital".

Ref: Kathy Carling

"I haven't a clue of where to start or who to talk to about getting the medical records, it's been so long. I find it very difficult to motivate myself to do anything and even get stressed just thinking about it. It would be great if somebody could support me in this and take an objective approach to this and organise everything. I am just too tired and too close to the situation".

Re: Molly Timmons

As a result of the key worker being assigned to each family within the research, and the needs being identified the following actions took place.

Within the McCroon family, the key worker initially met and worked with the hospital Social Worker sorting out the financial side of things for the carer. The key worker then moved forward and worked with the medical team on identifying the rehabilitative needs and relaying the information on to the mother explaining the plan of action. As the transition from in-patient to discharge to another specialised rehabilitation hospital came on board the key worker worked with the Social Worker of both hospitals to ensure the transition was as smooth as possible for the son and the family. Finally, the key worker worked with the social worker and the multi-disciplinary team of the rehabilitative hospital within the final discharge plan out to the community. Within this case management role, the key worker co-ordinated the discharge plan with the hospital staff, the community primary care team and the family to

ensure that all services were in place to support the family once their son was out of the hospital setting.

Within the Carling family, the case management role involved organising conferences with the family, the hospital staff, the community PCC team and staff from the intended nursing home to which the son was going to be discharged to. The case management role involved a lot of organising and planning of meetings, identifying the needs of the family and the son to the sharing of actions and information across the multi-disciplinary team of professionals. Within the hospital staff, the key worker worked alongside the Social Worker, the medical team and the family.

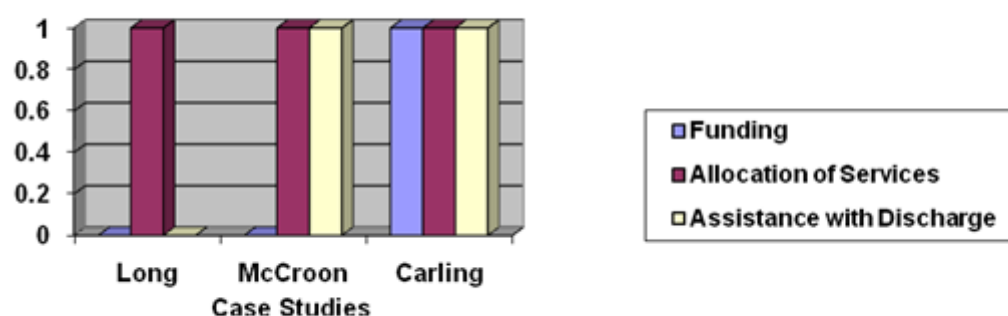
Finally, the last case study that involved the key worker fulfilling the case management role was in with the Timmons family. Within this case the husband had sustained his injury 27 years ago and was out of the hospital setting for many years. However, due to the length that had transpired since the gentleman's discharge, information was difficult to obtain. To address this need the key worker worked with the clinical head nurse on obtaining the necessary information for the family in order to address certain identified needs.

e) Health Service Executive Staff / Disability Manager

Within this section the HSE staff referred to the involvement of the area Disability Manager (DM). The role of the HSE Disability Manager is to co-ordinate the delivery of services to people with disabilities. This section involved the working in collaboration of the Disability Manager for three of the families, for instance: the Long, McCroon and Carling families.

The involvement of the DM was required for each of these cases to try and gain support of external services for the families. The key worker had gone through the normal route, initially contacting the PHN of the community rehabilitative team and was advised for each case of the barriers surrounding a shortage of staff and funding. The main areas of case management with the DM involved funding, allocation of community services and assistance with the discharging planning.

Figure 16 - Case Management with Disability Managers



Within the case of the Long family, the DM was invited to try and support a referral made for the husband's speech and language therapy. The initial referral made by the key worker was rejected due to staff shortages. A case conference meeting took place which involved the DM and the members of the PCC. During this case conference, all members discussed in length the need and the barriers. The conclusion to this meeting was successful and the gentleman was awarded community speech and language hours. The wife, Veronica reported:

"I don't think nobody would have been aware of my family's situation unless we contacted them. I think it is ridiculous that this contact does not happen automatically before an individual is discharged from hospital. You know nobody ever contacted me in over six years. Is it up to the family to notify the DM and team? It's not fair to expect the family to have to deal with this".

Ref: Veronica Long

Within the case of the McCroon family, the DM was contacted to ensure that they were aware of the needs of the family post-discharge stage. The referral also supported the application for the assignment of a PCC community team to follow on with the son's rehabilitation and support the family once he was discharged. Contact was made to promote better awareness and to be proactive as opposed to being reactive.

The mother, Mary reported:

"I feel happier now knowing that my family and son will have support. I was very nervous about him being discharged. At least I know I can contact the DM and they will be aware of my family's situation".

Ref: Mary McCroon

Finally in the case of the Carling family, the DM was invited into the multi-disciplinary team to support the need for financial assistance towards placing the son in an alternative accommodation, that is a nursing home whereby he could obtain the necessary rehabilitation therapy he required. In this case, the mother had voiced how she had tried unsuccessfully to make contact with all different areas of the HSE in order to support such a transition as they were not in a position to fund the nursing home. Within the case management, a conference was organised with the hospital staff, the nursing home staff, the family and the DM. Discussions took place surrounding financial sourcing. The meeting concluded with funding for the transfer to the nursing home being granted.

The mother reported:

“Nobody is listening to me for the past two and a half years. I feel so frustrated at times with the system. I really don’t know who to turn to or whether they will even listen to me. I know my son needs to move but I just don’t have the funds to facilitate it”.

Ref: Kathy Carling

The above findings may suggest that there is no strong practice of working in collaboration and sharing of information between the hospital discharging planning and the identification of community services process. These findings suggest, as outlined by Sloper (1998) how services are piecemeal and service-led rather than needs-led. However, at this stage consideration needs, as outlined by DeJong (1999) to be given to how such inference is predominately based on anecdotal information and individual case studies and further research would need to be conducted to prove or disprove this theory. The researcher feels within the case of the research that both sets of staff from the hospital and community services need to be working in conjunction with each other in order to best support the family and the individual with the TBI in the transition. The findings go on to suggest that once the relationship is established amongst these two divisions, the staff are willing to work together and the benefits for the family can be very rewarding.

f) Others Section:

Within the “Others” section of case management it surrounded the involvement of the community centres, educational settings, voluntary charitable organisation and other service providers. The findings reported on five out of the six carers, as Maura from the Coyle family

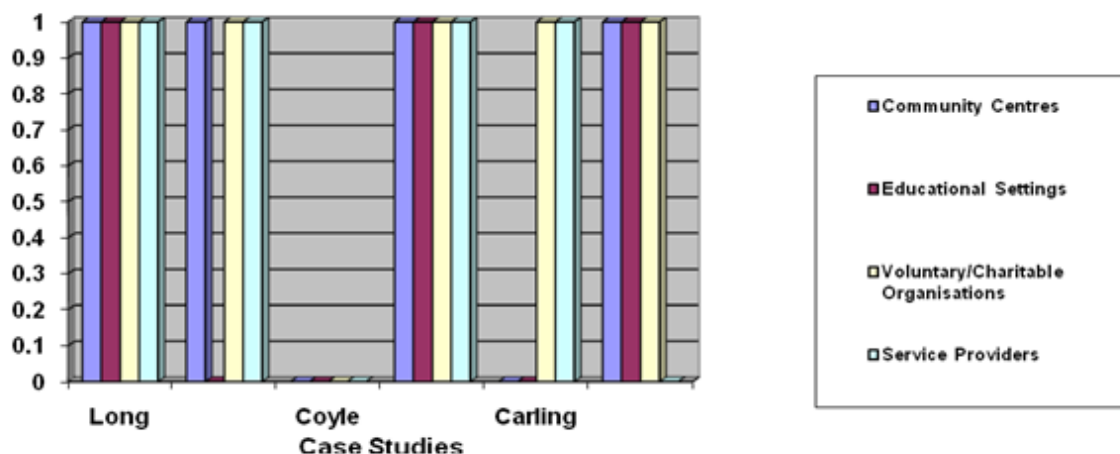
requested no assistance from the key worker within the case management side of things, noting that a family member was fulfilling that role:

“Even though I do feel that everybody should have a key worker to case manage their case, I don’t need one as my niece the clinical social worker is fulfilling that role”.

Ref: Maura Coyle

The breakdown for the remaining five carers categorising the case management into the different other services are noted in Figure 17 below:

Figure 17 - Case Management with Other Services



f) – 1 Community Centre

In breaking down these sections, the first case management role was working in collaboration with community centres of local partnerships that were set up with the aim of supporting families within their communities. Such support took on different forms, for instance: local bingo clubs, bridge clubs, yoga to plays being presented to which the families could attend and avail of. These local partnerships were contacted for carers of the following families, (Long, Timmons, McCroon and the Sterling family) with the aim of providing local community support whilst also promoting more integration for the family and in some cases the individual with the TBI. Some of the citations from the case studies are as follows:

“It gives my husband somewhere safe to go and mix. He loves the bridge club which is just around the corner. It also gives me a break whilst he is out for the hour once a week”.

Ref: Veronica Long

“I love the fact that I can pop down when I want to the local centre and have a cuppa and a chat with the ladies. I also love and really enjoy attending the yoga classes. It helps me to relax and gets me out of the house”.

Ref: Mary McCroon

“You know what I never knew there was a community centre near me and what they provided. It’s great to know that there are things I can avail of and it’s just on my doorstep”.

Ref: Claire Sterling

Upon reflecting on the key worker supporting this family need, it was identified how some families involved in the research were not aware of local amenities within their area to which they could avail of. It was as a result of the key worker exploring events within the community that these places were identified. Local amenities identified within the research promoted accessibility for a variety of activities which supported both the individual with the TBI and their family member. Such identification of the benefits of exploring local amenities formed a beneficial and rewarding aspect of the key workers role towards supporting the families who participated in the research.

f) – 2 Educational Settings

In breaking down the case management role within the educational settings, the key worker made contact with local training and college centres. The aim was to facilitate a desired vocational training need identified by the primary carer and support more social interaction within the community. Within this role, two of the primary carers, the wife of Mike Long, and the mother of John McCroon noted an interest in returning to education and participating in something light. They went onto note how it would give them something else to focus on whilst giving them a sense of achievement and control back of their lives. With each of these carers, the key worker supported them in exploring different possible options in different locations and in their application and attendance of the agreed course.

Within this concept, Veronica noted:

“I always wanted to go back to school but never felt I was good enough. It will give me something for me and give me a sense of normality back”.

Ref: Veronica Long

And Mary cited:

“I always wanted to do something, but with my son’s injury I just got caught up in everything. I now feel it is time for me to do something for me. Also the fact that the college is just around the corner is even better as I can arrange things accordingly and still be there for my son”.

Ref: Mary McCroon

During the research both carers reported how much they loved attending their courses and were making plans for continuing onto doing something else.

Veronica reported:

“Now that I have started, I am going to keep going. Try something else. I loved the course, meeting people and in some ways having a life outside of my husband”.

Ref: Veronica Long

Whilst Mary reported:

"It was more difficult than I thought. However, I feel really good about myself for the first time in ages as I got through the course. I am now thinking about what to do next".

Ref: Mary McCroon

Upon reflection, the key worker acknowledged the complexity and multiple needs of the family resulting from a TBI. In addressing such complexity, the key worker looked at identifying interests of the primary carer towards facilitating an identified need. Within the case of the research, the interest of returning to education was utilised to attend to the need of gaining some form of control back outside of the context of TBI.

f) – 3 Voluntary/Charitable Organisations

The case management role also involved the key worker working with charitable organisations, for instance Bri Advocacy, to local support groups for men and women. The aim of the inclusion was to explore, source and support the involvement of beneficial and suitable organisations that could support the family. Within this practice, each of the six family carers was introduced to different voluntary organisations within their local community that supported the family and indeed the individual with the TBI. However, only two carers, Veronica Long and Mary McCroon took up the referral and became involved in one service provider, Bri Advocacy. In both of these cases, the carers and their loved ones became actively involved in a social support group for families and individuals who have experience of a loved one with a TBI. Both Veronica Long and Mary McCroon went on to participate in a carers' weekend respite break. Their loved ones participated in the social club that runs once a month for individuals who have sustained a TBI. They reported:

"I really enjoyed the weekend away. It was time for me to relax and unwind. However I also learnt more about my husband's injury through the talks that took place. Also it is great for my husband. He gets to go to the club once a month and has made new friends".

Ref: Veronica Long

"It opened my eyes, meeting other families who have experienced a loved one with a TBI. There were families worse off than me. I know it's a terrible thing to say but it made me more understanding of my own son's situation".

Ref: Mary McCroon

Upon reflection, the key worker acknowledged the importance and benefits of exploring local voluntary/charitable organisations, which the primary carer and the individual with the TBI could avail of regardless of the length of time post-TBI. The aim of this exploration was to support the primary carer in broadening the level of support for the family unit within the community.

f) – 4 Service Providers

Finally the last of the case management roles to present findings on was surrounding the involvement of other service providers. These service providers consisted of state run services to accommodate the people within their locality. Within this area, there were three carers who became involved within this section. Within the case of the carer from the Long family, it was identified how the husband never received any rehabilitation in relation to his partial loss of vision. Within this capacity, the key worker made a referral and worked in partnership with the local service provider, the National Councils of the Blind of Ireland (NCBI) for the visually impaired. Assessments were completed and the necessary training was given to the husband and his family. The wife reported:

“My husband keeps bumping into things on his left- hand side. We were informed of his vision impairment by the hospital six years ago, but nobody gave us any guidance as to what or where to go for support”.

Ref: Veronica Long

In the case of the McCroon family, the same principle applied, the key worker made the referral to the service provider, assessments were completed and the necessary training was given. Within this case, the mother cited at the early hospital stage of her son’s recovery:

“We have been informed of my son’s vision loss. What happens when he leaves hospital? Where do we go to get help for him?”

Ref: Mary McCroon

Finally in relation to the last case study, the wife of Jack Timmons noted how her husband was involved in a state run sheltered workshop for people with mental health issues. The gentleman had been in such a service for over 22years whereby he attended 5 days a week on a full-time basis. Within this service he would complete piece work and receive a small pay

in relation to his work. In this case the role of the key worker was to contact the service provider and make links with the gentleman's key worker there. It is important to note how this link was made as the wife had noted how she felt that the service was not equipped for her husband's injury and were not fully providing a beneficial rehabilitative service for her husband. In this case the wife went onto cite:

"I am very grateful for the service and how it occupies my husband, however I feel that they don't understand my husband's injury as he is the only one there with a TBI and seem to be at a lost with how to handle him".

Ref: Molly Timmons

5. Advocating on behalf of the family

Finally the last key worker role reported on was the role of advocating on behalf of the family. Within the case of the key worker advocating on behalf of the family, the key worker worked with five out of the six carers on their behalf at different stages of the research. The only family the key worker did not advocate for was the Coyle family, as the mother noted how all was in order and that she did not have any identified needs for support as her niece was fulfilling that role. The mother reported:

"I don't need any help with advocating, I feel confident to advocate for my son and my family and then I have my niece to support me as well".

Ref: Maura Coyle

For the remaining five families: the Long, Timmons, McCroon, Carling and Sterling, the key worker advocated on their behalf. This involved advocating for referrals to professionals, hospital staff, HSE staff to other service providers deemed necessary within their identification of needs. However, at all times it was noted how the aim was to work in partnership with the family and to encourage empowerment as opposed to disempowerment or dependency. Therefore, as seen with the carers of the Long and McCroon families, the level of advocating reduced over time as the wife in the Long family and the mother in the McCroon family felt confident enough to fulfil the required action.

However in the cases of the Timmons, Carling and Sterling families the level of advocacy remained at a high level. As in the case of the Timmons family were the wife had cited:

“I have tried for 27years to get things to no avail and I don’t want and feel able to do anymore”.

Ref: Molly Timmons

In the case of the Carling family, the mother reported:

“There are just too many medical professionals and different services; I wouldn’t feel comfortable talking to them. I would rather if the key worker could do the talking and I would be listening”.

Ref: Kathy Carling

Finally in the case of the Sterling family, the wife reported:

“This is just so new to me. I am still very shaky over the whole situation. I don’t feel ready or strong enough to advocate for myself. I would like support on this area at least for a while”.

Ref: Claire Sterling

Findings from the Informal Exit Interview

To gain an overall understanding on how the role of the key worker supported each primary carer, the researcher conducted an informal interview at the cessation of the research. Within this interview, two questions were posed to the primary carers:

1. In what way did the role of the key worker support them in the community?
2. To what level was these needs met?

Please refer to Table 10 - The incorporation of Greco et al (2005) key worker roles into the research for statistical quantitative data of the findings.

Long Family Feedback:

Upon asking Veronica Long the first question as to what way did the role of the key worker support her in the community, the following was recorded:

Veronica advised that as result of the partnership with the key worker, 5 areas of need were identified:

- Education
- Emotional Support
- Identification of Needs
- Case Management
- Advocating on their behalf

In answering the second question surrounding her perception to the level of needs met, Veronica advised that she was very happy with the level of needs met. Veronica reported how the education and emotional support received was paramount in her understanding her husband's behaviour and difficulties. Veronica cited:

"I now have the knowledge and understanding of my husband's TBI that I never received. I feel stronger in myself in dealing with what the future may hold."

Ref: Veronica Long

The identification and addressing of each need empowered her due to the involvement within each action of the activity system. The case management and advocating on her behalf role of the key worker allowed her to be supported in the multiplicity of activities that was addressed. The combined overall support given by the key worker gave her the confidence to deal with barriers that occurred, for instance the S & L therapy service breakdown.

Veronica concluded with noting how without the involvement and support of the key worker within the research, she felt that none of the 5 identified needs would have being addressed, she would have remained without support, at a loss and disempowered. Veronica cited:

“I am so happy that I got the opportunity to be assigned a key worker. Without the role of the key worker, I don't know what I would have done. All of my needs were addressed and both myself and my husband have benefited greatly from the support of the key worker. I think all families should have the same support that I received”.

Ref: Veronica Long

Timmons Family Feedback:

Upon asking Molly Timmons the first question as to what way did the role of the key worker support her in the community Molly advised that as result of the partnership with the key worker, 4 areas of need were identified:

- Emotional Support
- Identification of needs
- Case Management
- Advocating on their behalf

In answering the second question surrounding her perception to the level of needs met, Molly reported that she was very happy with the level of needs met. Regarding the emotional support, Molly advised how it took her time to open up, but that she valued the support that was offered and noted the benefits of talking things out and being listened.

Molly cited:

“I know it took me a while to open up and allow the support to be taken on board. That is who I am. However, I appreciate the patience shown by the key worker and upon reflecting back over the past few months I know that I benefited a lot from being listened to.”.

Ref: Molly Timmons

Molly advised that with the identification of needs role, she found it to be very beneficial as she had being without supported for years with her family needs never being considered by anybody. The case management and advocating on her behalf supported her in still being involved in her husband's rehabilitation, whilst addressing her own self-care. The only area within the research that barriers occurred surrounded the implementation of the services

required by her husband. Her own identified needs were addressed and implemented accordingly. Molly advised that she understands that it was the shortfall of the HSE system that created the barriers, however she noted that without the assistance of the key worker, she would have given up and none of the needs were have being addressed. Molly cited:

“I found the support of the key worker to be great, which helped me identify and give back hope that myself and my husband needs would be addressed. I know the HSE has a long way to go to having a beneficial system, but through working with the key worker, it gave me the confidence and belief that activities could get done”.

Ref: Molly Timmons

Molly concluded with noting how without the support of the key worker she felt that nothing would have being achieved and she would have remained in isolation and alone.

The combined overall support given by the key worker was invaluable to myself and my family. The last few months of my husband’s life was a productive one with him receiving services and me getting my life back.

Ref: Molly Timmons

Coyle Family Feedback:

Upon asking Maura Coyle the first question as to what way did the role of the key worker support her in the community, the following was recorded:

Maura advised that as result of the partnership with the key worker, one area surrounding education was identified.

In answering the second question surrounding her perception to the level of needs met, Maura reported how through the assignment of a key worker, one unmet need of TBI Education was addressed and fulfilled. Maura noted how she was very happy with the level of education received and now felt able to better understand her son’s needs and capabilities. Maura cited:

“I know my niece who is a social worker helped my family greatly but I always lacked in education surrounding my son’s injury and TBI. Now that I have received the TBI education, I feel empowered

and more confident in supporting my son. I can also refer back to my notes should I need to do so later on.

Ref: Maura Coyle

Maura concluded with noting the importance of every family being assigned a key worker who could facilitate TBI Education in order to support families throughout the rehabilitative process. It was recorded that without the involvement and support of the key worker, Maura was doubtful that she would have ever obtained such valuable TBI Education.

Maura cited:

“After six years of trying to obtain TBI Education, I finally met that need. A lot makes sense now to me. I also know that if ever I need further information that I can contact you, within a key worker capacity. This support in itself is a very reassuring trait for me.”

