



By Kate Bohan

LIVING WITH AN ACQUIRED BRAIN INJURY DURING CHILDHOOD AND ADOLESCENCE:

An Irish Perspective

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Artwork created by pupils in the National Rehabilitation Hospital School.

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The Children's Research Centre was set up by Trinity College in 1995 as a joint initiative of the Department of Psychology and the Department of Social Studies. The Centre undertakes research and evaluation on issues and policies concerning children and young people. The Centre is multidisciplinary in approach and works in close collaboration with other members of the University, practitioners and policy-makers, and international colleagues. It also works through partnerships with statutory, voluntary and community bodies concerned with children and young people. The Centre has a range of publications.

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Foreword

Acquired Brain Injury has been termed the 'silent epidemic' of our modern times, its effects often underestimated and misunderstood. The sense of loss for survivors, their families and carers can be enormous, and perhaps never more so than when it is a child's life which has been so dramatically altered.

For the staff at the National Rehabilitation Hospital, who treat children with acquired brain injuries, there is an awareness that when families are discharged into their communities they are only at the beginning of a long journey. We send children home to an altered future and often to inadequate practical and emotional supports. These children are testament to the wonders of modern medicine, but what happens to these families in the longer term? What are the ongoing implications of having such an injury and how have we, as service providers, responded?

It was the desire to find out what happened to these families and their carers in the years following discharge from the National Rehabilitation Hospital which prompted this unique piece of research. The idea also had its origins in the United Nations Convention on the Rights of the Child, the National Children's Strategy and the Commission on the Status of People with Disabilities.

The Hospital, in partnership with the Eastern Regional Health Authority, the National Disability Authority, the Katherine Howard Foundation and the Society of St. Vincent de Paul Holy Cross Conference/South Dublin Area, commissioned the Children's Research Centre, Trinity College, Dublin to carry out this work on our behalf. The purpose of the research was to document the experiences not only of parents and professionals, but also those of the children themselves and their siblings. It was envisaged that this piece of research would identify gaps in existing services and provide a basis for the planning and development of further appropriate, effective service provision. Representatives of the National Rehabilitation Hospital, the Eastern Regional Health Authority and the National Disability Authority have been active members of the Steering Group during this project.

The particular concentration of this report on the experiences and needs of children and young people with Acquired Brain Injuries is extremely valuable and wholly appropriate. It is these individual experiences and needs that the planning and delivery of services must be tailored to meet. The importance of supporting families is also given proper recognition. Families play a hugely important role in care giving, but their own health, emotional and social needs can be overlooked. The report itself is testament to the approach of the National Rehabilitation Hospital and its staff, which is always to strive to respond as comprehensively as possible, and on the basis of best practice, to the needs of clients. The Eastern Regional Health Authority is committed to working in partnership with the National Rehabilitation Hospital, families and service providers to achieve the goal of a comprehensive service that fully reflects the needs and aspirations of young people with acquired brain injuries and their families.

Within the National Rehabilitation Hospital, this work was initiated and co-ordinated by members of the Social Work Team in co-operation with members of the Paediatric Nursing Team. Our thanks to these individuals and also to Dr Hugh Monaghan, Consultant Neuro-Paediatrician and the Paediatric Team for their invaluable contribution. A special thank you to Sister Stella Lambert, Ward Sister of the Children's Unit, who was so enthusiastic about the project from the outset and who has dedicated most of her professional life to these children. We would also like to commend the teachers in the NRH school and the group of inpatient children who provided the artwork for the cover of this document.

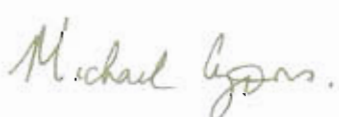
Most importantly this research would never have happened if it were not for the families who shared their experiences and their heartbreak and gave so willingly of their time. Many spoke of their desire to make a difference for their children and for those families who will inevitably come after them.

By their involvement we hope to educate the community at large about what it means to have an Acquired Brain Injury and, in partnership with these families and with each other, we hope to advocate for change.