Ref: Maura Coyle

McCroon Family Feedback:

Upon asking Mary McCroon the first question as to what way did the role of the key worker support her in the community, the following was recorded:

Mary advised that as result of the partnership with the key worker, 5 areas of need were identified:

- Education
- Emotional Support
- Identification of Needs
- Case Management
- Advocating on their behalf

In answering the second question surrounding her perception to the level of needs met, Mary advised that she found the level of support was paramount in her receiving all of the support needed. Mary reported how as a result of receiving the support of the key worker at the early stage of her son’s rehabilitation, she had the opportunity to receive TBI education which

aided her understanding of her son's rehabilitation when dealing with the multiplicity of team of professionals. Mary cited:

"Initially I was lost, I had never heard of a brain injury or even the word cognition. After receiving the education from my key worker I learnt a lot and more importantly I understood what was happening with my son. The literature I received also highlighted the need for me to look after myself during this process too, as you can quite easily lose yourself during this very traumatic time"

Ref: Mary McCroon

The identification and addressing of each need empowered Mary when working in partnership with the different professionals. Mary recorded how the key worker support had enabled her to feel on an equal footing within the activity system. The case management and advocating on her behalf role of the key worker supported Mary in dealing with the team of professionals' right through from the early acute stage in the hospital out into the community stage of the rehabilitative process. Mary also recorded how the identification of needs gave her the opportunity to address her own needs; something she feels she would never had done otherwise. Mary cited:

"There were so many needs to attend to; I didn't know where to start. My sole focus was on my son's needs. I got lost in the process and began to feel very overwhelmed. Through the support of the key worker my son received all of the support he needed. I also got the chance for somebody to listen and support me within the process. I even managed to sign up and attend to that course in the community I always wanted to do. It allowed me see that there was a light at the end of the tunnel".

Ref: Mary McCroon

Mary concluded with noting how as a result of the support of the key worker, support was offered right from the early stage of her son's rehabilitation in the hospital, through the discharge process and the out to the community. Her own needs were identified and met which gave her the strength and respite to keep going. Mary emphasised the importance of having the support of the key worker to assist them at a holistic level. Mary cited:

"I can't say how much I have gained from the support of the key worker. The role of the key worker is vital not just for the individual with the TBI, but that also of the family unit. My family are so appreciative of all of the support that was received.

Ref: Mary McCroon

Carling Family Feedback:

Upon asking Kathy Carling the first question as to what way did the role of the key worker support her in the community, the following was recorded:

Kathy advised that as result of the partnership with the key worker, 4 areas of need were identified:

- Emotional Support
- Identification of Needs
- Case Management
- Advocating on their behalf

In answering the second question surrounding her perception to the level of needs met, Kathy advised that she was very happy with the level of needs met. Kathy voiced how as a result of the support from the key worker her son, Danny finally got the services he required and was discharged from the hospital to a nearby community rehabilitative establishment. Kathy reported how the emotional support offered had empowered her in dealing with the multiple professionals that was encountered within the activity system. The identification of needs process conducted by the key worker was the first time that anybody had asked for her input and had listened to her.

Kathy cited:

“Finally I was being listened to and Danny’s needs were being addressed. It took over two years, but finally as a result of the key worker things began to get done”

Ref: Kathy Carling

The case management and advocating role of the key worker was found to be of high importance. Kathy reported that in addressing the identified needs, different professionals were sourced which would have being too stressful for her to deal with.

“There were so many different meetings and professionals involved in my son’s rehabilitation that I would have being lost without the support of the key worker. It was great knowing that she was there to support me all of the way”.

Ref: Kathy Carling

Kathy concluded with reporting how the support given by the key worker gave her the confidence to deal with the barriers that occurred, for instance within the sourcing of funding and the referral process in relation her son’s transfer from the hospital to a nursing home.

Kathy cited:

“I am so glad that I had the support of the key worker as my needs were identified and more importantly met. My son, Danny after two years was finally discharged to an appropriate nursing home and is now receiving a multi-disciplinary team of services. The key worker was invaluable in sourcing and dealing with the HSE system in relation to the funding for the nursing home for Danny. I feel that my family has gone through a tunnel and is now out of the other side”

Ref: Kathy Carling

Sterling Family Feedback:

Upon asking Claire Sterling the first question as to what way did the role of the key worker support her in the community, the following was recorded:

Claire advised that as result of the partnership with the key worker, 5 areas of need were identified:

- Education
- Emotional Support
- Identification of Needs
- Case Management
- Advocating on their behalf

In answering the second question surrounding her perception to the level of needs met, Claire advised that the support received through the key worker aided her family at the early stages of her husband’s rehabilitation early discharge. It was reported how through identifying the

need for TBI Education, information was given which aided the understanding of her husband Joe's behaviour.

Claire cited:

"Once my Joe was discharged, there was nothing. I didn't know where to go or who to turn to. I hadn't a clue of the effects of TBI and could not understand why my husband was behaving in a certain aggressive way. After working with the key worker on identifying needs, the need for TBI Education was identified and delivered. After receiving the training, both myself and my daughter feel better equipped to support my husband and we have a better understanding of the medical language previously used. I now feel more confident in speaking with the medical professionals as a result. "

Ref: Claire Sterling

Claire reported how as a result of the support of the key worker, she had somebody to seek guidance and support from. It was also reported how the key worker had supported the family at a holistic level, whereby the needs of Claire and her husband were established. Claire reported how the key worker had identified both of their needs which made her feel listened and valued too. Claire cited:

"I know my husband had a lot of needs and I really appreciated the support given by the key worker in identifying and addressing these needs. But I had needs too and the key worker supported me in acknowledging these needs. As a result of working with the key worker on my own needs, I feel more confident and know its ok to ask for help"

Re: Claire Sterling

The case management and advocating role of the key worker was reported to have supported the development of the activity system. Claire reported how the key worker had advocated for them in relation to making referrals for different services. Guidance was offered when barriers were experienced which enabled the activity system to progress.

Claire concluded with noting the importance of the role of the key worker, especially for families who have experience of a loved one with a TBI who are recently discharged from hospital. It was reported that without the support of the key worker at this early stage, Claire felt that no TBI Education would have been offered, no identification of needs processed and activity system generated which would have hindered her family unit. Claire cited:

“I can’t over emphasis the benefits of a key worker’s role for families who have a loved one with a TBI. My family would have been lost without the support of the key worker. No TBI Education would have been given, no needs identified and no activity system put in place not just for Joe but for myself too”.

Ref: Claire Sterling

Section 4.2 Multi-Disciplinary Team Reflection

Within the research, many different professionals became involved and assisted in the development of the action research for each case study. It is the intention now to present the findings in relation to those professionals who partook in the multi-disciplinary team. Personal comments from the professionals were not cited, as the professionals involved within each case management stressed how they did not wish to be cited in the research.

The section began with a table outlining the different categories of professionals that became involved in the multi-disciplinary team. Each group of professionals were presented noting the functionality within each of the six case studies. The researcher's own personal reflections on the collaborative process with each professional were then presented.

Table 12 below represents the multi-disciplinary teams consisting of hospital staff, HSE staff, social welfare and community PCTs utilised for each case study within the case management key worker's role of the research.

Table 12 – Multi-disciplinary teams

Case Studies	GP	Primary Care Team					Hospital Staff	HSE Disability Manager	Other
		PHN	OT	Physio	S & L	Social Worker/ Welfare Staff			
Long Family (CS1)	√	√			√			√	√
Timmons Family (CS2)	√	√	√	√	√	√	√		√
Coyle Family (CS3)	√								
McCroon Family (CS4)	√	√	√	√			√	√	√
Carling Family (CS5)	√	√					√	√	√
Sterling Family (CS6)	√	√		√					√

To gain a greater insight into the involvement process and findings resulting from the professionals within the research, individual professional categories will now be presented.

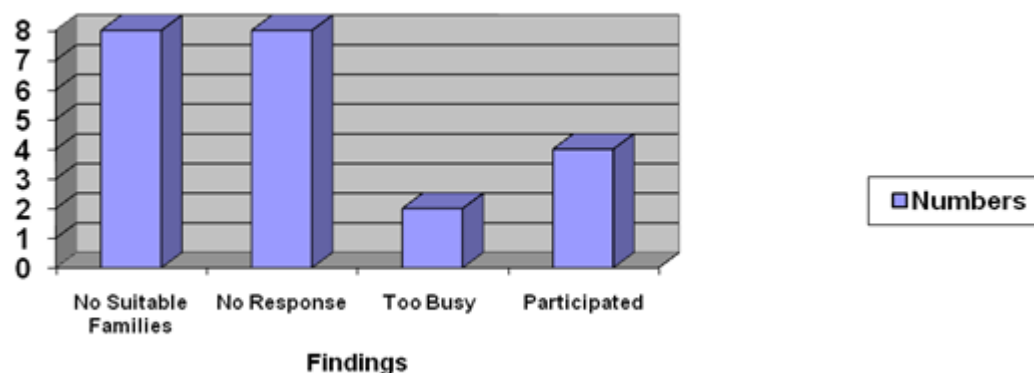
GPs

After issuing an invitation to participate within the research to twenty-two doctors over a three-month period, four doctors took up the offer. The first doctor nominated two families (Timmons and Coyle), the second doctor nominated the Sterling family, and the third doctor nominated the Long family. Finally, the fourth doctor nominated the McCroon and the Carling families.

In relation to those doctors who did not take up the invite to participate in the research, which was 18 doctors, the following was the general feedback:

Eight doctors advised that they had no suitable families within their surgery. Eight doctors gave no response after several attempts to communicate with them. Two doctors noted that they were just too busy to participate in the research. Findings are presented below in Figure 18.

Figure 18 - Doctors invited to take part in research



Researcher's Personal Reflection

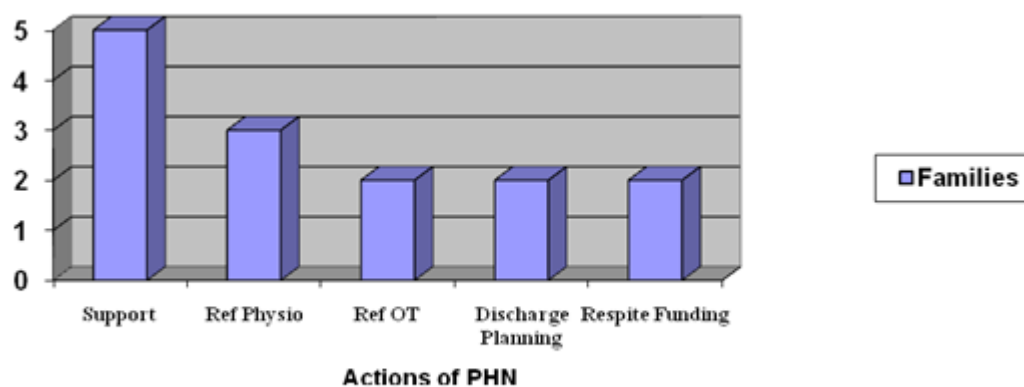
In the current financial climate, GPs and their clinics may struggle to fulfil their mandate in the face of shrinking resources. A survey conducted in 2013 by the National Association of General Practitioners (NAGP) of 72 practices found as many as 8pc of the GPs reported on the prospect of having to give up treating medical card holders because it was not financially viable after the latest cut back in fees €160m. Therefore, even though GPs are sensitive to community health and professional practice, some GPs and their clinical managers may view resources, budget constraints and timelines as vital concerns when invited to participate within research. Restrictions on their time or availability may be greater than a researcher. To accommodate and facilitate such complexities surrounding time, GPs were invited to participate at their discretion. When considering a clinic of GPs, the researcher asked them to nominate a GP within the surgery who could facilitate the time required to participate in the research. However, the indeterminate time demands of many action research projects made it difficult for the GPs and their clinics to assign a practitioner and justify the allocation of a valuable resource within the clinic. This consideration of time demands is seen within the statistic whereby two GP surgeries said “they are just too busy to participate”.

In relation to the research findings, the level of involvement of the four GPs who participated varied. Some GPs were more actively involved and hands-on within the case management process, whilst some GPs would sporadically participate within the research. Within the research, collective collaboration was evident within the Carling and McCroon cases whereby the same doctor applied. This GP was based in the same building as the PCT and met with them on a regular basis.

Public Health Nurses (PHNs)

The PHN works from local Health Centres. The role of the PHN is to provide a range of services free of charge to people within the community, for instance care on discharge from the hospital. The PHNs were the initial point of contact for the key worker for five out of the six carers who participated within the research, acting as the central referral point for the community team. Within the activity system of the participating case study families, the needs for referrals to community PCT services were identified as actions. To address this action, the activity of contacting the local PHN was initiated. Figure 19, represents the involvement and actions of the PHNs derived from the case study activity systems within the research.

Figure 19 - Involvement of PHNs



Researcher's Personal Reflection

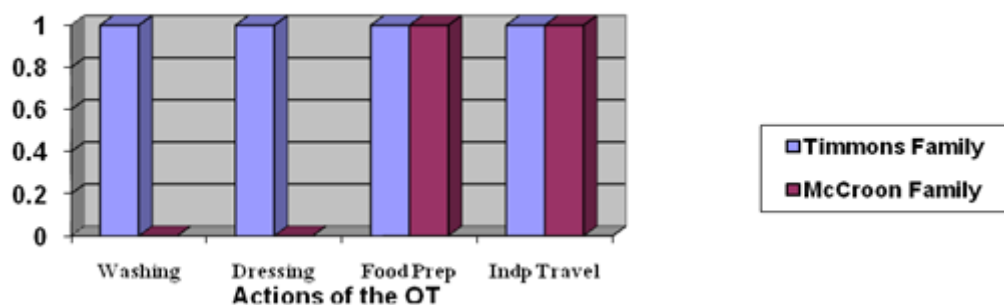
For each of the five PHNs contacted within the research, none of them were aware of the families in question prior to the key worker contacting them. This response to the action reflected how there was no follow-on notification of the families' details following discharge from hospital. The lack of transfer and flow of communication not only caused stress and strain to the families but to the PHNs. During the research, PHNs reported how they would have liked to support the families from the beginning and not just from when they were introduced by the key worker.

The PHNs reported how they found working within a multi-disciplinary team very rewarding both for them and their families as such practice promoted a form of shared learning and delegation of actions across the board. Each PHN was extremely helpful and very family focussed. In many cases they went out of their way to try and assist the family in their needs. This was especially seen in the Carling and McCroon cases whereby both PHNs were very co-operative and assisted in the referral for services. Also in the case of the Carling family, the PHN ensured time was allocated in her roster to attend and participate in the discharge planning meeting that took place in the hospital for Danny.

Community Occupational Therapists

Two families' actions surrounded the referral through the PHNs to the Community Occupational Therapist as seen in case studies 2 and 4. Figure 20 presents the involvement of the Community OTs within the research.

Figure 20 - Involvement of Occupational Therapists



Researcher's Personal Reflection

In relation to the activity of receiving an OT service for the Timmons family, both the key worker and the family found it very hard to accept the service being denied. In addressing this refusal, an action was made to present an argument to the OT services demonstrating how the gentleman in question had made progress whilst working with the key worker. The main argument given for the OT service being denied was a lack of staffing levels within the

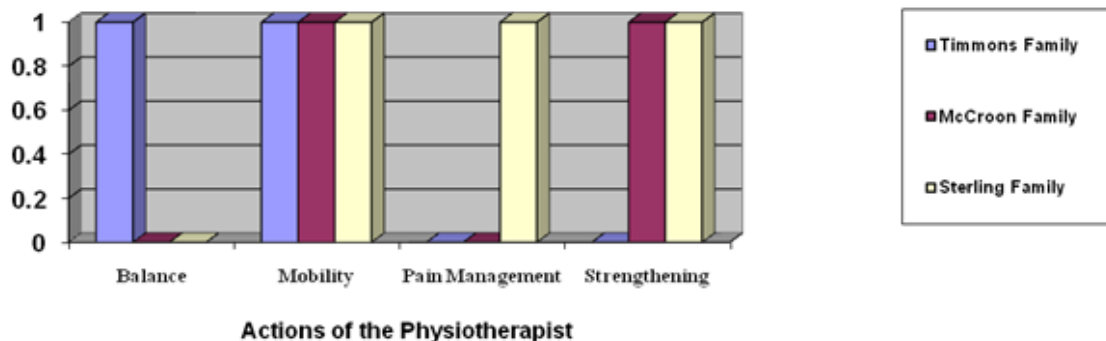
community. The action of receiving OT service then progressed onto the next activity, which was to submit an appeal was but unfortunately before the appeal was processed the gentleman in question passed away.

The key worker also processed a referral for OT services for the McCroon family. The application was successful and the OT met John on four occasions in the family home.

Community Physiotherapists

Findings for the Community Physiotherapist profession relates to three families; the Timmons, McCroon and the Sterling families. Each family desired access to a Physiotherapist and was referred through the PHN. Figure 21 below presents the involvement of the Community Physiotherapists within the research.

Figure 21 - Involvement of Physiotherapists



Researcher's Personal Reflection

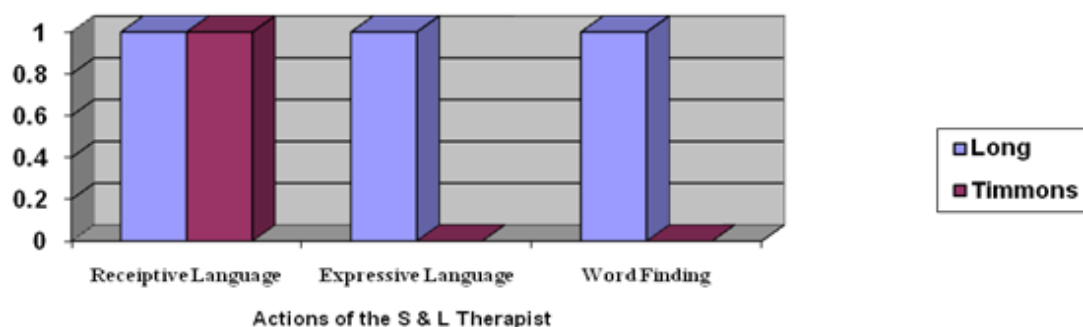
Referrals for two Community Physiotherapists' were conducted. The Physiotherapist for John McCroon was successful and collaborative in the approach towards working in partnership with the family and the key worker. However, the referral for Jack Timmons for Community Physiotherapy was denied due to issues surrounding a lack of staffing and time management. With regard to the key worker engaging with a private Physiotherapist for Joe Sterling, the

Physiotherapist did not wish to collaborate. Consideration was given to the limited involvement of the private Physiotherapy sector within the research. Further research would need to be explored before any validation could be forthcoming.

Community Speech and Language Therapists

The Long and Timmons case study families highlighted the need for S & L therapy for their loved one. The initial action was for the key worker to submit referrals for Mike Long and Jack Timmons. Figure 22 below represents the involvement of the Community S & L therapists within the research.

Figure 22 - Involvement of Speech and Language Therapists



Researcher's Personal Reflection

The S & L therapist for the Timmons family was not willing to cooperate with other agents. Communication flow from the S & L therapist was scarce and often took many calls to gain some form of feedback. A shortage of staff continued to be a problem causing delays in providing the service to the family. The referral process itself differed from other PCTs, as each sector appeared to work independently and not collectively. This was evident in relation to the different forms the Timmons family was required to complete for each department.

In maintaining the development of the activity system for the Long family surrounding the action of S & L, barriers leading to delays became evident within the process. To address these barriers, it was agreed that the next action was to invite the assistance of the DM. This assistance resulted in the service being offered. However, when the service was in place, a breakdown in the working alliance with the S & L therapist occurred and caused strain on the family. The sessions ceased after eight weeks and unfortunately have yet to be reinstated.

Community Social Workers

Within the Timmons family's activity system, the need for a Social Worker was identified. The action cycle began with a referral for the assignment of a Social Worker. Below, Figure 23 represents the involvement of the Community Social Worker within the research and the proposed involved actions.

Figure 23 - Involvement of Social Workers



Researcher's Personal Reflection

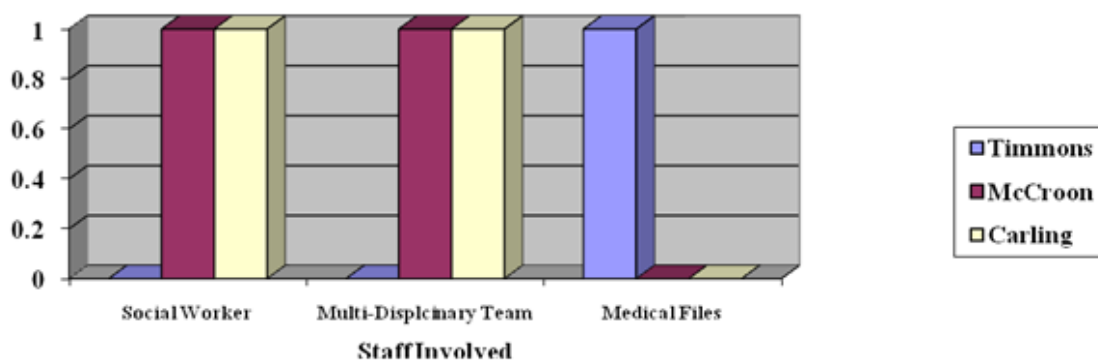
Within the National Overview of Social Workers in Mental Health Services Ireland (2012), [Accessed March 20th 2015], Social Workers reported how a lack of resources was a major problem, referring to insufficient staffing on multidisciplinary teams, increased demands on services and reduced training opportunities. These difficulties became evident within the

research, as neither of the two referrals made for a Social Worker within the research were successful. During the research the key worker was advised by one Social Worker of how due to low staffing levels they were only able to offer a service to either children or individuals over 65 years of age. However, the Social Worker went onto highlight how the HSE intends to address this area.

Hospital Staff

Within this area, four hospitals and their staff became involved in the case management of the families. One hospital supported the early acute stage for the McCroon family. Another hospital was providing long term care for the Carling family. The third hospital became involved with the transition for John McCroon to a specialised rehabilitative setting. The last hospital obtained records of the husband's in-patient stay for Jack Timmons. The graph below presents a visual format of the activities surrounding the involvement of hospital staff within the research.

Figure 24 - Involvement of Hospital Staff



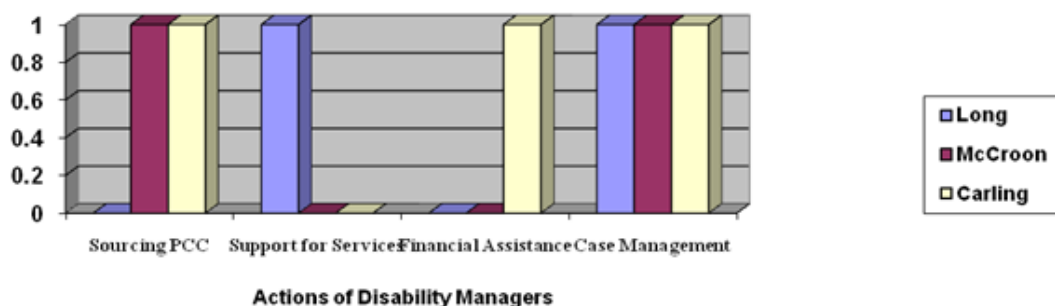
Researcher's Personal Reflection

With the early acute hospitals, one hospital was very supportive of working in collaboration and transdisciplinary learning occurred. There was an atmosphere of openness to working with external agents for the benefit of the individual and their family. In contrast, the second hospital appeared to be more closed off to working with external agents. However, after an initial introductory easing in period the staff became more sympathetic to working in co-operation with the family and the key worker. Consideration was given to how a certain amount of trust may need to have occurred before the staff felt comfortable with working in partnership. Finally, the last hospital was very supportive in providing copies of medical files for Headway in relation to a referral made by the key worker for a rehabilitative service. Consent was sought and granted by the family before the request was made to the hospital. In general, working in collaboration with hospital staff was found to be very rewarding and beneficial. When true collaboration occurred, the benefits were great for the family and the individual with the TBI. The researcher acknowledged that for a true collaborative practice to occur, time needs to be given to all parties to support the development of trust by all.

Disability Managers

Three DMs were invited to participate in the research to support case management actions for the Long, McCroon and Carling families. Different DMs were required due to each family residing in different catchment's areas. Figure 25 below presents findings on the involvement and actions of the HSE DMs.

Figure 25 - Involvement of Disability Managers



Researcher's Personal Reflection

Three family case studies action plans required the involvement of the DM in order to support the development of certain PCT services. The object of receiving certain services was identified and the action of referrals sought. However, difficulties occurred in receiving these services so after reviewing the activity system, action seeking the assistance of the DMs was warranted. Each of the families referred for the support of the DM varied in length post TBI, from six years to three months. During this process, the key worker found the DM's to be very co-operative and supportive towards attending to the family needs. It was also hoped that through working with the DM's, the partnership would promote awareness and familiarity of the family which would support the continuum of care following cessation of the research. Upon contacting the DM's, the key worker found that none of the DMs was aware of the families within their catchments area or of their situations. To explore this service further, additional research would be required on a wider scale, to include the input of DMs within the multidisciplinary team process of discharge planning.

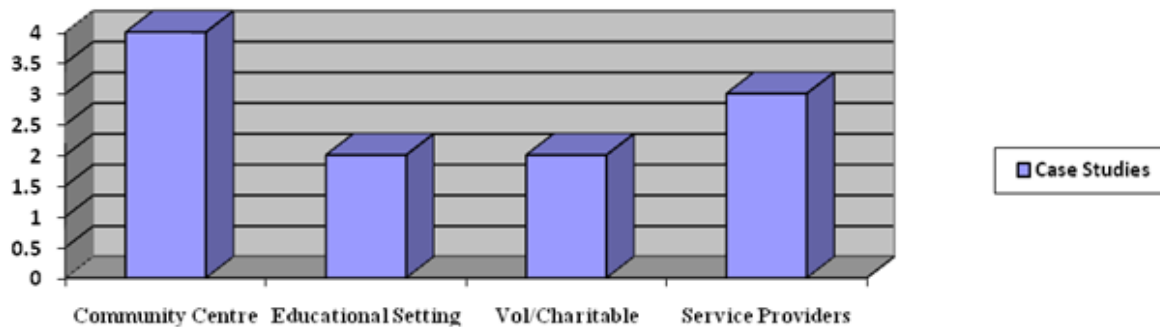
Other

Individuals within community centres, educational settings, and voluntary/charitable organisations to local service providers also participated within the research. Five out of the six carers received some form of support within this "other" section within the community.

Two family primary carers, Veronica Long and Mary McCroon availed of community education courses which acted as a form of respite and community integration activities within their activity plan. One individual with the TBI, Joe Sterling explored the possibility of community educational courses. For the service providers section, three case studies (Long, Timmons and McCroon) were advised and referred by the key worker to TBI rehabilitation service providers for further ongoing support. In relation to the local community centres, four family case studies, Long, Timmons, McCroon and the Sterling families were referred to local area partnerships for exploration into activities that the family could get involved in to facilitate respite and integration.

Below, Figure 26 presents the above statistical records of the involvement of different areas within the community.

Figure 26 – Other Involvement



Researcher's Personal Reflections

Initially, some of the community members questioned their involvement in the research. Queries surrounded in what capacity were they being invited on to the research, for instance within a professional or personal capacity. To address this query, each community member was invited to participate within a professional capacity. However, through such professional involvement it is worth noting how the findings only relate to the services involved and do not represent the broader geographic community. To address the possibility of the community involvement setting up an insider-outsider status, the key worker adopted the role of the community resident researcher as the research took part within her local community.

Overall, the involvement of other non-medical services within the local community was found to be very welcoming and supportive of the research. Each service was open to working collaboratively to best serve their local population in whatever way they could.

Overall Personal Reflection on frontline practitioners

When reflecting on the initiation of the action research, the researcher experienced two dilemmas; the first concerned how to enter the community and secondly deciding on the inlet. The researcher decided to approach GPs within her area. This approach was adopted as it was the intention that through the partnership with the GP, the integration into the community would be better supported. Through such form of sponsorship the researcher found different levels of entry and involvement with the community. Some GPs were more involved within the community, participating more with the services provided by the front line practitioners whilst others were more on the sidelines. Variances in participation impacted on the level of entry into the community as those who were more integrated, supported and assisted the entry and collaborative process more. This was evident with the GP for the McCroon and Carling family. The GP became very involved in the research and was an active member of the PCT. Such involvement assisted in the development and implementation of the activity plans for each of the families surrounding referrals for services.

The second dilemma surrounded the protracted time involved in the process of building community connections. Time was paramount to the successful collaboration and implementation of the research as without such building of a network, suitable designated actions could not have taken place for the case studies. As each case study began to develop, the time taken to explore community connections grew and drew on a lot of time. Different connections and networks were required for each family due to their own unique needs. The researcher found that in order to support her time management within the research, she was required to become flexible in her approach towards organising times outside of the normal working hours for meetings and follow-up calls with practitioners.

Section 4.3 Activity Theory Framework

The research explored Activity Theory through the understanding that learning occurs from completing an activity. Such activity cannot be understood or analysed outside of the context in which it occurred. In the case of the research, the activity took place within the community. Therefore, when analysing the findings of the research, the human activity was analysed not only through the activity itself but also through analysing the human involvement within such activity. This involved reflecting on the participant's personal goals, intentions, objects or products that resulted in such activity, to the rules and norms that circumscribe each activity within the community.

The analysis began with presenting the components of the activity system in relation to the research, as proposed by Engestrom (1987). The intention was to enhance the practical understanding of how the Activity Theory framework was utilised within the research. Each component within the activity system, namely the subject, object, community, rules and division of labour was presented. Underlining assumptions of Activity Theory within the research were analysed to relate the role each played within the research. The analysis concluded with focussing on the activity system dynamics within the research, identifying and describing how each component affected each other.

Activity system

When exploring the Activity Theory first, the components of each activity were organised into the model proposed by Engestrom (1987). With the top half of the pyramid indicating the production status of an object in which the activity was accomplished.

Such production level involved:

- **Subject** – This referred to the individual or the group engaged in the activity. Within the case of the research, the subjects were the participants, for instance: the key worker, the PCT to the family members themselves.
- **Object** – The object of the activity referred to the physical or mental product sought. The object was driven by what motivated the participant's needs. In the case of the research, the object was mainly driven by the family. The family's motivation was the human need to achieve supportive services for them and their loved one.
- **Tools used** – They are anything used in the transformation process. Within the research, tools ranged from the skills of the professionals, the knowledge of the family, answering of questions surrounding pre- and post-history, computers for recording of data purposes to the development of flow charts to aid the understanding of the transition process.
- **Community** – consisted of interdependent aggregate, for instance within the research, GPs, medical professionals, PCT, community services all of whom shared to some degree a set of social meaning.
- **Rules** – inherently guide, at least to some degree, the actions or activities acceptable by the community. Therefore the signs, symbols, tools, models and methods were used to mediate the process. Within the research an example of such rules surrounded the professional code of conduct, the rules and behaviour surrounding the HSE, for instance; medical versus social paradigm differences.
- The **division of labour** prescribes the task specialisation by the individual members of the group within the community. Within the research the division of labour surrounded medical professionals, community officers, to the key worker role. Each brought their own specialisation to the activity.

When incorporating the Activity Theory into the analysis of the activities and setting of the research, findings commenced with clarifying the purpose of the activity system. This was achieved through posing questions:

- 1) What are the participant's goals and motives?
- 2) What are their expectations about the outcome?

The purpose of this step was twofold (a) to gain a greater understanding of the context in which activities occurred and (b) to reach a thorough, understanding of the motivations for the activity being modelled and any interpretations of perceived contradictions.

The next step involved defining the depth of the components of the given activity, namely the subject, object, community, rules and division of labour. This was required to understand and identify the subject who will be the driving force of the activity system, and the object and how it will fulfil the goals or intentions of the activity system. It was identified that the subject was the key worker/family who were confronted with the dilemma. The object was the resolution of the dilemma. The community (residing area of the family) determined the dilemma context and the division of labour (predominately the PCT) determined with whom the individual must interact while manipulating the problem.

In developing the utilisation of Activity Theory within the research, a key process to analysing the activity structure was the acknowledgement to how activities consist of individuals and co-operative actions and chains of operations. Followed with an acknowledgement of how such hierarchy of activity, actions, and operations describes the activity structure. In addressing this acknowledgement, the researcher presented findings on the description and process adopted within the activity structure.

The top level of the activity system was the intentional level due to its focus on the intentions or motives as emphasised by Linnard (1995). This level focussed on the conscious needs, values, and desires of the members to its driving force for instance: the motivation and desire in providing a beneficial service. Without this desire and motivation, the activity system would not have progressed at all. The next action level as noted by Linnard (1995) was the functional level was the planning and problem solving of actions took place. Within the

research, such planning and problem solving was evident within the needs assessment process with the family, to planning towards the prediction of demands from different services/professionals for each case study. The outcome at this stage of the activity analysis promoted clarity and understanding by enabling the researcher to be descriptive of the activities, actions and operations evolving from the needs of the family.

The next step was to elaborate on the relationship with the underlining assumptions of Activity Theory surrounding the research. To do this, the researcher commenced with exploring the first assumption, minds in context

Minds in Context

Within this section, the researcher focussed on the concept proposed by Kaptelinin (1996) of how the most fundamental assumption of Activity Theory was the unity of consciousness and activity. To review this assumption the researcher considered activities which involved interactions between participants and the conscious activities that formed part of such interactions. Findings from the research on the belief surrounding an activity as a precursor to learning, varied amongst participants. Some professionals adopted a social paradigm of how learning occurs through fulfilling an activity. This was reflected in many of the collaborative processes adopted within the case studies, for instance the GP's wiliness to participate collaboratively within the multi-disciplinary team for the McCroon and Carling families in designing the activities. However, difficulties can occur if participants object to this belief. One example recorded within the research was in relation to the S & L therapist for the Long family. Within this case, the S & L therapist worked independently with Mike and did not wish to collaborate with the wife and other members of the team.

When commencing the analysis the researcher began with seeking information to describe "how things got done in context". The researcher acknowledged how different contexts impose distinctively different practices. Some of the areas of exploration were as follows:

- The social relations and division of labour required to be represented in the problem context? Within the research the division of labour involved agreed members of the family unit, medical professionals to on occasion, external agency's of various services,

for instance: community colleges, within the community. These features made the environment structured and complex due to the cross division amongst the HSE and the community sector. It also promoted more relevance and meaning for the families as the relations and division of labour was nominated and designed to cater towards their activity plan.

- Through analysing the activity in context and identifying how some contextual elements were related to alternative cases, it provided assistance with the families when accessing services. Within the research, one analysis surrounded the activity of rehabilitation in context within the community. Different services and divisions of labour were identified. As a result, families gained assistance through understanding the activity in context when accessing services within the HSE system and the PCT services.
- The tools and mediators used by professionals were considered. This was required, as often accessing cases or moving between cases or problems was often based on similarity of contextual elements. Within the research, one tool utilised by members of the PCT was the referral form. During the research, the key worker found that separate referral forms were required to be completed for each department within a PCT, for instance: Physiotherapy and S & L. This resulted in multiple similar information forms about the family being created.
- Finally, the kinds of conversation and collaboration tools that were required to support the activity structure were explored. Some of the questions posed here were:
 - What kinds of interactions were the managers allowed with other professionals, both internally and externally?
 - How did they normally communicate with each of these people?
 - What were the communication protocols?

Outcome

The outcomes of these actions were a description and understanding of the problem context, which supported the implementation of the activity structure out into the community. The above actions also supported the community of participants' needs being identified along with considerations surrounding capabilities, restrictions, actions, privileges, and so on. Those attributes formed the basis for connecting the participants and their relationships within the community.

Consciousness in the World

Consciousness within the Activity Theory notes an activity is comprised of people and artefacts and how there is a need to analyse the activities and the performers in totality. As consciousness is embedded within the wider activity system of the participant's activities, any changes in the physical, mental or social conditions of that person's situation can be internalised and can directly reflect in their consciousness activities.

When reflecting on the research, such impact was recorded on several occasions:

- Surrounding the impact on professionals, changes were seen in their conscious activity when there was a staff shortage or more work was placed on them. The professional's level of attention, memory and indeed reasoning was affected.
- In relation to the families, there was a clear change when things began to move within each case study's management. The family member's consciousness in relation to attention and intention was affected when results were gained. However, in contrast this changed when things were either halted by some obstructive force, for example the HSE structure or things were denied. Other obstructions surrounded financial concerns to medical needs and the stress and strain placed on the family. This caused the family to occasionally back away and their level of motivation and intention towards the activity decreased.

Intentionality

Another consideration surrounded the intentionality assumption. When exploring intentionality, Activity Theory notes how the initial purpose focuses on the determined actions that materialise through the conscious intentions. People interact within their environment and learn about the world through such interactions in order to achieve a goal. However, before intentions can be manifested into actions planning needs to take place.

When relating such intentionality into the findings of the research, the goal was to achieve a more supportive service for families who have experience of a loved one with a TBI within the community. The measurement of this goal was obtained through feedback from the primary carers and the outcomes of each case study activity system. Within the research each primary carer noted the benefits of participating in the research and working collaboratively within the activity system. Findings on this were recorded within the key worker and family needs section. Each of the identified objects within the activity systems were implemented and acted upon. However it was noted how some identified objects were met with barriers, for instance the lack of staff within the PCTs. To address these barriers, the activity system reevaluated the action and adjusted accordingly.

To address the intentionality of the research, the researcher considered BSRM National Clinical Guidelines (BSRM, 2003) of TBI best practice. Planning took place initially with the family to identify the desired goal, and assist with the development of the activity system. The planning progressed with the identified participants and the complete process commenced again. It was through such interactions with the participants that the learning took place and the activity system developed. In accordance with the Activity Theory, intentions emerged from contradictions that became apparent amongst the team towards what they believed they knew to what was actually known. This was evident when initially an activity system was designed amongst each team but altered as the process developed due to exposure of the difference in what was thought to be known to what was actually known.

Findings reflected how some members were more open to identifying and acknowledging variances in their perceptions of what they thought they knew to what they actually knew. Differences occurred within different PCTs whereby some were more open to addressing the

contradictions then others. In relation to those who were not open to exploring such contradictions, barriers were created towards the intentionality of the complete Activity Theory process. Some participants became fixed on their own perceptions and would not alter, therefore their intentions became personal, as if to try and prove a point that they were right. This perception was evident within the Long family in relation to availing of the S & L therapy services. Within this action, the therapist was not open to promoting the involvement of the wife within the design of the services offered.

Object-Orientedness

Activity Theory claims how learning and doing are inseparable and are initiated through intention. When considering the source of the research intention, it evolved from the need of families to gain support within the community. This source of intention fuelled and motivated each object within the activity system.

In relation to the research, the object-orientedness was on providing a supportive structure for families in the community. This object, coupled with the human intention and level of consciousness drove the design and implementation of the activity system by all participants for each case study. When considering this relationship towards the findings of the research, such level of human intention and level of consciousness varied amongst different case studies and their participants. Some participants housed a greater object focus than others which resulted in a more committed focus and drive on the activity system. This was seen within the variances within different PCTs. The PCT involved with the McCroon and Carling family portrayed a strong motivation towards focussing on the object of supporting the family, which resulted in a progressive activity system. Even though barriers existed, the team worked collectively towards promoting the progression of each action.

Community: A Dialectic Context

As noted above, activities are socially and contextually intertwined. Therefore, when analysing and describing an activity system within the research, the researcher noted how such analysis could only be completed in the context of the community in which it occurred.

With regard to the research, the community, and the participants within each case study negotiated and mediated the rules towards the supporting of each different activity. Each specialised profession keep their own records of their designated activities within the case study activity system, for instance the Physiotherapist for the physiotherapy needs to the OT for the occupational needs of the individual and the family. Such assignment of the activity between each participant defined the division of labour which was mediated by the rules and social negotiation. Dialectic varied amongst the different sectors; however, when possible the use of non-medical language was promoted amongst the team to encourage the act of transdisciplinary learning and understanding amongst all.

Another important finding surrounding dialectic context, was the recognition that all participants were simultaneous members of various communities, for instance, the community in which we live, the community we create, to the professional community in which we work. As a result of such facets, each individual was required to continuously alter their own beliefs in order to adjust to the socially mediated expectations of the case management team. However, findings reflected how conflicts did occur between different roles which lead to transformational activities being required in order to harmonise such contracting expectations. This was seen in the different expectations between medical professionals and the families. Some professionals presented with a belief that certain activities was not within their remit or fell outside of their catchments workload area. Different responses occurred as a result of this. For some case studies, transformational activities were taken up whereby professionals either took on the activity or alternatively advised of a different route to take and aided in the process. This was seen within the referral process for the PCT who worked with the McCroon and Carling family. Within this process it was identified how the HSE policy originally required for the forms to be completed by the family without assistance. After discussions took place surrounding the need for assistance, the action was taken by some professionals to support the family in the completion of the forms.

Historical-Cultural Dimension

When we consider this assumption of Activity Theory, we need to consider how activities are historically developed phenomenon. This means that activities are developed and evolve over

a period of time within our culture. There is a need to understand the dynamics of a particular situation and understand the changes or evolutions that may occur over time.

Findings on this assumption noted how each catchments area differed. At the time of the research, some catchments areas were going through development and change. This change evolved from a regeneration project that was occurring within one area and the development of the PCT structure within the community surrounding the Long, Carling and McCroon families. Within these developing areas, the key worker found the professionals were more actively involved within the community. It was also identified how participants were more open to a cultural change and adopted more of a holistic view of offering support.

However, when the key worker worked with areas that did not have an established PCT, nor had an established community network, collaboration and perceptions differed. It was found within the Timmons, Coyle and Sterling families' community that professionals presented with a very objective, strict structure and were not open to transformative learning, collaboration or change.

Tool Mediation

When considering the tool mediation within the components of the activity system (subject, community and object), it was acknowledged how such tools did not act directly on each other, but impacted through the interactions mediated by signs and tools. These signs and tools provided the direct and indirect communication between the objects within the activity system of the research. Within the research, one such artefact utilised was a referral form from specific PCT services. Some professionals altered the procedure after the initial action of requesting the service was placed and the need for assistance was identified. They adopted the action of spending time with the family, assisting and explaining the referral process in depth. Alternatively, other professionals remained within the HSE guidelines and posted out the form without offering assistance thereafter. Upon reflecting on the professional's feedback regarding the referral process, the researcher acknowledged the staff shortages. Professionals reported due to low staffing levels, existing staff had not got the time to offer this support. This area was evident within the Timmons activity system whereby it was

recorded that staffing levels were low and could not support one to one support for the family.

Another common form of tool utilised by many service providers was the computer system. Within the research, the incorporation of information technology was used to serve as a tool in manipulating and transforming actions which were directed by the object. An example within the research was the use of the flow through model. This tool was used to act as a visual progression route chart for the families and professionals.

Collaboration

The last assumption of Activity Theory surrounded collaboration. The research adopted an approach that any meaningful activity would be achieved individually but would be accomplished collectively. When reporting on the findings of the research, it was seen how individuals who became involved in a particular activity, simultaneously became members of other activity groups with different objects, tools and social relations. This was seen in relation to how, for instance, Community Physiotherapists were initially involved in their own activity of providing physiotherapy for the individual. However as a result of the collaboration amongst each case management team, different individuals automatically became involved in the case management group. Within the research, each case study activity system involved multiple professionals, ranging from members of the PCT to service providers within the community. When exploring the collaboration across different activity groups, case studies surrounding the McCroon and the Carling families who had the same GP and utilised similar groups were more open to working in partnership and supported transformational learning. As a result of such collaboration, the activity system flowed more fluidly and there appeared to be less strain amongst the team as support and a shared object were evident. However, when participants within a team worked in isolation and not collaboratively as presented in the Long, Timmons and Sterling activity groups, activities became sporadic and less fluid and there appeared to be strain evident amongst the team.

Final stage reflection

The final stage of the analysis focussed on the researcher taking a step back from the system to describe and assess how components affected each other. To complete this stage of the analysis, the researcher reviewed the implementation process of Activity Theory in relation to the research by ensuring that:

1. The object, (the action being sought) promoted motivation amongst the subjects. This can be seen in the object-orientedness assumption of Activity Theory.
2. The research promoted the concept that knowledge was learnt through completing actions and not before. This practice supported the collaborative and transformational learning process of all participants.
3. When considering analysing context, the researcher obtained a clear understanding of the background information on various different processes, for instance: the referral process for services within the HSE. This information supported the development of the activity system and strengthened understanding of the desired activity.
4. When considering the consciousness in the world, the researcher analysed the people and the activity together, not separately. This enabled a more holistic and in-depth understanding of the possible impact of the activity for all concerned.
5. To support the assumption of intentionality, participants were required to have a conscious intention of attending to the activity system for each case study within a collaborative manner to support the flow of the activity structure itself.
6. There was also a need to understand how individuals within the team were also members of other groups. This is seen within the dialectic context assumption of Activity Theory. Such understanding was required to enable each member to appreciate and support each other within the activity.
7. Participants were required to be open to change and acknowledge how activities could be completed differently. This is seen within the historical/cultural dimension assumption of Activity Theory whereby a resistance to change disrupted the flow of the activity system.
8. There was a need for participants to be open to explore and consider possible impacts of tools utilised when attending to actions. This was required to promote better communication and understanding between the object and the desired action.

9. Within the practice of collaboration, the researcher felt how individuals could achieve certain goals, but collectively greater actions could be achieved in partnership. Through the analysis, the researcher found that when one member of the group refused to work in collaboration; it had a ripple effect amongst the team blocking the development of the Activity Theory system, and possibly isolating that individual from the rest of the team.

CHAPTER FIVE – DISCUSSION

Section 5.0 Research Limitations

Although the research was carefully prepared, the researcher is aware of its limitations and shortcomings. For the purpose of the thesis, limitations are categorised into six headings.

Limitations of the Referrals Process:

First of all, the research was conducted utilising a small group of referral agents, solely from one group of professions, the GP.

- **General Practitioners**

In addressing the limitation of GP referrals, the researcher would suggest inviting a larger population of GPs from outside of the five mile radius of where the researcher lived. The research could initially focus on inviting GPs to make referrals and participate in the research from the Dublin urban area, followed by a national ran study.

- **Hospitals**

The researcher would also suggest going forward for the research to look at inviting referrals to be made from hospitals, initially within Dublin (where there are two main Neurological/ Rehabilitative units based) followed by a national research. This form of referrals from the hospital would support the BSRM National Clinical Guidelines of best practice and the “Slinky Model” of rehabilitation through the continuum of care.

- **Community Referrals**

Finally, to widen the referral process to include possible community service providers, for instance Headway or ABI Ireland to nominate case studies and become involved within the research process. This form of collaboration supports the BSRM National Clinical Guidelines of best practice by promoting the continuum of care out into the community amongst all stakeholders.

PCC

When considering the limitations of the action research methodology, Heller (1976) raises concerns surrounding the risk of lack of generalisability, sometimes called external validity. Within the research, only three PCCs were involved in the study. In addressing this limitation, the researcher would recommend as supported by Hamilton (1981) for the research findings and practices be tried out amongst a wider network of PCC, initially in Urban Dublin, and then on a national scale. The methodology of the research could be utilised as a pilot project towards exploring and developing the Primary Health Care System within Ireland in addressing the needs of the population within the community.

Sample Size & Location

The researcher acknowledged the small scale sample size of the research, consisting of six case studies. The case study families resided within a 5 mile radius of where the researcher lived. A limitation of the research surrounds the small scale study and the small catchment area. Going forward, the research would need to be more wide spread outside of the 5 mile radius to promote a more logistical collection of data and include a larger population of families. This would aim to expand on the research findings towards creating national figures on the needs of families in Ireland.

Gender Imbalance

- The six case studies within the research were all male. This was not by choice, but as a result of the referral process. Therefore, a limitation of the research could surround the need for a more equal gender base to be sought going forward to consider, how, if applicable gender could impact on findings.
- The six case studies consisted of 4 spouses (wives) and two mothers. Therefore, another limitation of the research surrounds the need to explore the impact of TBI not

just on wives or mothers but also on husbands and fathers of those who have experience of a loved one with a TBI.

Duration of Research

- The research ran for approximately six months only. The researcher feels going forward; the need for research to be conducted over a longer period of time to promote a longer continuum of care of collection of needs.
- Another limitation of the research was the key worker's lack of flexibility surrounding the allocation of time to the research during the working day. Going forward, the researcher should have the opportunity to be flexible in their time management and be supported in allocating sufficient time to families during day time.

Reliance on the Views of the Researcher

Finally, another limitation lies not with the source but with the researcher, in that the interpretation may be from the point of view of the researcher. Within the research, the researcher took on the role of the key worker which formed the basis for the research. The researcher acknowledges the reliance placed on her views in gathering and interpreting evidence and how her professional involvement (Kanuha, 2000) within the area of rehabilitation may have compromised (Serrant-Green, 2002) aspects of the study. Therefore to address this concern, the researcher would recommend for future research to be conducted not by one researcher, but by a team of researchers.

Section 5.1 Discussions and Recommendations

When reflecting on the aim of the research surrounding:

“Exploring how the role of the key worker can support families in the community who have experience of a loved one with a Traumatic Brain Injury”

Initially, the researcher considered the role of the designed key worker out of concerns raised in the Philips Report (2008) surrounding the lack of services and support for families and individuals in the community. Within the research, the key worker worked in collaboration with the development of a multi-disciplinary team towards identifying supportive structures and services for the six families involved in the research. Measurement was focussed on the level of identified and addressed needs of the family, along with their feedback during each of the case study families’ activity systems. Findings suggest each family benefited from the assignment of a key worker in identifying and implementing a supportive system in attending to their unique needs. This was recorded throughout the development and implementation of each of the family case studies activity systems. A range of needs were identified and addressed by a multiplicity of services, ranging from professional support from the PCC teams, the development of supportive networks from charitable organisations to education on TBI being given to all involved in the research.

Conclusions and Recommendations from Phase 1

Invitation Process

The first area to address within the research was the recruitment of families for the research. Six families were identified and referred by local GPs in the community. The group of co-researchers who developed each activity system consisted of the primary carer, the researcher acting as the key worker, the GP, PCC teams and external agencies. Collective discussions took place towards prioritising and delegating actions. Procedures were devised surrounding the method of recording and feedback process. *In relation to the small scale of the referral*

process, the researcher would recommend further research be conducted surrounding expanding the inclusion of a larger population of GPs and Hospitals

Multidisciplinary Team

- **Community/Voluntary Service Providers**

Within the identification of the team phase, the multi-disciplinary team consisted of various different medical and social service providers within the community. One identified service provider was that of a voluntary support service. Findings recorded for the Long and McCroon family identified the need to include a voluntary agency to address the need of feeling isolated. The voluntary agency provided respite and a social outlet for the primary carer and the individual with the TBI indefinitely. *The researcher would recommend for the acknowledgment of the uniqueness and multiplicity of professionals that may be required to address the family's activity system. Community/Voluntary services need to be considered as possible service providers of additional support for families. The researcher would therefore recommend further studies be conducted on exploring the collaboration of community services within community based rehabilitation over a longer period of time. This recommendation of the inclusion of community services/voluntary towards supporting community rehabilitation supports findings from studies conducted by Wren et al (2014), Walsh et al (2013), Horgan et al (2013), and the NAI Report (2010).*

- **PCC**

One of the major participants within the identification of the team was the PCCs. The research findings indicated the multitude of services provided by the PCC greatly benefited the family, for instance: PHN, OT, S & L therapy. However, the research also recorded the impact of when a community did not have a fully developed PCC. This was evident within the Timmons and Sterling family area, whereby due to a shortage of staff and a lack of a fully developed complement of a team of professionals services were affected. *The researcher would recommend due to the success of the established PCC teams within the research, for*

the HSE to review the current structure of the PCC system and assess the development of all areas in order to have a full complement of professionals within each community.

Key worker Role

The need for the key worker to offer early and continuous support was also identified, regardless of the length of time post TBI. This was evident in the findings, as the length of time post – TBI ranged from 3 months to twenty seven years. Five out of six families voiced and availed of support in addressing their needs, from the early acute stage of rehabilitation, as seen in the McCroon family and throughout the years as seen with the Timmons family. *To address this finding, the researcher would recommend that the flow-through model be implemented, and the role of the key worker be adopted at the early acute stage of rehabilitation by a member of a rehabilitative team to ensure early and continuous support is available for the family. This form of best practice supports recommendations advocated by the National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland (2011) and the “Slinky Model” of good clinical practice outlined by BSRM National Clinical Guidelines (BSRM, 2003).*

Within the collective discussion of identifying needs, the key worker addressed the family as a complete unit. Holistic needs were identified and prioritised for five out of the six case study families. Initial information on the level of time post-TBI and family reactions were obtained to establish grounding for the research. Findings from this section indicated, as emphasised by Ragnarsson (2002) and Rose (1999) for the need of longevity of care and support for the family and the individual with the TBI. Data on how the role of the key worker supported each family within the community was recorded into 5 main functions. They consisted of the need for education on TBI, Emotional support, identifying and addressing the family needs, providing case management services to advocating on their behalf. *When considering recommendations surrounding this action phase, findings suggest the need for the key worker and participants of the activity system to focus on the complete family unit and not to solely focus attention on the individual with the TBI to ensure a more holistic approach is implemented.*

When suggesting recommendations for the next two parts of phase 1, prioritising and the delegations of needs, findings reflect the process of recruiting some of the co-researchers in relation to the PCC took time due to current low staffing levels. This was recorded within the Timmons and Long family activity system when referring for services was halted due to a low staffing level. *The researcher would recommend for key workers to factor in possible time delays when prioritising and delegating actions and ensure families are made aware of possible delays from the outset to avoid misconceptions.*

In conclusion to the first part of phase 1, the research promoted the utilisation of an agreed collaborative recording and feedback procedure within each team. However, the research data recorded how not all teams were open to such a process. Findings reflect that when the team was in agreement to such a practice, as recorded within the Carling and McCroon multidisciplinary team, the activity system progressed. Alternatively, when there was no consistency in the recording and sharing process as presented in the Timmons and Long family, the activity system became compromised. *Recommendations surrounding the procedure of feedback and recording process highlight the need for the team to be open to share information in order to ensure the smooth development of the rehabilitative plan for the family.*

Conclusions and Recommendations from Phase 2

In phase two, the co-researchers became involved and acted as co-subjects in addressing the delegated actions. Actions were recorded and reflected upon which supported the learning aspect of the action. Findings reflected in the case studies of Carling and McCroon, of which the same PCC applied, how the team of professionals were open to practicing self and group reflection on actions. Alternations occurred, as recorded within the referral process and adjustments were made going forward. Should the willingness to reflect on one's own perception and work not be there, barriers can occur and the activity cease or become jeopardised. This was seen within the findings reflected in the case of the Long family, whereby the S & L therapist was not open to practice self-reflection and adapt the next cycle of events. This caused a breakdown in communication between the family and the therapist and eventually the service itself. *Recommendations for this phase surround the need for all participants within an activity system to be considerate of critical evaluation generated by*

the team on procedures and be open to challenge and change certain tasks in order to benefit the family in question.

Conclusions and Recommendations from Phase 3

Within phase 3, the co-subjects (all participants) became fully immersed within the activity system. Trust amongst the team evolved, supporting the reflection process on experiences and completed actions. Findings reflected once the activity system was up and running for a while, trust developed amongst the hospital staff and the researcher for the McCroon family and within the PCC teams for five out of the six families which resulted in the practice of reflection and experiences being shared. During this phase of the activity system the shortage of staff became a barrier for five out of the six case studies when referrals were sought for PCC services. *When addressing the shortage of allocation of time and staff within the HSE, the research supports recommendations suggested by Wren et al (2014), Horgan et al (2013), and The NAI Report (2010) for the HSE to allow additional time for existing staff to cater towards the longevity of each activity system, whilst also revisiting the recruitment embargo that currently exists in Ireland.*

Conclusions and Recommendations from Phase 4

This fourth phase focussed on the team reassembling to evaluate and share on their experiences and data collected. During this action stage, findings reflect most of the teams for the case studies collectively reviewed and shared on their experiences, leading to the development of each activity system. This evaluation and sharing of experiences from the PCC members was reflected in the research recordings within the McCroon and Carling family surrounding the referral process and for the Long family surrounding the invitation of the Disability Manager to support the development of an action to obtain S & L therapy. Alternatively, when this practice of reflection and evaluating did not occur, the activity system became compromised. Findings reflect in the case of the PCC referral process for the Timmons family, how some professionals were hesitant to engage in a collaborative process from external agents.

When reflecting on this phase of action when working in collaboration with hospital staff, findings reflected the need for time to be given to promote trust amongst all and for the team members to become comfortable with each other. This was evident within two of the case studies, the McCroon and Carling families where initially it was recorded a hesitancy to work collectively with the key worker who was an external agent from outside of the hospital staff. However, after time and the promotion of communication trust were established which supported the development of the activity system.

Alternatively, families also formed part of the team feedback, sharing on their experiences of actions. This was evident through the research findings, whereby each family identified their needs prompting the development of services. As a result of the inclusive feedback process, five out of the six families recorded a lot of their needs were addressed which gave them a sense of empowerment and being listened to.

Conclusions and Recommendations on the Activity Theory Framework

The activity theory was the framework incorporated to act as a lens in analysing the research findings. Background information on each activity and assumptions to design were implemented and presented within the research. Due to the collaborative process that evolved within each case study, the framework proved to be an invaluable tool towards the promotion of a better understanding of the complexities and understanding of each of the case studies needs and actions. When reflecting on the Activity Theory framework within the research, some limitations occurred.

Within the intentionality assumption and dialectic context, findings reflected how some participants were more open to identifying and acknowledging variances in their perceptions of what they thought they knew to what they actually knew. *To address and learn from this aspect of the framework, the researcher would recommend, for future research to continue the practice of openness amongst participants and support each participant in being flexible and reflective in their way of thinking and working.*

Conclusions and Recommendations on the Case Study Tool

To aid in the understanding of the collaborative process and the individual family's needs, case studies were used as a research study tool. Different categories, selection methods and variations of sources of data for the case studies were considered as proposed by Yin (1984). Yin's (1994) good case study practice and protocol was presented to outline the developmental flow of each of the six case studies. The researcher found through the incorporation of the case study tool, it gave a clear in-depth understanding of the complexities and unique needs of each of the families.

When reviewing the current situation of the case studies involved in the research, five out of the six families involved in the research continue to journey down the route of rehabilitation. The identification and implementation of each individual plan continues to be maintained. Each team, especially surrounding the community PCC involvement in each case study family continues to communicate collectively. Unfortunately, one individual from the case study families passed away not long after the research concluded. The key worker continues to be in contact with the wife in order to provide support. As a result of the participation from local PCC and professionals, the lines of communication continue to remain open towards working collectively together addressing the needs of the family's within the community.

Dissemination and Publication of Research Findings

In relation to the publication of the research findings, Baskerville (1999) outlines how the volume of data can be difficult to condense and present within a journal or article format. To address this concern, various publications will be considered within the educational and rehabilitative sector in Ireland and if required, the length will be condensed accordingly.

To promote the dissemination of the research findings, the researcher would suggest a condensed format of the research be sought to be published within the Irish Medical Journal and the Health Research Centre for Primary Care Research. The research could complement existing studies conducted in the area of primary care and TBI and promote a greater understanding of the needs of the family within the community.

The research could be also shared with existing service providers of community based rehabilitation, for instance: Headway and ABI Ireland to broaden and share the findings towards providing a better supportive service for the families of those with a traumatic brain injury.

Further Recommendations

In exploring the possible on-going needs of primary carers post TBI, the researcher feels that the research could benefit from further study in considering the needs of families following referral to Community Rehabilitation Services providers, for instance Headway and ABI Ireland.

In addition, due to the short 6 month duration of the research, the researcher feels the study would benefit from a follow-up study to be conducted with each case study one year after cessation of the research to establish any developments.

Finally, the research solely focussed on TBI only. In order to provide an overall identification of need for primary carers following a brain injury, the researcher feels the study would benefit from further studies to include other forms of brain injury, for instance Stroke and for the researcher to work in collaboration with Stroke Association Ireland.

REFERENCES

- Aaraas, I., Søråasdekkkan, H., and Kristiansen, I.S. (1997). Are general hospitals cost saving? Evidence from a rural area of Norway. *Family Practice*, Vol. 14, pp.397-402.
- Abosch, S., Dahmer, E., and Willer, B. (1990).Epidemiology of disability from traumatic brain injury.In R.L.I. Wood (Eds).*Neurobehavioral Sequelae of Traumatic Brain Injury* (pp. 18-33). UK: Taylor and Francis.
- ABI Ireland. (Accessed February 23rd 2015). www.abiireland.ie. [Accessed February 23rd 2015].
- ABI Ireland, NAI National Conference 2011(Accessed March 4th 2015) How critical the voluntary sector is to the provision of rehabilitation services Innovation, Effectiveness and Value for Money. http://www.nai.ie/assets/72/DD772BAB-E3F0-A97E-7A6978E7FC5B2529_document/NAI_Presentation_-_ABI_Ireland.pdf [Accessed March 4th 2015].
- Adler, N., Shani, A.B., and Styhre, A. (2004). *Collaboration Research in Organisations*. London: Sage.
- Ahmed, J.U. (2009). Action Research: A New Look, *KASBIT Business Journal*, Vol. 2 (1 & 2), pp. 19-32.
- Alfano, D.P. (1994). Recovery of function following brain injury. In M.A.J. Finlayson, and S.H. Garner (Eds.), *Brain Injury Rehabilitation: Clinical Considerations*. USA: Williams and Wilkins, pp. 34-53.
- Allen, K., Linn, R.T., Gutierrez, H., and Willer, B.S. (1994).Family burden following traumatic brain injury. *Rehabilitation Psychology*, Vol. 39(1), pp. 29-48.
- Altricher, H., Posch, P., and Somekh, B. (1993).*Teachers investigate their Work: An Introduction to the Methods of Action Research*, London, Routledge.
- Altman, I.M., Swick, S., Parrot, D., and Malec, J.F. (2010). Effectiveness of Community-Based Rehabilitation after Traumatic Brain Injury for 489 program completers compared with those precipitously discharged. *Archives of Physical Medicine and Rehabilitation*, Vol. 91(11), pp. 1697-1704.
- Anderson, E.T. and McFarlane, J. (2000).*Community as partner: Theory and practice in nursing* (3rded). Philadelphia: Lippincott Williams and Wilkins.
- Anderson, M., Parmenter, T. & Mok, M. (2002). The relationship between neurobehavioural problems of severe traumatic brain injury (TBI), family functioning and the psychological

well-being of the spouse/caregiver: path model analysis. *Brain Injury*, Vol. 16(9), pp.743-757.

Andriessen, T.M., Horn, J., Franschman, G., van derNaalt, J., Jacobs, B., Steverberg, E.W.m and Vos, P.E. (2011) Epidemiology, severity classification, and outcome of moderate and severe traumatic brain injury: a prospective multicenter study. *Journal of Neurotrauma*, Vol. 28, pp. 2019-2031.

Angelo, M. (1999). Abrir-se para a família: superando desafios. *Fam Saúde Desenv*, Vol. 1. pp. 7-14.

Angelo, M., and Bousso, R.S. (2001). Fundamentos da Assistência à Família em Saúde. In *Manual de Enfermagem*, Brasil. Ministério da Saúde (Org) p. 14-7. Ministerio da Saúde.

April, H.M. (1997). *The impact of traumatic brain injury on the family*. Unpublished master's thesis, University of Port Elizabeth, Port Elizabeth.

Argyris, C. (1995). Action science and organisational learning. *Journal of Managerial Psychology*, Vol. 10(6).

Arango-Lasprilla, J.C., Quijano, M.C., Aponte, M., Ceurvo, M.T., Nicholls, E., Rogers, H.L. and Kreutzer, J. (2010). Family needs in caregivers of individuals with traumatic brain injury from Colombia, South America. *Brain Injury*, Vol. 24. pp. 1017-1026.

Araz, O., Demirci, E., Ucar, E.Y., Calik, M., Pultur, D., Karaman, A., Yayla, M., Altun, E., Halici, Z., and Akgun, M. (2013). Comparison of reducing effect on lung of dexamethasone and bosentan in acute long injury: an experimental study. *Multidisciplinary Respiratory Medicine*, Vol. 8, pp. 74.

Atun, R. (2004). *What are the advantages and disadvantages of restructuring a health care system to be more focussed on primary care services ?* Copenhagen, WHO Regional Office for Europe.

Avison, D., Lau, F., Myers, M. and Nielsen, P.A. (1999). Action Research, *Communication of the ACM Article*, Vol 42. pp. 1.

Baicker, K., and Chandra, (2004). A. Medicare spending, the physician workforce, and beneficiaries' quality of care. *Health Affairs* (Millwood); (Suppl Web Exclusives): W184-97.

Baker, J.E., Goldacre, M., Muir Gray, J.A. (1986). Community hospitals in Oxfordshire: their effect on the use of specialist inpatient services. *Journal of Epidemiology and Community Health*, Vol. 10, pp. 117-120.

Barker, C., Pistrang, N. and Elliott, R. (2002). *Research Methods in Clinical Psychology*. An Introduction for Students and practitioners. 2nd Ed. Wiley. pp 95.

Barnes, M.T. (1999). Rehabilitation after traumatic brain injury. *Oxford Journal of Medicine*, Vol. 55, (4). pp. 927-943.

- Barton, L., and Clarke, L. (2006). *Altogether Now*. An evaluation of the Key Working Process in Warwickshire: Final Report. Professional and Parental Views, Integrated Disability Services. Stareton, Warwickshire.
- Baskerville, R. (1999). Investigating Information Systems with Action Research, *Communications of AIS*, Vol. 2, Article 19.
- Baskerville, R., and Wood-Harper, A. (1996). A critical perspective on action research as a method for information systems research. *Journal of Information Technology*, Vol. 11(4), pp. 235-246.
- Baum, F. (1995). Researching public health: Behind the qualitative-quantitative methodological debate. *Social Science and Medicine*, Vol. 40(4), pp. 459-468.
- Beasley, J.W., Starfield, B., van Weel, C., Rosser, W.W. and Haq, C.L. (2007). Global Health and Primary Care Research, *Family Medicine*, Vol. 20(6).
- Becvar, D.S. and Becvar, R.J. (2000). *Family therapy. A systemic integration*. (4th Ed). USA: Alan and Bacon.
- Bekker, K.A. (2000). *Family needs following traumatic brain injury*. Unpublished master's thesis, University of Port Elizabeth, Port Elizabeth.
- Bell, K.R., Hoffman, J.M., Temkin, N.R., Powell, J.M., Fraser, R.T., and Esselman, P.C. (2008). The effect of telephone counselling on reducing post-traumatic symptoms after mild traumatic brain injury: a randomised trial. *Journal of Neurology, Neurosurgery and Psychiatry*, Vol. 11, pp. 1275–1281.
- Beresford, B. (1995). *Expert Opinions: a survey of parents caring for a severely disabled child*, Policy Press, Bristol.
- Berg, J., Tagliaferri, F., and Servadei, F. (2005). Cost of trauma in Europe. *European Journal of Neurology*, Vol. 12(1), pp. 85-90.
- Bloomfield, L.M.I., and Espie, C.A., Evans, J.J. (2010). Do sleep difficulties exacerbate deficits in sustained attention following traumatic brain injury? *Journal of the International Neuropsychological Society*, Vol. 16(1), pp. 17-25.
- Bødker, S. (1991a). Activity theory as a challenge to systems design. In H.E. Nissen, H.K. Klein and R. Hirschheim (Eds.), *Information system research: Contemporary approaches and emergent traditions*. Amsterdam: Elsevier.
- Boerma, W.G.W, Van der Zee, J, Fleming, D. (1997). Service profiles of general practitioners in Europe. *British Journal of General Practice*, Vol. 47, pp.481-486.
- Bolton, G. (2010). *Reflective Practice, Writing and Professional Development* (3rd edition), SAGE publications, California.

- Borton, T. (1970). *Reach, Touch and Teach*, London, U.K.: Hutchinson.
- Boutilier, M., Mason, R., and Rootman, I. (1997). Community action and reflective practice in health promotion research. *Health Promotional International*, Vol.12 (1).
- Brewer, J. and Hunter, A. (1989). *Multimethod research: a synthesis of styles*, Newbury Park: Sage, 1989, Sage Library of Social Research Series, Vol. 175.
- British Psychological Society (1993). Ethical principles for conducting research with human participants. *The Psychologist*, Vol. 6, pp.33-35.
- British Society of Rehabilitation Medicine and Royal College of Physicians Rehabilitation following acquired brain injury: national clinical guidelines. London: BSRM, 2003.
- Bromley, D.B. (1986). *The Case-Study Method in Psychology and Related Disciplines*, John Wiley, Chichester, Great Britain.
- Brooks, N., Campsie, L., Symington, C., Beattie, A., and McKinlay, W. (1986). The five year outcome of severe blunt head injury: a relative's view. *Journal of Neurology, Neuropsychiatry, and Psychiatry*, Vol. 49(7), pp. 764-770.
- Brydon-Miller, N., Greenwood, D., and Maguire, P. (2003). Why Action Research? *Action Research*, Vol. 1(1), pp. 9-28.
- Burns, A. (1999). Collaborative Action Research for English Language Teachers. Cambridge, CUP.
- Busetto, L., Luijkx, K.G., and Vrihoef, H.J.M. (2014). Implementation of integrated care for type 2 diabetes: a protocol for mixed methods research. *International Journal Integrated Care*.
- Busse R, and Riesberg A. (2004). *Health care systems in transition: Germany*. Copenhagen, WHO Regional Office for Europe on behalf of the European Observatory on Health Systems and Policies, 2004.
- Burke Johnson, R., and Christensen, L. (2013). *Educational Research: Quantitative, Qualitative, and Mixed Approaches*, (5th ed). Chapter 11. Sage.
- Camplair, P.S., Kreutzer, J.S., and Doherty, R.D. (1990). Family outcome following adult traumatic brain injury. In J.S. Kreutzer, and P. Wehman (Eds), *Community integration following traumatic brain injury*. Kent: Edward Arnold, pp. 207-223.
- Care Co-ordination Network UK. (2006). Developing a Key Workers Service for Families with a Disabled Child. A resource pack: York: Publications Office, University of York.
- Carr, W. and Kemmis, S. (1986) *Becoming Critical: Education, Knowledge and Action Research*. London: Falmer.

Carson, P. (1993). Investing in the comeback: Parent's experience following traumatic brain injury. *Journal of Neuroscience Nursing*; Vol. 25(3), pp. 165-173.

Chawla-Duggan, R. (2007). "Breaking Out, Breaking Through: Accessing Knowledge in a Non-Western Overseas Educational Setting – Methodological Issues for an Outsider." *Compare*, Vol.37, pp. 185-200.

Chevalier, J.M. and Buckles, D.J. (2008). *SAS2: A guide to Collaborative Inquiry and Social Engagement*. Sage India and IDRC, Ottawa and New Delhi. E-ISBN 978-1552504185.

Chevalier, J.M. and Buckles, D.J. (2013). *Participatory Action Research: Theory and Methods for Engaged Inquiry*, Routledge UK. ISBN 978-0415540315.

Clinical Practice Guidelines. (2009). *Management of concussion/mild traumatic brain injury*. The Management of Concussion/mTBI Working Group.

Cochrane, S.H. and Zachariah, K.C. (1983). *Infant and child mortality as a determinant of fertility. The policy implications*. (Staff working paper No: 556). Washington, World Bank.

Coco, K., Tossavainen, K., Jääskeläinen, J.E., and Turunen, H. (2011). Support for Traumatic Brain Injury Patients' Family Members in Neurosurgical Nursing: A Systematic Review, *American Association of Neuroscience Nurses*, Vol. 43(6).

Cook, T.D. and Campbell, D.T. (1979). *Quasi-Experimentation: Design and Analysis for Field Settings*. Rand McNally, Chicago, Illinois.

Creswell, J.W. (2009). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*. Thousand Oaks, CA: SAGE.

Creswell, J.W. (2003). *Research design: qualitative, quantitative and mixed methods approaches*. 2nd ed. Thousand Oaks, CA: L Sage.

Curry, J. (2011). Irish Social Services, Dublin: IPA .

Daniel, L.C. (1991). *Stress and coping in families with a stroke survivor*. Unpublished Master's thesis, University of Port Elizabeth, Port Elizabeth.

Davies, S. (2007). *Team around the Child: Working together in early intervention*. Wagga Wagga: Kurra Early Intervention Service.

Degeneffe, C.E. (2001). Family caregiving and traumatic brain injury. *Health and Social Work*, Vol. 26 (4), pp. 257-269.

DeJong, G. (1999). Access to brain injury rehabilitation and other post-acute services. In K. Ragnarsson (Ed.), Report of the NIH consensus development conference on the rehabilitation of persons with traumatic brain injury. Bethesda, MD: U.S. Department of Health and Human Services, pp. 121-124.

Department of Health [UK] (2009). National Definition Set for Specialised Services No: 7; “Complex specialised rehabilitation for brain injury and complex disability [adult].

Department for Work and Pensions, Department of Health, and Health and Safety Executive [UK] (2005) Health, Work and Well-being – Caring for Our Future. London: Department of Health and UK Health and Safety Executive.

Department of Health [UK] (2002). Specialised Services National Definition Set.

Department of Health [UK] (2001). Primary care, general practice and the NHS Plan: information for GPs, nurses, other health professionals and staff working in primary care in England.

Department of Health [Ireland] (2014). *The Path to Universal Healthcare*. White Paper on Universal Health Insurance.

Department of Health (2012), Future Health: A Strategic Framework for Reform of the Health Service 2012-2015.

Department of Health, Health Service Executive [DoH, HSE], (2011). National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland 2011-2015.

Department of Health (2004). Disabled Child Standard, National Service Framework for Children, Young People and maternity Services. Department of Health Publications.

Dikmen, S.S., Corrigan, J.D., Levin, H.S., Machamer, J., Stiers, W., and Weisskopf, M.G. (2009). Cognitive Outcome Following Traumatic Brain Injury. *Journal of Head Trauma Rehabilitation*.

Dillman, D.A. (2000) *Mail and Internet surveys: the tailored design method*. 2nd ed. Hoboken (NJ): John Wiley and Sons.

Disability Act (2005). Department of Health and Children. The Disability Act: The Stationery Office, Dublin.

Douglas, J.M, and Spellacy, F.J. (2000). Correlates of depression in adults with severe traumatic brain injury and their carers. *Brain Injury*, Vol. 14, pp. 71-88.

Doyle, M. (2007). A Reflective Critique Of Learner-Managed Learning: An Emerging Curriculum Model For A Foundation Degree. *Reflective Practice*, Vol. 8(2), pp. 193-207.

Droitcour, J. A. (1997). Cross design synthesis: Concept and application. In: E. Chelimsky, & Shadish, W. R. (ed.), *Evaluation for the 21st Century: A Handbook*. Thousand Oaks, CA: Sage Publications, pp. 360–372.

Dunst, C.J., Trivette, C.M. and Deal, A.G. (1994) *Supporting and Strengthening Families, Vol. 1: methods strategies and practices*, Brookline Books, Cambridge, MA.

Dwyer, S., and Buckle, J.L. (2009). "The Space Between: On Being an Insider-Outsider in Qualitative Research." *International Journal of Qualitative Methods*, Vol. 8, pp.54-63.

Eames, P.G. (2001). Distinguishing the neuropsychiatric, psychiatric, and psychological consequences of acquired brain injury. In R.L.I. Wood, and T.M. McMillian (Eds.), *Neurobehavioral and Social Handicap Following Traumatic Brain Injury*. USA: Taylor and Francis, pp. 29–45.

Elliott, J. (1991). *Action Research for Educational Change*, Buckingham, Open University Press.

El-Menyar, a., El-Hennawy, H., Al-Thani, H., Asim, M., Abdelrahman, H., Zaeour, A., Parchani, A., Peralta, R., and Latifi, R. (2014). Traumatic injury amongst females: does gender matter? *Journal of Trauma Management and Outcomes*, Vol. 8, pp. 8.

Engeström, Y. (1987). *Learning by expanding: An Activity-Theoretical Approach to Developmental Research*. Helsinki, Finland: Orienta-Konsultit Oy.

EPSEN Act (2004). Department of Education and Science. The Education of Persons with Special Educational Needs: The Stationery Office, Dublin.

Ergh, TC., Rapport, LJ., Coleman, RD., and Hanks, RA. (2002). Predictors of caregiver and family functioning following traumatic brain injury: social support moderates caregiver distress. *Journal of Head Trauma Rehabilitation*, Vol. 17(2). pp. 155-174.

Evans, M. (1994). *An Action Research Inquiry into Reflection in Action as Part of My Role as Deputy Head-teacher*, PhD thesis, University of Bath, via Internet.

Faul, M., Xu, L., Wald, M.M., and Coronado, V.G. (2010). Traumatic brain injury in the United States: emergency departments visits, hospitalizations and deaths 2002-200. *Centres for Disease Control and Prevention, National Centre for Injury Prevention and Control*.

Feagin, J., Orum, A. and Sjoberg, G. (1991). *A case for a case study*. Chapel Hill, NC: University of North Carolina Press.

Fetterman, D. (1996). Empowerment evaluation: An introduction to theory and practice. In D. Fetterman, S. Ksaftarian and A. Wandersman (Eds.), *Empowerment evaluation: Knowledge and tools for self-assessment and accountability*. Thousand Oaks, CA: Sage.

Foley, G.M. (1990). 'Portrait of the arena evaluation: assessment in the transdisciplinary approach' in: Gibbs E.D. and Teti, D.M., editors. *Interdisciplinary Assessment for Early intervention Professionals*. Baltimore: Paul H. Brookes. pp. 274.

Fordyce, D.J. (1994). Neuropsychologic assessment and cognitive rehabilitation: Issues of psychologic validity. In M.A.J. Finlayson, and S.H. Garner (Eds.), *Brain Injury Rehabilitation: Clinical Considerations*. USA: Williams and Wilkins. pp. 187-211.

French, S. and Swain, J. (1997). "Changing Disability Research: Participation and emancipatory research with disabled people". *Physiotherapy*, Vol. 83 (1), pp. 26-32.

Friedman, V.J. (2001). Action Science: Creating Communities of Inquiry in Communities of Practice in Reason, P. and Bradbury, H. (Eds), *Handbook of Action Research*, 2nded, London: Sage, pp. 131-143.

Gasman, M. and Payton Stewart, L. (2006). "Twice Removed: A White Scholar Studies the History of Black Sororities and a Black Scholar Responds." *International Journal of Research and Method in Education*, Vol.29, pp. 129-149.

Gibbs, G. (1988). *Learning by doing: A guide to teaching and learning methods*. Oxford Centre for Staff and Learning Development, Oxford Polytechnic. London: Further Education Unit, Section 4.3.5.

Giles, G.M. (2001). The effectiveness of neurorehabilitation. In R.L.I.Wood, and T.M. McMillan (Eds.), *Neurobehavioral Disability and Social Handicap Following Traumatic Brain Injury*. USA: Taylor and Francis. pp. 231-255.

Glenn, J.C. (2010). Ch 4: Research Methods of Qualitative and Quantitative. *Handbook of Research Methods*. New Delhi, India, Oxford Book.

Golijani-Moghaddam, N. (2014). Applying family life cycle concepts in psychological practice with children and young people. *Applied Psychological Research Journal*, Issue 2, pp. 26-33.

Gomm, R., Hammersley, M., and Foster, P. (2000). "Case Study and Generalization", in Roger Gomm, Martyn Hammersley, and Peter Foster (eds.), *Case Study Method: Key Issues, key Texts*, sage, Thousand Oaks, CA. pp. 98-115.

Goodinge, S. (1998). *Removing Barriers for Disabled Children: Inspection of Services to Disabled Children and Their Families*, Department of Health.

Gordon, D., Parker, R. and Loughran, F. (1996). *Children with Disabilities in Private Households: a re-analysis of the OPCS investigation*, University of Bristol, Bristol.

Greco, V., and Sloper, P. (2004). *Care co-ordination and key worker schemes for disabled children: results of a UK-wide survey*. Child: Care, Health and Development, Vol. 30(1), pp.13-20.

Greco, V., Sloper, P. and Webb, R., and Beecham J. (2005, 2006). *An Exploration of Different models of Multi-Agency Partnerships in Key worker Services for Disabled Children: Effectiveness and Costs*. University of York.

Greenwood, R. (1999). The consequences of brain injury: Classification and assessment of outcome. In S. Fleminger, and J. Powell (Eds.), *Evaluation of outcomes in brain injury rehabilitation*. UK: Psychology Press Ltd. pp. 231-240.

Greer, B.G., Knack, M.A., and Roberts, R. (1992). Closed head injury and family structure: Factors contributing to dysfunctional dynamics. In C.J. Long and L.K. Ross (Eds.), *Handbook of head trauma: Acute care to recovery*, pp.357-368. New York: Plenum Press.

- Grundy, S. (1982). Three Models of Action Research, *Curriculum Perspectives*, Vol. 2 (3), pp. 23-34.
- Guba, E.G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. *Journal of Educational Communication and Technology*, Vol. 29, pp. 75-91.
- Haase, J.E. and Myers, S.T. (1988). Reconciling paradigm assumptions of qualitative and quantitative research. *Western Journal of Nursing Research*, Vol. 10. pp. 128-137
- Hall, D. and Hill, P. (1996). Services for disabled children. *The child with a disability*, Blackwell Science, pp. 116-130.
- Hallet, J.D., Zasler, N.D., Maurer, P., and Cash, S. (1994). Role change after traumatic brain injury in adults. *American Journal of Occupational Therapy*, Vol. 48. pp. 241-246.
- Ham, C., Robinson, R. and Benzeval, M. (1990). *Health Check*. Health care reforms in an international context. London, King's Fund Institute.
- Hamilton, D. (1981). Generalization in the Educational Sciences: problems and purposes. In: Popkewitz, T.S. and Tabachnik, B.R. (eds). *The Study of Schooling: field based methodologies in educational research and evaluation*, New York, Praeger.
- Hammersley, M. (1991). *Reading Ethnographic Research: A Critical Guide*. London: Longman.
- Hampton, T. (2011). Traumatic Brain Injury a Growing Problem Among Serving in Today's Wars. *JAMA*, Vol. 306(5), pp. 447-179.
- Hancock, R. (2007). 'We were unable to speak'. Minor Thesis for Master of Social Change and Development. The University of Newcastle, Australia.
- Hancock, B. (2002). *An Introduction to Qualitative Research*. Trent Focus Group. pp. 14.
- Hardgrove, H. (1991). Special issues for a child. In J.M. Williams and T. Kays (Eds.), *Head Injury: A Family Matter*. Baltimore: Paul H. Brookes, pp. 25-27.
- Harrison, J. (2007). Individual Family Service Plans as a means to Evaluate Transdisciplinary Practice. In: Davies, S. editor. *Team Around the Child: Working together in early intervention*. Wagga Wagga: Kurrajong Waratah.
- Harrison, A. (2013). The English Health Care System, 2013. *International Profiles of Health Care Systems*. pp. 37.
- Hartley, S., Finkenflugel, H., Kuipers, P., Thomas, M. (2009). Community-based rehabilitation: opportunity and challenge. *Lancet* 2009, 374(9704), pp. 1803-1804.
- Headway. www.headway.ie [Accessed January 30th 2011].

Health Service National Service Plan 2014 (NSP2014).

Health Service Executive (Governance) Act 2013.

Health Service Executive, (2012). Rehabilitation Medicine Programme: update December 2012. Dublin: Health Service Executive; 2012.

Health Service Executive, (2009). The Education and Development of Health and Social Care professionals in the Health Services 2009-2014.

Health Service Executive (2005). Towards Better Health Care.

Health Strategy (2001). Department of Health and Children.

Heller, F.A. (1976). Group feedback analysis as a method of action research. In A.W. Clark, *Experimenting with organisational life*. New York: Plenum.

Hendricks, J., Mooney, D., and Berry, C. (1996). "A practical strategy to use the reflective practice in critical care nursing". *Intensive and Critical Care Nursing*, Vol. 12 (2), pp. 97-101.

Hennessey-Lavery, S., Lau Smith, M., Avila Esparza, A., Hrushow, A., Moore, M., and Reed, D.F. (2005). The Community Action Model: A Community-Driven Model Designed to Address Disparities in Health. *Journal Public Health*, Vol. 95(4), pp. 611-616.

Heron, J. (1996a). *Co-operative Inquiry: Research into the Human Condition*. London: Sage Publications.

Heron, J. and Reason, P. (1981). *Co-counselling: an Experimental Inquiry*. Guildford: University of Surrey.

Heron, J. and Reason, P. (1985). *Whole Persons Medicine: a Co-operative Inquiry*. London: British Postgraduate Medical Federation.

Heron, J. and Reason, P. (2001). The Practice of Co-operative Inquiry: Research with rather than on people. In P. Reason and H. Bradbury (Eds.), *Handbook of Action Research: Participative inquiry and practice* (pp. 179-188). London: Sage Publications.

Hoel, A.W., Kayssi, A., Brahmanandam, S., Belkin, M., Conte, M.S., and Nguyen, L.L., (2009). Under-representation of women and ethnic minorities in vascular surgery randomised controlled trials. *Journal of Vascular Surgery*, Vol. 50(2). pp. 349-354.

Hofmarcher, M., and Rack, H.M. (2006). Health care systems in transition: Austria. WHO Regional Office for Europe on behalf of the European Observatory on Health Systems and Policies, 2006.

Hogskola, S. (2005). *Perspectives on Poverty and Agriculture in Rural Tanzania*. pp.6.

Holly, M.L. (1989). Reflective Writing and the Spirit of Inquiry, *Cambridge Journal of Education*, Vol. 19. pp. 71-80.

Holmes, G.E. (1990). The institutionalization of disability myths: impact on vocational rehabilitation services, *Journal of Rehabilitation*, Vol. 56. pp. 1.

Horgan, F., Walsh, M, Galvin, R., Macey, C and Loughynane, C. (2013). National Survey of Stroke Survivors 2013: Experiences and long-term needs reported by stroke survivors living in the community in Ireland.

Hughes, I. (2008). "Action research in healthcare", in P. Reason and H. Bradbury (eds), *The SAGE Handbook of Action Research: Participative Inquiry and Practice*. London: SAGE.

Humphrey, I., Wood, R.L., Philips, C.J., and Macey, S. (2013). The cost of traumatic brain injury: a literature review. *ClinicoEconomics and Outcomes Research*, Vol. 5, pp. 281-287.

Hyder, A.A., Wunderlich, C.A., and Puvanachandra, P. (2007). The impact of traumatic brain injuries: a global perspective. *Journal of Neurorehabilitation*, Vol. 22, pp. 341-353.

Iemmi, V, Kumar, K.S., Blanchet, K., Hartley, S., Murthy, GVS, Patel, V., Weber, J., Wormald, R, and Kuper, H. (2013). Community-Based Rehabilitation for People with Disabilities in Low-and Middle-Income Countries. Protocol, The Campbell Collaboration.

Institute of Health Promotion Research, The University of British Columbia and the BC Consortium for Health Promotion Research (1995) *Study of Participatory Research in Health Promotion* The Royal Society of Canada, Ottawa.

Ireland, P. and Thomalla, F. (2011). The Role of Collective Action in Enhancing Communities' Adaptive Capacity to Environmental Risk: An Exploration of Two Case Studies from Asia. *PLOS Current Disasters*.

Irish Medical Times article, "Some 423 PCTs are 'in place' countrywide" 2014) (Accessed March 18th 2015). <http://www.imt.ie/news/latest-news/2014/02/some-423-pcts-are-in-place-countrywide.html> [Accessed March 18th 2015].

Jacob, H.E. (1988). The Los Angeles head injury survey: Procedures and initial findings. *Archives of Physical Medicine and Rehabilitation*, Vol. 69, 425-431.

Jackson, A., and Haverkamp, B.E. (1991). Family response to traumatic brain injury. *Counselling Psychology Quarterly*, Vol. 4 (4).

Jackson, W.T., and Gouvier, W.D. (1992). Group psychotherapy with brain-damaged adults and their families. In C.J. Long, and L.K. Ross (Eds.), *Handbook of head trauma: Acute care to recovery*. New York: Plenum Press, pp. 309-327.

Jagsi, R., Motomura, A.R., Amarnath, S., Jankovic, A. Sheets, N., and Ubel, P.A. (2009). Under-presentation of women in high-impact published clinical cancer research. *Cancer*, Vol. 115(14), pp. 3293-3301.

Johnsen, JR. (2006). *Health Systems in Transition: Norway*. WHO Regional Office for Europe on behalf of the European Observatory on Health Systems and Policies, 2006.

Jonassen, D.H., and Rohrer-Murray, L. (1999). Activity theory as a Framework for designing Constructivist Learning Environments. *Educational Technology, Research and Development*, Vol. 47(1): Research Library.

Kanuha, V.K. (2000). "Being' Native versus 'Going Native'; Conducting Social Work Research as an Insider." *Social Work*, Vol. 45, pp. 439-447.

Kaptelinin, V. (1996). Computer-mediated activity: Functional organs in social and developmental contexts. In B. Nardi (Ed.), *Context and consciousness: Activity theory and human-computer interaction*. Cambridge: The MIT Press, pp. 45-68.

Karpman, T., Wolfe, S., and Vargo, J.W. (1985). The psychological adjustment of adult clients and their parents following closed-head injury. *Journal of Applied Rehabilitation Counselling*, Vol. 17(1), pp. 28-33.

Karver, C.L., Wade, S.L., Cassedy, A., Taylor, G.G., Stancin, T., Yeates, K.O., and Walz, C.C. (2012). Age at Injury and Long-Term Behaviour Problems After Traumatic Brain Injury in Young Children. *Rehabilitation Psychology*, Vol. 57(3), pp. 256-265.

Katz, S., Kravetz, S., and Grynbaum, F. (2005). Wives' coping flexibility, time since husbands' injury and the perceived burden of wives of men with traumatic brain injury. *Brain Injury*. Vol. 19(1), pp. 59-66.

Kay, T. and Lezak, M. (1990). The nature of head injury. In D. Corthell (Ed.), *Traumatic brain injury and vocational rehabilitation*. Menomonie, Wisconsin: Stout Vocational Rehabilitation Institute, pp. 25-65.

Kemmis, S. and McTaggart, R. (1988). *The Action Research Reader* (3rd ed), Deakin University Press, Victoria.

Kemmis, S., and McTaggart, R. (2005). Participatory action research: Communicative and the public sphere. In N. Denzin and Y. Lincoln (Eds), *Handbook of Qualitative Research* (3rd ed). Thousand Oaks, CA: Sage, pp. 559-604.

Kenny, K. and McGilloway, S. (2007). Caring for children with learning disabilities: an exploratory study of parental strain and coping. *British Journal of Disabilities*, Vol. 35(4), pp. 221-228

Kerstetter, K. (2012). Insider, Outsider, or somewhere in between: The impact of researchers' identities on the community-based research process. *Journal of Rural Social Sciences*, Vol. 27(2), pp. 99-117

Khan, F., Baguley, I.J., and Cameron, I.D. (2003). Rehabilitation after traumatic brain injury. *Rehabilitation Medicine*, Vol. 178, pp. 290.

King, A. (2001). *The Primary Health Care Strategy*. New Zealand, Wellington: Ministry of Health; 2001.

Knight, R.G., Devereux, R., and Godfrey, H.P.D. (1998). Caring for a member with a traumatic brain injury. *Brain Injury*, Vol. 12, pp. 467-481.

Knowler, H. (2007). *Interviews in Education Research*. A Hannon, Faculty of Education, University of Plymouth. pp.10,12.

Kolakowsky-Hayner, S.A., Miner, K.D., and Kreutzer, J.S. (2001). Long-term life quality and family needs after traumatic brain injury. *Journal Head Trauma Rehabilitation*, Vol. 16 (4), pp. 374-385.

Koshy, E., Waterman, H. and Koshy, V. (2010). *Action Research in Healthcare*. Sage Publications Ltd.

Kreutzer, J.S., Leininger, B.E., and Harris, J.A. (1990a). Family needs after brain injury: A quantitative analysis. *Journal of Head Trauma Rehabilitation*, Vol. 9, pp. 104-115.

Kreutzer, J.S., Serio, C.D., and Bergquist, S. (1994). Family needs after brain injury: A quantitative analysis. *Archives of Physical Medicine and Rehabilitation*, Vol. 73, pp. 771-778.

Kreutzer, J.S., Zasler, N.D., Camplair, P.S., and Leininger, B.E. (1990b). A practical guide to family intervention following adult traumatic brain injury. In J.S. Kreutzer, and P. Wehman (Eds.), *Community integration following traumatic brain injury*, Kent: Edward Arnold, pp. 249-273.

Kuutti, K. (1996). "Activity theory as a potential framework for human-computer interaction research". In B.A. Nardi, (ed.), *Context and Consciousness Activity Theory and Human Computer Interaction*, Cambridge, MA, MIT Press.

Lam, P., and Beaulieu, M. (2004). Experiences of families in the neurological ICU: "A beside phenomenon." *Journal of Neuroscience Nursing*, Vol. 36, pp. 142-155.

Lather, P. (1986). Research as Praxis. *Harvard Educational Review*, Vol. 56(3), pp. 257-77.

Lau, F. (1997). A Review of action research in information systems studies. In *Information Systems and Qualitative Research*, Lee, A., Liebenau, J., and DeGross, J. eds. Chapman And Hall, London, U.K. pp. 31-68.

Lees, M. (1988). The social and emotional consequences of severe brain injury: The social work perspective. In I. Fussey & G.M. Giles (Eds.), *Rehabilitation of the severely brain injured adult: A practical approach* (pp. 166-182). Baltimore: Paul H. Brookes.

Lefebvre, H., Pelchat, D., Swaine, B., Gelinas, I., and Levert, M.J. (2005). The experiences of individuals with a traumatic brain injury, families, physicians and health professionals regarding care provided throughout the continuum. *Brain Injury*, Vol. 19, pp. 585-597.

Lefebvre, H., and Levert, M.J. (2006). Breaking the news of traumatic brain injury and incapacities. *Brain Injury*, Vol. 20(7), pp. 711-718.

Lefebvre, H., Levert, M.J., Pelchat, D., and Lepage, J.G. (2008). Nature, sources, and impact of information on the adjustment of family caregivers: A pilot project. *Canadian Journal of Nursing Research*, Vol. 40, pp. 143-160.

Leont'ev, A.N. (1981). The problem of activity in psychology. In J.V. Wertsch (ed.), *The concept of activity in Soviet psychology*. Armonk, NY: Sharpe.

Lewin, K (1946). Action Research and Minority Problems, in G. W. Lewin (Ed.) *Resolving Social Conflicts*. New York: Harper and Row.

Lewin, K. (1952). Group Decision and Social Change. In G.W. Swanson, T.M. Newcomb and E.L. Hartley (Eds) *Readings in Social Psychology*. New York: Henry Heath and Co. Reprinted in S. Kemmis and R. McTaggart (1988) *the Action Research Reader* (3rd ed.). Geelong: Deakin University Press.

Lewis, F.D., and Horn, G.J. (2013). Traumatic Brain Injury: Analysis of Functional Deficits and Posthospital Rehabilitation Outcomes. *Journal of Special Operations Medicine*, Vol. 13(3).

Lezak, M.D. (1978). Living with the characterologically altered brain injured patient. *The Journal of Clinical Psychiatry*, Vol. 39, pp. 592-598.

Lezak, M.D. (1988). Brain damage is a family affair. *Journal of Clinical and Experimental Neuropsychology*, Vol. 10 (1), pp. 111-123.

Lezak, M.D. (1995). *Neuropsychological Assessment* (3rd ed.). New York: Oxford University Press.

Linnard, M. (1995). New debates on learning support. *Journal of Computer Assisted Learning*, Vol. 11. pp. 239-253.

Lofland, J. and Lofland, L.H. (1995). *Analysing Social Settings: A Guide to Qualitative Observation and Analysis*. (3rd ed). Elmont, Calif: Wadsworth.

Lo Scalzo, A., Donatini, A., Orzella, L., Cicchetti, A., Profili, S., and Maresso, A. (2009). Health care systems in transition: Italy. WHO Regional Office for Europe on behalf of the European Observatory on Health Systems and Policies.

Maas, A. I., Stocchetti, N. & Bullock, R. (2008). Moderate and severe traumatic brain injury in adults. *Lancet Neurol*, Vol. 7, pp. 728–741.

Macaulay, A.C., Freeman, W.L., Gibson, N., McCabe, M.L., Robbins, C.M. and Twohig, P.L. (1998). Responsible Research with Communities: Participatory Research in Primary Care.

- Machamer, J., Temkin, N., and Dikmen, S. (2002). Significant other burden and factors related to it in traumatic brain injury. *Journal of Clinical and Experimental Neuropsychology*, Vol. 24(4), pp. 420-433.
- Macinko, J., Starfield, B., and Shi, L. (2003). The contribution of primary care systems to health outcomes within Organisation for Economic Cooperation and Development (OECD) countries, 1970-1998. *Health Services Research*, Vol. 38(3), pp. 831-865.
- Makama, J.G., Garba, E.S., and Ameh, E.A. (2012). Under representation of women in surgery in Nigeria: by choice of design? *Oman Medical Journal*, Vol. 12(1), pp. 66-69.
- Maeseneer, J.M.D., van Driel, M.L., Green, L.A., van Weel, C. (2003). *The need for research in primary care*. *Lancet*, Vol. 362, pp. 1314-1319.
- Maia, C.R., Terra, M.B., Coimbra, M. (2003). Programmas de auxílio aos padecentes de TCE e aos seus familiares. In: *Neuropsiquiatria dos traumatismos cranioencefálicos*, Souza, C.A. C.Revinter, pp. 245-262. Rio de Janeiro.
- Malec, J.L. and Lezak, M.D. (2008). The Mayo-Portland Adaptability Inventory (MPAI-4) for adults. *Child Adolesc Manual*, pp. 1-84.
- Marion, D.W. (1999). *Traumatic brain injury*. USA: Theme Medical Publishers, Inc.
- Market Research Society (MRS), (1998). *Qualitative Research Guidelines*, Section 1, pp 3.
- Marshall, C., and Rossman, G. (1980). *Designing Qualitative Research*. Newbury Park, CA: Sage.
- Marshall, J. (2001). Self-reflective Inquiry Practices. In Reason, P. and Brabury, H. (2008). *Handbook of Action Research*, Chapter 32, pp. 335.
- Marshall, J. and Reason, P. (1998). "Collaborative and self-reflective forms of inquiry in management research", in J. Burgoyne and M. Reynolds (eds.), *Management Learning*. London: Sage Publications. pp. 227-242.
- Martin, D.A. (1988). Children and adolescents with traumatic brain injury: Impact on the family. *Journal of Learning Disabilities*, Vol. 21, pp. 465-468.
- Martin, G.N. (1998). *Human Neuropsychology*. England: Prentice Hall Europe.
- Masel, B. and DeWitt, D.S. (2010). Traumatic Brain Injury: A Disease, Not an Event. *Journal of Neurotrauma*. Vol. 27, pp. 1529-1540.
- Mathis, M. (1984). Personal needs of family members of critical ill patients with and without brain injury. *The American Association of Neuroscience Nurses*, Vol. 16, pp. 36 – 44.
- Mauss-Clum, N., and Ryan, M. (1981). Brain injury and the family. *Journal of Neurosurgical Nurses*, Vol. 13, pp. 165-169.

Mauritz, W., Wilbacher, I., Lajdan, M., Leitgeb, J., Janciak, I., Brazinova, A., and Rusnak, M. (2008). Epidemiology, treatment and outcome of patients after severe traumatic brain injury in European regions with different economic status. *European Journal of Public Health*, Vol. 18(6), pp. 575-580.

McAlees, D. (1987). *Traumatic Brain Injury*. The RTC Connection, Stout Vocational Rehabilitation Institute, Vol. 8(3).

McAllister, T.W. (2011). Neurobiological consequences of traumatic brain injury. *Dialogues in Clinical Neuroscience*, Vol. 13(3). pp. 287-300.

McCabe, P., Lippert, C., Weiser, M., Hilditch, M., Hartridge, C., and Villamere, J. (2007). Community reintegration following acquired brain injury. *Brain Injury*, Vol. 21(2), pp. 231-257.

McDaid D, Wiley M, Maresso A and Mossialos E. (2009). Ireland: Health System Review. *Health Systems in Transition*, Vol. 11(4), pp. 1-268.

McDonald, S. (2013). Impairments in Social Cognition Following Severe Traumatic Brain Injury. *Journal of the International Neuropsychological Society*, Vol. 19, pp. 1-16.

McDonough, J. and McDonough, S. (1997). *Research Methods for English Language Teachers*. London: Arnold.

McKernan, J. (1996). Curriculum action research: a handbook of methods and resources for the reflective practitioner, (2nd ed.). London, Kogan Page.

McLean, P. and Porpora, D.V. (2001). Participatory Research: Three Models and an Analysis.

McMordie, W.R., and Barker, S.L. (1988). The financial trauma of head injury. *Brain Injury*, Vol. 2(4), pp. 357-364.

McNiff, J. and Whitehead, J. (2010). *You and Your Action Research Project*, 3rd (ed.), Routledge.

Meikle, L. (2002). Disability, poverty and development. *World hospitals and health services*, Vol. 38(1), pp. 21-33.

Menahan, K. (2012). *Jobs to Careers: Transforming the Front Lines of Health Care*. Robert Wood Johnson Foundation.

Mertens, D.M. (2015). Mixed Methods as Tools for Social. Change. *Journal of Mixed Methods Research*, Vol. 5. pp. 195-197.

Merriam, S.B. (1998). *Qualitative research and case study applications in education*, San Francisco: Jossey-Bass.

Messick, S. (1980). Test validity and the ethics of assessment. *American Psychologist*, Vol. 35, pp. 1012-1027.

Meyer, J. (2000). Using qualitative methods in health related action research, *British Medical Journal*, Vol. 320, pp. 178-181.

Mills, A. and Drummond, M. (1987). Value for money in the health sector: the contribution of primary health care. *Health Policy and Planning*, Vol. 2(2), pp. 107-128.

Mitchell, E.S. (1986). Multiple triangulation: A methodology for nursing science. *Advances in Nursing Science*, Vol. 8(3), pp. 18-26.

Morgan, D.L. (1998). "Practical Strategies for Combining Qualitative and Quantitative Methods: Applications for Health Research". *Qualitative Health Research*, Vol. 8, pp. 368-376.

Moore, A.D., Stambrook, M., Peters, L.C., and Lubusko, A. (1991). Family coping and marital adjustment after traumatic brain injury. *Journal of Head Trauma Rehabilitation*, Vol. 6(1), pp. 83-89.

Morgan, D.L. (1998). Practical strategies for combining qualitative and quantitative methods: Applications to health research. *Qualitative Health Research*, Vol. 8, pp. 362-376.

Morley, D. (1991). Resources Analysis as Action Research. *Resource Analysis Research in Developing Countries*. Ed. Paul. F. Wilkinson and William C. Found. Toronto: York University, pp. 1-16.

Moser, D., Sauer, R., and Xu, R. (2014). How do qualitative and quantitative research differ? Doctoral Seminar Research Methodology 1. Swiss Federal Institute of Technology Zurich.

Mubarak, R. (1997). "*Helping mothers of young children with Cerebral Palsy in Bangladesh*", Unpublished Master's Thesis, Centre for International Health, Institute of Child Health, University College of London.

Murray, P. (2000). Disabled Children, Parents and Professionals: partnership on whose terms? *Disability and Society*, Vol. 15, pp. 683-698.

Murray, G.D., Teasdale, G.M., Braakman, R., Cohadon, F., Dearden, M., Iannotti, F., Karimi, A., Lapierre F., Maas, A., Ohman J., Persson, L., Servadei, F., Stocchetti, N., Trojanowski, T., and Unterberg, A. (1999). The European Brain Consortium Survey of Head Injuries. *Acta Neurochir. (Wien)*, Vol. 141, pp. 223-236.

Murray, C.J.L., and Lopez, A.D. (1996) The global burden of disease: A comprehensive assessment of mortality and disability from diseases, injuries and risk factors in 1990 and projected to 2020. Global Burden of disease and Injury Series. Cambridge: Harvard University Press.

Nampiaparampil, D.E. (2008). Prevalence of chronic pain after traumatic brain injury. *Journal of the American Medical Association*, Vol. 300, pp. 711-719.

Nardi, B.A. (1996). Studying context: A comparison of activity theory, situated action models, and distributed cognition. In B.A. Nardi (Ed.), *Context and consciousness: Activity theory and human-computer interaction*. Cambridge, M.A: MIT Press.

National Service Plan of 2014. Health Service Executive. (Accessed February 10th 2015). <http://www.hse.ie/eng/services/Publications/corporate/serviceplan2014/nationalserviceplan2014.pdf> [Accessed February 10th 2015].

National Institute for Health and Care Excellence (formerly National Institute for Health and Clinical Excellence): Guidance 2003. London. National Institute for Health and Care Excellence (UK); 2003 (Accessed February 26th 2015). <http://www.ncbi.nlm.nih.gov/books/NBK11822/> [Accessed February 26th 2015].

National Institute of Health. (1998). Rehabilitation of persons with traumatic brain injury. *NIH Consensus Statement*, Vol. 16(1), pp. 26-28.

National Overview of Social Worker in Mental Health Services in Ireland (2012). (Accessed March 20th 2015). http://www.mhcirl.ie/File/NO_2012_SW.pdf [Accessed March 20th 2015]

Neill, J. (2006). Analysis of Professional literature. Class 6: Qualitative Research 1.

Nenty, H.J. (2009). Writing a Quantitative Research Thesis, *International Journal of Educational Science*, Vol. 1(1), pp. 19-32.

Neurological Alliance of Ireland (NAI) Report (2010). The Future for Neurological Conditions in Ireland: A Challenge for Health Care; An Opportunity for Change.

Neurophysiology Services. Dublin: Unpublished report. Accessed (March 9th 2015) http://www.nai.ie/assets/70/7F0DE6E9-D279-0C61-137BD29D602E9570_document/NAIDraft3-1-44.pdf [Accessed March 9th 2015].

NHS news archive article: *NHS England launches major exercise to shape the future of specialised services*. (Accessed February 24th 2015). <http://www.england.nhs.uk/2013/11/06/spec-serv/> [Accessed February 24th 2015].

NHS Executive. (1994). *Developing NHS purchasing and GP fund holding: towards a primary care led NHS*. EL (94). 79. Leeds, National Health Service Executive.

Nonaka, I. and Takeuchi, H. (1995). *The Knowledge-Creating Company*. NY: Oxford University Press.

Nodell, A. (1990). The forgotten feelings, fears and family: sibling issues from a parent's perspective. *Cognitive Rehabilitation*, Vol. 8, pp. 6-7.

Nolte, E., and Pitchford, E. (2014). WHO Report : “What is the Evidence of Economic Impact of Integrated Care?”.

NRH’s 33rd Annual Report 2013 (Accessed March 10th 2015) <http://www.nrh.ie/wp-content/uploads/2014/06/2013-Annual-Report.pdf>, published 10th June 2014 [Accessed March 10th 2015].

O’Brien, P. (1998). (Accessed July 25th 2012). An Overview of the Methodological Approach of Action Research. <http://web.net/robrien/papers/arfinal.html> [Accessed July 25th 2012].

Oddy, M., Coughlan, T., Tyerman, A., and Jenkins, D. (1985). Social adjustment after closed head injury: A follow-up study seven years after injury. *Journal of Neurology, Neurosurgery and Psychiatry*, Vol. 48, pp. 564-568.

Orsillo, S.M., McCaffrey, R.J., and Fisher, J.M. (1993). Siblings of head-injured individuals: A population at risk. *Journal of Head Trauma Rehabilitation*, Vol. 8(1), pp. 102-115.

Panting, A., and Merry, P. (1972). The long-term rehabilitation needs of severe head injuries with particular reference to the need for social and medical support for the patient’s family. *Rehabilitation*, Vol. 38, pp. 33-37.

Parker, A.W., Walsh, J., and Coon, M. (1976) A normative approach to the definition of primary health care. *Milbank Memorial Fund Quarterly*, Vol. 54, pp. 415-438.

Parker, R.S. (1990). *Traumatic brain injury and neuropsychological impairment*. USA: Springer-Verlag New York Inc.

Perri 6, Leat, D. Seltzer, K. and Stoker, G. (2002). *Holistic Governance: the New Reform Agenda*, Basingstoke: Palgrave.

Philips Report. National Traumatic Brain Injury in the Republic of Ireland (2008). Traumatic Brain Injury Research Group. pp. 1,6,13,33,59.

Ponsford, J., Olver, J., Ponsford, M. and Nelms, R. (2003). Long-term adjustments of families following traumatic brain injury where comprehensive rehabilitation has been provided. *Monash-Epworth Rehabilitation Research Centre*, Epworth Hospital, Melbourne.

Povlishock, J.T., and Valadka, A.B. (1994). Pathobiology of traumatic brain injury. In M.A.J. Finlayson, and S.H. Garner (Eds.), *Brain Injury Rehabilitation: Clinical Considerations*. USA: Williams and Wilkins, pp. 11-33.

Powell, J., Heslin, J., and Greenwood, R. (2002). Community based rehabilitation after severe traumatic brain injury: a randomised controlled trial. *Journal of Neurology Neurosurgery Psychiatry*, Vol. 72(2), pp. 193-202

Powell, G.E., and Wood, R.L.I. (2001). Assessing the nature and extent of neurobehavioral disability. In R.LI Wood, and T.M. McMillan (Eds.) *Neurobehavioral disability and social handicap following traumatic brain injury*. USA: Taylor and Francis, pp. 65-90.

Prigatano, G.P. (1999). *Principles of Neuropsychological Rehabilitation*. USA: Oxford University Press, Inc.

Purves, R., Riddel, S. and Weedon, E. (2008). *The Development of Care co-ordination Services in Scotland: A Report To Care Co-Ordination Network UK*, Centre for Research in Education Inclusion and Diversity, University of Edinburgh, pp, 3, 25,26.

Ragnarsson, K.T. (2002). Results of the NIH consensus conference on “Rehabilitation of persons with traumatic brain injury”. *Restorative Neurology and Neuroscience*, Vol. 20, pp. 103 -108.

Rao, V., Rosenberg, P., Bertrand, M., Salehinia, S., Spiro, J., Vaishnavi, S., Rastogi, P., Noll, K., Schreten, D.J., Brandt, J., Cornwell, E., Makely, M., and Miles, Q.S. (2009). Aggression after Traumatic Brian Injury: Prevalence and Correlates. *Journal of Neuropsychiatry Clinical Neuroscience*, Vol. 21(4), pp. 420-429.

Reason , P. and Bradbury, H. (2008). *The SAGE Handbook of Action Research: Participative Inquiry and Practice* (2nd ed.). London: SAGE.

Reason, P. (2002b). Special Issue: The Practice of Co-operative Inquiry. *Systemic Practice and Action Research*, Vol. 15(3), pp. 16-270.

Reason, P. and Bradbury, H. (2001). *Handbook on action research: participative inquiry and practice*. London: SAGE Publications.

Reason, P. (1999a). “Integrating Action and Reflection through Co-operative Inquiry”, *Management Learning Special Issue: the Action Dimension in Management: Diverse Approaches to Research, Teaching and Development*, Vol. 30 (2), pp. 207-227.

Reason, P. (1994a). *Participation in Human Inquiry*. London: SAGE Publications.

Reason, P. (1988c). “Whole person medical practice”, in P. Reason (Eds.), *Human Inquiry in Action*. London: SAGE publications, pp. 102-126

Reason, P. and Rowan, J. (1981). *Human Enquiry: A Sourcebook in New Paradigm Research*. Chichester: Wiley.

Reichardt, C.S., and Rallis, S.F. (1994). Qualitative and quantitative inquiries are not incompatible: A call for a new partnership. *New Directions for Program Evaluation*, Vol. 61, pp. 85-91.

Riddell, S. and Tett, L. (2004). ‘New community schools and inter-agency working: assessing the effectiveness of social justice initiatives’ *London Review of Education*, pp. 219-228.

- Riel, M. (2010). (Accessed May 5th 2013). *Understanding Action Research*. Retrieved from Pepperdine University, Centre for Collaborative action Research website: <http://cadres.pepperdine.edu/ccar/define.html> [Accessed May 5th 2013].
- Rivara, B. (2015). Family Functioning Following Paediatric Traumatic Brain Injury.
- Robey, D. (1997) Research commentary: Diversity in information systems research – Threat, promise, and responsibility. *Information Systems Research*, Vol. 7(4), pp. 400-408.
- Robson, C. (2002). *Real World Research*. (2nded.). Blackwell, Oxford, pp. 279.
- Rolfe, G., Freshwater, D. and Jasper, M. (2001). *Critical Reflection for Nursing and the Helping Professions*. Basingstoke, U.K: Palgrave, pp. 26-35.
- Romanow, R. J. (2002). Building on Values: The Future of Health Care in Canada. Final Report of the Commission on the Future of Health Care in Canada. National Library of Canada. Cat. No. CP32-85/2002E-IN.
- Roozenbeek, B., Maas, A.I.R., and Menon, D.K. (2013). Changing patterns in the epidemiology of traumatic brain injury. *Nature Reviews Neurology*, Vol. 9, pp. 231-236.
- Rose, V.L. (1999). NIH issues consensus statement on the rehabilitation of persons with traumatic brain injury. *American Family Physician*, Vol. 59 (4), pp. 1051 -1054.
- Rotondi, A.J., Sinkule, J., Balzer, K., Harris, J. and Moldovan, R. (2007). A qualitative needs assessment of persons who have experienced traumatic brain injury and their primary family caregivers. *Journal of Head Trauma Rehabilitation*, Vol. 22, pp. 14-25.
- Rusnak, M., Janciak, I., Majdan, M., Wilbachr, I., and Mauritz, W. (2007). Severe traumatic brain injury in Austria I: introduction to the study. *Wien Kli n. Wochenschr*, Vol. 119, pp. 23-28.
- Sachs, P.R. (1991). *Treating Families of Brain-Injury Survivors*. New York: Springer.
- Said, E. (1991). *The World, the Text and the Critic*. London, Vintage.
- Sale, J.E.M., Lohfield, L.H. and Brazil, K. (2002). Revisiting the Quantitative - Qualitative Debate: Implications for Mixed Methods Research. *Quality and Quantity*, Vol. 36, pp. 43-53.
- Sander, A.M., and Kreutzer, J.S. (1999). A holistic approach to family assessment after brain injury: In: *Rehabilitation of the adult and child with traumatic brain injury*, Rosenthal, M. Griffith, E.R., Kreutzer, J.S., Pentland, B. Philadelphia: F.A. Davis, pp. 199-215.
- Selener, D. (1997). Participatory action research and social change. Ithaca, NY: Cornell Participatory Action Research Network.
- Serio, C.D., Kreutzer, J.S., and Witol, A.D. (1997). Family needs after traumatic brain injury: A factor analysis study of the Family Needs Questionnaire. *Brain Injury*, Vol. 11 (1), pp. 1-9.

Serna, E.C.H. and Sousa, R.M.C. (2006). Mudanças nos papéis sociais: uma consequência do trauma crânio-encefálico para o cuidado familiar. *Rev Latino Am-enfermagem*, Vol. 14(2), pp. 183-189.

Serna, E.C.H., and Sousa, R.M.C. (2005). Depressão: uma possível consequência adversa do trauma crânio-encefálico para o cuidador familiar. *Acta Paul Enferm*, Vol. 18(2), pp. 131-135.

Serrant-Green L. (2002). "Black on Black; Methodological Issues for Black Researchers Working in Minority Ethnic Communities." *Nurse Researcher*, Vol. 9, pp. 30-44.

Shank, G. (2002). *Qualitative Research. A Personal Skills Approach*. New Jersey: Merrill Prentice Hall.

Shannon, J. (2011). (Accessed January 20th 2013). "Fulfilling a duty of care" http://www.medicalindependent.ie/5062/fulfilling_a_duty_of_rehabilitative_care , Medical Independent Article. [Accessed January 20th 2013] .

Shavelson, R.J., and Towne, L. (2002). *Scientific Research in Education*, National Academy Press, Washington, DC.

Shea, S., Misra, D., Ehrlich, M.H., Field, L., and Francis, C.K. (1992). Predisposing factors for severe uncontrolled hypertension. *New England Journal of Medicine*, Vol. 327, pp.776-781.

Shenton, A.K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, Vol. 22, pp. 63-75.

Silver, J.M., McAllister, T.W., and Yudofsky, S.T. (2005). *Textbook of Traumatic Brain Injury*. American Psychiatric Pub.

Sjoberg, G., Williams, N., Vaughan, T., and Sjoberg, A. (1991). The case study approach in social research. In Feagin, J., Orum, A., and Sjoberg, E. (Eds.).(1991). *A Case for Case Study*. Chapel Hill, NC: University of North Carolina Press, pp. 27-79.

Sloper, P. (1998). Models of service support for parents of disabled children. What we know? What do we need to know? *Social Policy Research Unit*. University of York, Heslington, York, UK. Blackwell Science Ltd, Vol. 25(2). pp. 85-99.

Sloper, P. and Turner, S. (1992). Service needs of families of children with severe physical disability. *Child: Care, Health and Development*, Vol. 18, pp. 259-282.

Sloper, P., Greco, V. and Webb, R. (2006). *Key worker services for disabled children: what characteristics of services lead to a better outcomes for children and families?* *Child; Care, Health and development*, Vol. 32 (2), pp. 147-157.

Sousa, RMC. (2006). Traumatismo Cranioencefálico- Bases teóricas e intervenções de Enfermagem, In: *Enfermagem em neurociência: fundamentos para a prática clínica*, Koizumi, MS.; Diccini MS, (Ed), pp 209-231, Atheneu, ISBN 85-7379-840-8, São Paulo.

Spivack, M.P. (1994). Pathways to policy: A personal perspective. *Journal of Head Trauma Rehabilitation*, Vol. 9(2), pp. 82-93.

Stake, R.E. (1995). *The Art of Case Study Research: Perspective in Practice*. London: SAGE.

Stambrook, M., Moore, A., Gill, D., and Peters, L. (1994). Family adjustment following traumatic brain injury: A system,-based, life cycle approach. In M.A.J. Finlayson, and S.H. Garner (Eds.), *Brain injury rehabilitation: Clinical considerations*. USA: Williams and Wilkins, pp. 332-351.

Starfield, B. (1992). *Primary Care: Concept, Evaluation and Policy*. New York, Oxford University Press.

Starfield, B., and Shi, L. (2002). Policy relevant determinants of health: An international perspective. *Health Policy*, Vol. 60, pp. 201-216.

Starfield, B., Shi, L. and Macinko, J., (2005). *Contribution of primary care health systems and health*. Milbank Q, Vol. 83, pp. 457-505.

Stebbins, P. (1997). Long term changes in family needs after brain injury: A preliminary review. *Australian Journal of Rehabilitation Counselling*, Vol. 3(1), pp. 30-39.

Stebbins, P., and Leung, P. (1998). Changing family needs after brain injury. *Journal of Rehabilitation*, Vol. 64 (4), pp. 15-23.

Steckler, A., McLerory, K.R., Goodman, R.M., Bird, S.T., and McCormick, L. (1992). Toward integrating qualitative and quantitative methods: An introduction. *Health Education Quarterly*, Vol. 19, pp. 1-8.

Stein, S. C., Georgoff, P., Meghan, S., Mizra, K. & Sonnad, S. S. (2010). 150 years of treating severe traumatic brain injury: a systematic review of progress in mortality. *Journal of Neurotrauma*, Vol. 27, pp. 1343–1353.

Stone, E. and Priestley, M. (1995). ‘Parasites, pawns and partners: disability research and the role of non-disabled researchers’. *British Journal of Sociology*, Vol. 47, pp. 696-716.

Stringer, E.T. (2007). *Action Research*. Thousand Oaks, Ca: Sage.

Strub, R.L., and Black, B.W. (1988). Close head trauma. In: *Neurobehavioral disorders: A Clinical Approach*. Philadelphia. PA: FA Davis, pp. 313-348.

Suarez-Balcazar, Y. and Orellana-Damacela, L. (1999). A university-community partnership for empowerment evaluation in a community housing organization. Socio-logical Practice: *Journal of Clinical and Applied Research*, Vol. 1, pp. 115-132.

Sullivan, A.L., and Artiles, A.J. (2011). Theorising Racial Inequity in Special Education: Applying Structural Inequity Theory to Disproportionality. *Urban Education*, Vol. 46(6). pp. 1526-1552.

Tagliaferri, F., Compagnone, C., and Korsic, M. (2006). A systematic review of brain injury epidemiology in Europe. *Acta Neurochir (Wien)*, Vol. 148, pp. 255-268.

Tashakkori, A., & Teddlie, C. (1998). Mixed methodology: combining qualitative and quantitative approaches. Thousand Oaks, CA: Sage.

Tellis, W. (1997). Introduction to Case Study. *The Qualitative Report*, Vol 3.

The Journal (2012), (Accessed March 20th 2015). <http://www.thejournal.ie/hse-178000-waiting-to-see-a-consultant-at-an-outpatient-clinic-409073-Apr2012/>
<http://www.thejournal.ie/hse-178000-waiting-to-see-a-consultant-at-an-outpatient-clinic-409073-> [Accessed March 20th 2015].

The World Medical Association (2000). Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects. Helsinki: The World Medical Association.

Thompson, H.J., Weir, S., Rivara, F.P., Wang, S.D., Salkever, D., MacKenzie, E.J. (2012). Utilisation and Costs of Health Care after Geriatric Traumatic Brain Injury. *Journal of Neurotrauma*, Vol. 29(10). pp. 1864-1871.

Thornhill S., Teasdale, G.M., Murray, G.D., McEwen J., Roy, C.W., and Penny, K.I. (2000). Disability in young people and adults one year after head injury: prospective cohort study. *British Medical Journal*, Vol. 320, pp. 1631–1635.

Thurman D.J., Kraus, J.F., and Romer, C.J. (1995). Standards for surveillance of Neurotrauma. World Health Organisation : Safety Promotion and Injury Control Division of Emergency and Humanitarian Action. Geneva, Switzerland.

Townsley, R., Abbott, D., and Watson, D. (2004). Making a difference? *Exploring the impact of multi-agency working on disabled children with complex health care needs, their families and the professionals who support them*. Bristol: The Policy Press.

Treasure, R.A., and Davies, J.A. (1990). Contribution of a general practitioner hospital: a further study. *British Medical Journal*, Vol. 300, pp. 644-646.

Trexler, L.E., Trexler, L.C., Malec, J.F., Klyce, D., and Parrott, D. (2010). Prospective randomised controlled trial of resource facilitation on community participation and vocational outcome following brain injury. *Journal of Head Trauma Rehabilitation*, Vol. 25(6), pp. 440-446.

Turocy, P.S. (2002). Survey research in athletic training: the scientific method of development and implementation. *Journal of Athletic Training*, Vol. 37, pp. 174-9.

Tully, M.P. (2014). Research: Articulating Questions, Generating Hypotheses, and Choosing Study Designs. *The Canadian Journal of Hospital Pharmacy*, Vol. 67(1), pp. 31-34.

- Tyerman, A., and Booth, J. (2001). Family interventions after traumatic brain injury: A service example. *Journal of Neurorehabilitation*, Vol. 16, pp. 59-66.
- van Zomeren, A.H., and van den Burg, W. (1985). Residual complaints of patients two years after severe head injury. *Journal of Neurology, Neurosurgery, and Psychiatry*, Vol. 4, pp. 21-28.
- Vender, J.C. (2001). Community Action Research: A Three-Part Service learning Course Model. *Innovations in Undergraduate Research and Honours Education: Proceeding of the second Schreyer National Conference 2001*. Paper 28.
- Vogenthaler, D. (1987). An Overview of head injury: Its consequences and rehabilitation. *Brain Injury*, Vol. 1(1), pp. 113-127.
- Vrangbaek, K. (2013). The Danish Health Care System, 2013. *International Profiles of Health Care Systems*, pp. 28.
- Vuorenskoski, L. (2008). *Health care systems in transition: Finland*. WHO Regional Office for Europe on behalf of the European Observatory on Health Systems and Policies.
- Vygotsky, L.S. (1978). *Thought and Language*. Cambridge, MA: MIT Press, pp.7.
- Wallerstein, N., and Duran, B. (2008). "The Theoretical, Practical, and Historical Roots of CBPR." Pp. 25-46 in *Community-based Participatory Research for Health: From Process to Outcomes*, edited by M. Minkler and N. Wallerstein. San Francisco, CA: Jossey Bass.
- Walsh, F. (1996). Conceptualisation of normal family processes. In F. Walsh (Ed.), *Normal family processes* (2nd ed.). pp. 3 -72.
- Walsh, M., Galvin, R., Macey, C., McCormack, C., and Horgan, F. (2013). National Survey of Stroke Survivors: Documenting the Experiences and Levels of Self-Reported Long-Term Need in Stroke Survivors in the First 5 years. Systematic Review: Factors Associated with Community Re-integration in the First 12 months Post Stroke: A Qualitative Synthesis. Dublin: Royal College of Surgeons in Ireland, 2013.
- Ward, P. Huddy, J., and Hargreaves, S. (1996). Primary care in London: an evaluation of general practitioners working in an inner city accident and emergency department. *Journal of the American Emergency Medicine*, Vol. 6, pp. 11-15.
- Waters-Adams, S. (2006). *Action Research in Education*. Faculty of Education, University of Plymouth.
- Webster, G., Daisley, A., and King, N. (1999). Relationship and family breakdown following acquired brain injury: The role of the rehabilitation team. *Brain Injury*, Vol. 13, pp. 593-603.
- WellFlorida Council Inc. (2007) (Accessed March 17th 2015). Traumatic brain injury in State: A needs and resource assessment: Executive summary. (Accessed 17 March 2015): <http://wellflorida.org/wp-content/uploads/2012/07/Excutive-Summary-TBI-Needs-Assessment.pdf>. [Accessed March 17th 2015].

Wesolowski, M.D., and Zencius, A.H. (1994). A practical guide to head injury rehabilitation: A focus on postacute residential treatment. New York: Plenum Press.

Whelan, D. (2010). An evaluation of the cost effectiveness of Acquired Brain Injury Ireland Case Management in the North East Area (Meath, Cavan/Monaghan and Louth). Unpublished MA Thesis, Institute for Public Administration.

Whitehead, J. (1996). Lecture Notes for EdD Sessions. University of Bristol, July 1996. Developed from a lecture, On a Better Way to Professionalism: living our values in our practice, Kingston University.

WHO and World Bank (2011). World Report on Disability. Geneva, Switzerland: World Health Organisation.

WHO (2010a). Community-Based Rehabilitation: CBR Guidelines. Geneva, Switzerland: World Health Organisation.

WHO Report (2006), Neurological Disorders: public health challenges, World Health Organisation, Vol. 3(10): Traumatic brain injuries.

WHO Report (2004). *What are the advantages and disadvantages of restructuring a health care system to be more focussed on primary care services?*. WHO Regional office for Europe's Health Executive Network (HEN):

WHO Report (2000). Health Systems: Improving Performance.

Wienke, G.B.W, Groenewegen, P. and van der Zee, J. (1988). General practice in urban and rural Europe: The range of curative services. *Social Science and Medicine*, Vol. 47, pp. 445-453.

Wilkinson, S. (1999). Life After Brain Injury. *Nursing Standard*, Vol. 14(2), pp. 172-177.

Willemijin S., W., Kroneman, M., Boerma, W., Van der Berg, M., Westert, G., Devillé, W. and van Ginneken, E. (2010). *Health Systems in Transition: Netherlands*. WHO Regional Office for Europe on behalf of the European Observatory on Health Systems and Policies.

Willer, B., Flaherty, P.M., and Coallier, S. (2001). Families living with the effects of acquired brain injury. In R.L.I. Wood, and T.M. McMillan (Eds.), *Neurobehavioral disability and social handicap following traumatic brain injury*. USA: Taylor and Francis Inc, pp. 47-63.

Willer, B., Allen, K., Liss, M. and Zicht, M.S. (1991). Problems and coping strategies of individuals with traumatic brain injury and their spouses. *Achieves of Physical Medicine and Rehabilitation*, Vol. 72. pp. 460-464.

Williams, C. (2007). Research Methods. *Journal of Business and Economic Research*, Vol. 5(3). pp. 65-71.

Winstanley, J., Simpson, G., Tate, R., and Myles, B. (2006). Early indicators and contributors to psychological distress in relatives during rehabilitation following severe traumatic brain injury: Findings from the brain injury outcomes study. *Journal of Head Trauma Rehabilitation*, Vol. 21(6). pp. 453-466.

Winter, R. (1989). *Learning from Experience: principles and practice in action research*. Lewes, Falmer.

Wood, R.L.I. (2001). Understanding neurobehavioral disability. In R.L.I. Wood and T.M. McMillian (Eds.), *Neurobehavioral disability and social handicap following traumatic brain injury*. USA: Taylor and Francis, pp. 1-27.

Wood, R.L., and Yurdakul, L.K. (1997). Change in relationship status following traumatic brain injury. *Brain Injury*, Vol. 11(7), pp. 491-501.

Wren, MA., Gillespie, P., Smith, S., Kearns, K., Wolfe, C., Parkin, D., Crichton, S., Hickey, A., Horgan, F., Wiley, M., Cowman, S., Delargy, M., Murphy, S., O'Neill, D., Williams, D., and Loughnane, C. (2014). Towards Earlier Discharge, Better Outcomes, Lower Costs: Stroke rehabilitation in Ireland. Dublin: Economic and Social Research Institute.

Wright, L.M. and Leahey, M. (2002). Enfermeiras e famílias. *Um guia para avaliação e intervenção na família*. Trad.de Silvia M. Spada. Roca, ISBN 85-7241-346-4, São Paulo

Yin, R.K. (2004). *Case Study Methods*, Revised draft, COSMOS Corporation.

Yin, R.K. (1994). *Case Study Research: Design and Methods*. 2nd Ed. SAGE Publications, London, U.K.

Yin, R. (1989). *Case Study Research.: Design and methods*. (rev.ed.). Newbury Park, CA: SAGE Publishing.

Yin, R.K. (1984). *Case Study Research: Design and Methods*, Beverley Hills, Calif: SAGE Publications.

Yin, R., and Moore, G. (1987). The use of advanced technologies in special education. *Journal of Learning Disabilities*, Vol. 20 (1), pp. 60.

Yuriko, W., Shiel, A., Toyoko, A., Kenji, T., and Kazuo, T. (2000). An evaluation of neurobehavioral problems as perceived by family members and levels of family stress 1–3 years following traumatic brain injury in Japan. *Clinical Rehabilitation*, Vol. 14 (2), pp. 172-178.

Zaidah, Z. (2003). An Investigation into the effects of Discipline-Specific Knowledge, Proficiency and Genre on Reading Comprehension and Strategies of Malaysia ESP Students. Unpublished Ph.D Thesis. University of Reading.

Zaidah, Z. (2007). Case study as a research method. *Journal Kemanusiaan bil 9*. University Technology, Malaysia.

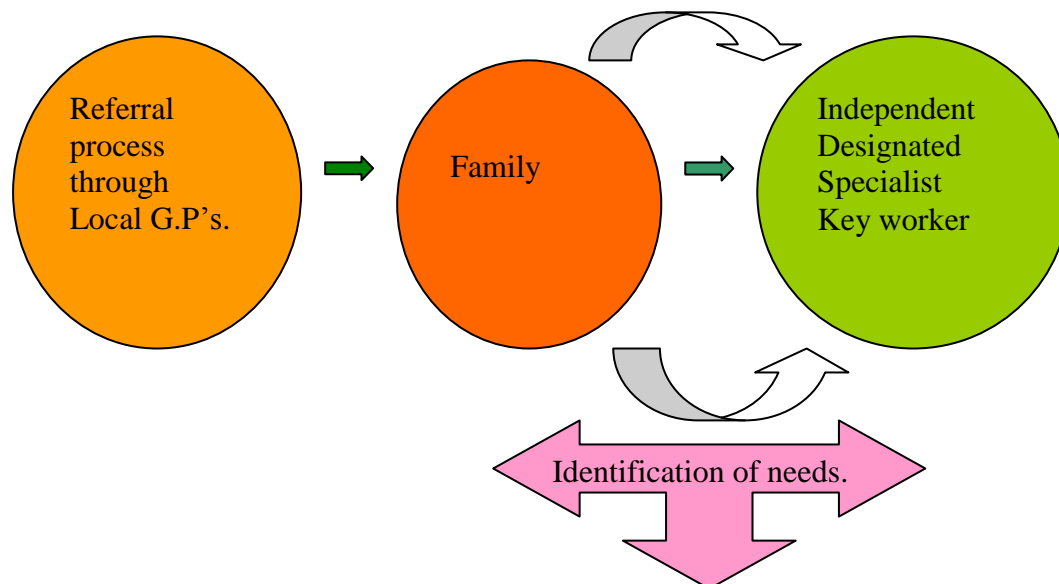
Zonabend, F. (1992). The monograph in European ethnology. *Current Sociology*, Vol. 40(1), pp. 49-60.

APPENDICES

Appendix One - Designated Specialist Key Working Model

Diagram 1

"Flow through designated specialist key working model"



Multi – Disciplinary Team:

The multi-disciplinary team will depend on the needs of the individual family, for example:

General Practitioners,

Medical Professionals, i.e. Physiotherapists, Occupational Therapist, Public Health Nurses.

Service Providers, i.e. Vocational TBI Service Providers.

Social Workers,

Community Services, i.e. Local Community Welfare Officers and Voluntary Organisations.

Appendix Two (A) - Family Identification of Needs Spreadsheet

Family (A) Example of Identification of Needs Spreadsheet

Case Study 4 (Mary McCroon)

First Name	Surname	Ph No:	Address	Relationship to individual with TBI	Identified Needs for family
Mary	McCroon	XXXXXX	xxxxxxx	Son	Self care for Mary.
					Offered family support grp, but decline until John is settled in the [REDACTED] Hospital. Wishes to attend to her son's needs – Visual Impaired Service first Access good support structure.
					To-Do:
					For Mary to take time out for herself during the wk and come in one morning a wk late. During this time she is to look after herself, maybe have a shower, have a coffee etc. See File note 10.09.10 2nd visit. Mary advised that she had taken a half day to clean out the house and that she had now registered for a course once a wk for 1hr on Mindfulness to promote more self-care for herself.

Appendix Two (B) – Individual Identification of Needs Spreadsheet

Individual (B) Example of Identification of Needs Spreadsheet

Case Study 4 (John McCroon)

Name of Individual with TBI	Date of TBI	Information on TBI	Identified Needs for Individual
John	75 days ago	John fell 50 feet 75 days ago from a height.	To Do:
			Contact the [REDACTED] for the local CRO. Contacted Visual Impaired Service 03.09.10, J.N is the officer. Ph No: 01 xxxx. Left word for J to ring me back. J rang 06.09.10 Discussed situation. Request Eye Cert. See File note 06.09.10. Spoke with J 10.09.10 and agreed J to request the eye cert. Referral officially made to [REDACTED] for John. Updated Mary. See file notes 10.09.10 (Community Resource Officer (CRO)-Visual Impaired Service)
	(approx June '10)	Sustained multiple injuries, head injury mainly upper frontal lobe, broken collar bone and internal injuries.	
		John was placed into an induced comma upon arrival at [REDACTED] Hospital.	The intention is for the CRO to visit and assess John, whilst also supporting Mary.
		Has severed the optic nerves on his left eye which is slightly drooped.	Contacted BD 06.09.10, Social worker 2nd Hospital. On hols for 1wk. Left message. See file note 06.09.10
		Right eye peripheral vision deficits to his right side, lower quadrant.	For Mary (mother) to advise when John is due to be discharged to the [REDACTED] Hospital. Mary advised moved to the [REDACTED] Hospital of the 20.09.10.
		STM Difficulties, Word finding & recall diff	Following release from the [REDACTED] hospital, the CRO and a PCC team is to set up to assess the home transition.
		Advised was moved to the Mater hospital to attend to his physical injuries.	Obtained correct PHN for John, from practice. See file note 07.09.10. Spoke with [REDACTED] today. See File note 10.09.10
		Receiving Physio there for his arm/shoulder	At Present:

		Recently underwent operation for a removal of a cyst from the stomach.	At the ■ Hospital rec physio.
		Has lost a lot of weight, was getting tube feed.	Also recently underwent surgery for
		John is a vegetarian. He is in a band and plays the guitar.	removal of cyst in stomach.
		Awaiting to be moved to the ■ once well enough to do so.	Moved to ■ Hospital wk of 20.09.10.
			Spoke with CS NRH S.W. Ph No: 2xxxx. See file note 28.09.10
			Requested referral to be sent out from TBI Community Based service. 28.09.10

Appendix Three – Information Sheet

Research participant information sheet

Research into exploring how the role of the key worker can be developed out into the community for families who have experienced a loved one with a Traumatic Brain Injury.

Information for participants.

Background to the study

I am a PhD student at the School of Education, University of Birmingham, and my research is looking into ways to which to develop the role of a key worker out in the community for families of those who have a loved one with a Traumatic Brain Injury (TBI). A main aim will be to explore how families who have experienced a loved one with a TBI have dealt with problems associated with accessing and maintaining suitable services for the rehabilitation of people with a TBI. The research will seek in particular to examine how the role of the key worker may support the development of a supportive collaborative service for families who have a loved one with a TBI. Even though all efforts will be made to identify and address the needs of the family within the research, the researcher would like to highlight that there is a possibility that the proposed support may not be feasible, or may not work in the way that is planned. This may be down to various reasons, for example: lack of resources, services and length of referrals for services.

The information being collected for this research is the perspectives and accounts of the families and possible different professional groups (such as health professionals and other disciplines) who may throughout the research become involved in the research. In addition, the researcher also hopes to interview and ask the families to assist in the design and development of a questionnaire surrounding the needs of families of those who have experienced a loved one with a TBI.

The questionnaire, once designed should take no longer than 15 minutes to complete. The returned questionnaires will be confidential to the researcher and anonymous – no individual will be identified.

The interviews will take no longer than 30 minutes and will seek to explore the family's perspectives and knowledge on their experiences and thoughts surrounding a development of

how a key worker could support them in the future. Interviews will take place between the researcher and the family. The study should be completed by October 2010.

During the research, the families will be asked to attend two Focus Groups. The first Focus Group will surround reviewing collectively the designed key worker questionnaire to ensure clarity and agreement in the design. This meeting should last no longer than 1hr. The time/date and location of the Focus Group will be flexible to accommodate the families. The second Focus Group will take place at the end of the research. The aim of this Focus Group will be to gather feedback from the participating families on their evaluation of the research. This Focus Group may last for approximately 1½ to 2hrs. Again, the time/date and location will be flexible to accommodate the commitments of the families.

Following on, in addressing the development of a care plan, please note that each family will be required to meet with the researcher on possible multiple occasions in order to arrange the care network. Each of these meetings will last for approximately 1hr. These times/dates and locations will be organised in conjunction with the family in order to accommodate the family's everyday commitments.

Confidentiality

It is important for families to consider that through participating within the research surrounding the design and completion of a questionnaire and interviews, the families will also be engaging with the researcher as a family link worker and therefore personal information will be shared on this basis. Furthermore, families should be made aware that complete confidentiality will not be guaranteed as the research will involve the families participating within two Focus Groups.

Following on, Interviews and Focus Groups will be fully transcribed. The transcripts will be stored in a secure location and only the researcher and her two supervisors will have access. People's names or job titles will not be included in reports, but participants should be aware that they may be identifiable through comments that they make. Participants will be offered a copy of their Interview transcript, completed questionnaire along with a copy of both transcripts from the Focus Groups. Families will be provided with the opportunity to take out or amend any part of it that they do not wish reported in the findings.

Participants should also be aware that the researcher has a legal obligation to disclose information relating to unethical or criminal behaviour.

We hope you will be able to help with this important area of research. If you agree to take part please complete the consent form. You are still free to withdraw at any time and without reason.

How will the results be used?

The data from this research will be used for:

1. PhD thesis

2. Academic research papers and presentations
3. A summary report to be circulated to all interested participants or participating organisations.

Please indicate on the consent form if you would like to receive a summary of the results.

Please get in touch if you would like further information:

Niamh Rowe – [REDACTED]; [REDACTED]

Supervisor for research:

- Dr. Penny Lacey – [REDACTED]; [REDACTED]

Thank you.

Appendix Four – Consent Form for Interview & Questionnaire

Consent Form – Interviews

Research into exploring how the role of the key worker can be developed out into the community for families who have experienced a loved one with a Traumatic Brain Injury.

- I am willing to take part in the interview and design and completion of a questionnaire for this research.
- I am willing to accept that for the interview to be recorded.
- I understand that no-one will have access to the recording beyond the researcher and her two supervisors.
- I understand that any personal statements made in the interview or questionnaire will be confidential. As far as possible all comments will be anonymous in any reports or papers that are produced as a result of the research. People's names or job titles will not be included in reports, but there is a possibility that I may be identifiable through comments that I make.
- I understand that I will be offered a copy of my interview transcript and completed questionnaire and will be provided with the opportunity to take out or amend any part of it that I do not wish to be reported in the findings.
- I understand that taking part in the research is voluntary and that I may withdraw at any time.
- I understand that the data from this research will be used for three things:
 1. PhD thesis.
 2. Academic research papers and presentations
 3. A summary report to be circulated to all interested participants or other interested parties.

Name of Respondent: _____

Signature of respondent: _____

Date: _____

Name of Researcher: _____

Signature of Researcher: _____

Appendix Five – General Practitioners

Invitation Letter

Research into exploring how the role of the key worker can be developed out into the community for families who have experienced a loved one with a Traumatic Brain Injury.

Invitation Letter for General Practitioners.

Date:

Niamh Rowe,
Add 1,
Add 2.
Ph No: 11111

Dear Dr. 1,

This research is being conducted by Niamh Rowe on behalf of my PhD studies with the University of Birmingham, surrounding exploring ways of developing a key worker system for families who have a loved one with a Traumatic Brain Injury (TBI). My experience to – date surrounds working within the area of TBI rehabilitation for the past eight years. It is during these eight years and working with families, that I have identified the need to develop community supportive services for the families of a loved one with a TBI. Therefore, the focus of this project will be to identify ways in which the key worker can assess the needs of the family and work collectively with the family to develop a beneficial Individualised Care Plan.

In order to obtain such data, the survey will consist of two data collection methods:

- Self-report Questionnaire (this questionnaire will be collectively developed with the family participants and completed thereafter accordingly).
- Interview.

Once the questionnaire is developed, the completion will take about 15 minutes to complete. The returned questionnaires will be confidential to the researcher and anonymous – no individual will be identified. With regard to the interview, the process should take approximately 30 minutes. Focus Groups for the participants will also take place initially, to identify the needs of families with a loved one with a TBI, so that a beneficial questionnaire may be designed and developed. Following on, each family will be met individually to complete the data collection process.

It is within this regard, that I would appreciate if you could recommend two families within your surgery who have experienced a loved one with a TBI, who may be interested in participating within the research. I would also ask that you identify potential “extra” families, but not contact them unless they are required to partake in the research in the event of a family opting out of the research. Their participation will provide important information to shape both my PhD research and hopefully assist in the development of services surrounding rehabilitative needs for families who have a loved one with a TBI. I look forward to hearing from you and thank you for your contribution. I have also enclosed an information sheet on the research for both yourself and the families to review. I would be happy to discuss my research in person to both yourself and the families before commencing my research. My contact details are noted above. Alternatively, I will follow-up on this letter within two weeks of the date of issue.

We hope you will be able to help with this important area of research. If you agree to take part please complete the consent form. You are still free to withdraw at any time and without reason.

Yours faithfully,

Niamh Rowe

Ph No: [REDACTED]

Contact Details:

Niamh Rowe – [REDACTED]; [REDACTED]

Supervisor for research:

- Dr. Penny Lacey – [REDACTED]; [REDACTED]

Appendix Six – General Practitioners Consent Form

Research into exploring how the role of the key worker can be developed out into the community for families who have experienced a loved one with a Traumatic Brain Injury.

Consent Form for General Practitioners.

I _____, hereby give permission to participate in the research

completed by _____.

Participant's Signature: _____ Date: _____

Witness by: _____ Date: _____

Appendix Seven - Spreadsheet Recording

General Practitioners Invitations

1st Dr. Letters Invitations

Dr's Names	Address	Contact Details	Issued	Due to Follow-Up	Comments	
					Notes	Dates
Dr. XXXX	xxxxxxx	Ph No: xxxxx	01.07.10	12.07.10	Dr. will explore clients and get back before wkend. Dr. M rang me on the 10.09.10 with two names for me to contact: Case Study 3 Ph No: 01 XXX (Son) and Case Study 2 (Husband TBI 20yrs plus ago) Ph No: 01 XXXX	CASE STUDY 2 AND 3 CONFIRMED
Dr. XXX	xxxxxxx	Ph No: xxxxx	01.07.10	11.08.10	Said didn't rec. Hand delivered 13.07.10	Rang 16.07.10 Advised on hols for 3wks. Req I ring him back 2nd wk of Aug. Rang back on the 7th of Aug. Advised by sec no go. The Dr had reviewed his patients and they had no suitable participants.
Dr. XXX	xxxxxxx	Ph No: xxxxx	01.07.10	12.07.10	Sec said will explore but unsure of whether they will participate	Rang 16.07.10. Advised by practice manager no go too busy.
Dr. XXX	xxxxxxx	Ph No: xxxxx	01.07.10	12.07.10		

Appendix Eight - File Note from Mary (Case Study 4)

04.10.10

Mary rang me at around 6pm to update me on the meeting with the [REDACTED] hospital last Friday. She advised that she felt that nothing was prepared by the team and that they were more prepared through the work that I had done with them and the questions I had given them. She advised that she felt that the Social Worker was not prepared and had nothing written up to present. Mary advised that she was thankful that I had given them details on the plan that was previously agreed with the Social Worker. She went onto say that she felt that the [REDACTED] hospital was angry with them for discharging themselves early as they said that John was missing out on specialist treatment and that he would have to wait for the outpatients Physio and OT and that he would not be priority. The Social Worker had said it will be at least 6wks plus. They also said that John could not avail of counselling through the [REDACTED] hospital. Mary advised that the Social Worker did complete the TBI service provider no. 1 referral form. We spoke about counselling and how the TBI service provider no. 1 could support that. We spoke about the second TBI service provider no. 2 referral form and agreed to hold off for a few wks to see how John presents as it is too early to identify any deficits. Mary agreed to note down anything she sees.

She went onto talk about John wishing to go over to England later on in the mth to play with the band. Said he would need to clear this with the Dr as it was still very early days left. She advised that John would get tired in the evening but that he was managing very well. She advised that he was eating well and that he had made himself some scrambled eggs and toast the other day.

Agreed for Mary to speak with her GP this Wed and update her on the situation and for the Dr to review John. I asked her to note about the possible delay with the physio and OT and enquire about the community team being assigned earlier. Mary agreed to discuss this with the GP.

She also noted about John's visit to his surgeon the other day about his face and how that had gone really well. She said she felt a bit uncomfortable and got bits teary eyed upon passing the building where John had sustained his TBI. We spoke about her feelings associated with this.

She also told me about John getting the clip removed from the mouth that was left in by one of the hospitals and how it had all gone really well. She advised that John has an apt this Frid in the [REDACTED] hospital with the neurosurgeon to see how things are going.

Mary said she would keep me informed of all of the appointments and outcomes of same. She thanked me for the material re: the hospitalisation stage and about TBI, noting that it was helping her understand a lot.

She went onto say about the dietician and I explained about neuroplasticity and the importance of a good healthy diet to help promote brain function and rehabilitation. It was agreed for her to speak with the Dr about referral for same.

Overall Mary noted that my help was invaluable and how both herself and her husband noted that they felt that I had performed the work of the other professionals and that without me they would have being lost. She said she would be informing the GP of the work done and how it had helped her and her family.

We spoke about her and the need to continue to look after herself and attending the meditation on a Tues. She said she was due to go tomorrow to the mindfulness course and that she had gotten a massage the other day and it was great.

Niamh

Appendix Nine - File Note from Public Health Nurse

29.10.10

PHN returned my call. Discussed the following

I advised PHN of the situation with John now at home and problems with the scar on his stomach.

I advised that the family had visited their GP Dr. H.

PHN advised that she has not received any discharge plan from the [REDACTED] Hospital. She said it was terrible and that she should have gotten some report on the same day or the next day but has never had to wait 3/4wks following discharge.

She advised that she cannot see John (Case Study 4) unless the Dr refers him to her for the monitoring of the scar. Suggested that the family go to the GP and see what happens. Also to note the delay in the discharge plan with the GP to see about follow up with the [REDACTED] Hospital.

Thanked her for returning my call and for the support.

Niamh

Appendix Ten - Case Study Protocol

Stage 1:

1. Initial invites sent out to GPs within my area, requesting their assignment of possible suitable families for the research.
2. Families were referred by their GPs.
3. Six families sought from GPs.

Stage 2:

1. Initial meeting with families to review my research and seek consent.
2. Resulting from the initial meeting, needs were identified for the family and the individual with the TBI.
3. An agreed Individual Rehabilitation Plan (IRP) prioritising the needs of the family was outlined.
4. A transition plan was developed with the above IRP to promote visualisation of the individual case study's action plan.
5. I then commenced working with the family on their IRP.
6. Work was initially delegated between me and the family. As the case grew and the team became bigger, work was delegated accordingly.

Stage 3:

1. All participants worked collectively on an equal partnership basis.
2. I adopted the role as a researcher and worked within the team as an equal participant.