Derek Greene

CEO
National Rehabilitation
Hospital



Michael Lyons

CEO
Eastern Regional
Health Authority



Claire O'Connor

Director
National Disability
Authority

Origins of the study

The idea for this piece of research originated within the Social Work Department and we played an important role in bringing it to fruition.

As Social Workers, we are engaged in listening to our clients and their families, enabling them to connect with both their own resources and the services available within the wider community. We play a role in influencing Social Policy and highlighting gaps in services.

For those of us who work with people affected by Acquired Brain Injury, it has been our experience that many of these families have little or no service provision following discharge from the National Rehabilitation Hospital. Parents and carers of these clients are almost totally dependent on their own resources to cope with the enormous tasks they face. The children who attend the paediatric service are reviewed as they grow and develop. These children offer a unique insight into the often devastating and long-term impact of Acquired Brain Injury on the family unit. We hope that this research will give voice to the struggle in their daily lives.

An enormous amount of 'behind the scenes work' went into this project, co-ordinating with the Children's Research Centre, Trinity College, Dublin, accessing funds and liaising with the stakeholders.

My particular thanks to all my colleagues on the Social Work team, particularly Anne O'Loughlin, Senior Medical Social Worker. Other people who worked alongside me in the hospital were, Sister Stella Lambert, Bernadette Lee, Clinical Risk Manager, Claire Conway, Acting Ward Sister, Dr. Hugh Monahan, Consultant Neuro-Paediatrician and Derek Greene, C.E.O. It was through our combined efforts that this invaluable piece of research was made possible.

The Social Work Department is committed to working towards adequate and appropriate services for children affected by Acquired Brain Injury. Our role in BRÍ (meaning strength and understanding) the Acquired Brain Injury Advocacy Association, is dedicated to advocating for all those affected by Acquired Brain Injury. We are working in partnership with families towards achieving these goals.

'We cannot wait for great visions from great people because they are in short supply... We must light our own small fires in the darkness' (Charles Handy)

We look forward to the contribution this research will make, to future government policy and service provision.



Rosaleen Maguire

**Head Medical Social Worker
National Rehabilitation Hospital**

Authors' acknowledgements

The authors would like to thank all those who contributed to the present study and assisted the research team throughout the research process.

We would particularly like to acknowledge the funders of this study, the National Rehabilitation Hospital (NRH), the National Disability Authority (NDA), the Eastern Regional Health Authority (ERHA), the Katherine Howard Foundation and St. Vincent de Paul Holy Cross Conference/South Dublin Area.

We would especially like to thank the members of our advisory group, who provided much needed support, advice and enthusiasm in their efforts to oversee this research to its completion.

Within the NRH itself, numerous individuals played a central role in supporting and advising the research team. We would like to express a special thanks to Rosaleen Maguire, Anne O' Loughlin, Sr. Stella Lambert and Claire Conway. Our thanks also to Dr. Hugh Monaghan, consultant Neuro - Paediatrician, and the Paediatric Team for their invaluable contribution.

We would also like to thank our colleagues in the Children's Research Centre for their words of wisdom, interest and support in this research endeavour. We would like to express our gratitude to Aoife Fitzpatrick and Frances Allwright who provided support and assistance at vital stages of the research, and to extend a special thanks to Anne O' Neill who provided on-going support in the production of the report. We also wish to convey our gratitude to Prof. Robbie Gilligan for his informative feedback during the preparation of this report.

We gratefully acknowledge the contributions of the teachers and health professionals who gave of their time and spoke with honesty about their experiences of working with children with ABI. However, our greatest thanks is reserved for the children, siblings and parents who welcomed the researchers into their homes and openly described the journey of their family in the aftermath of this stressful life event. The children and young people themselves who have suffered from ABI played a vital role in enhancing our understanding of what it is like for young people following an acquired brain injury.

Executive Summary

Introduction

The aim of this research was to explore the experiences of children and their families following an acquired brain injury (ABI). In addition, the study aimed to identify the service and support needs of children and their families following discharge from the National Rehabilitation Hospital (NRH) into their home community. Thus the primary focus of this report is on families' community-based needs and experiences.

Method

A qualitative approach was used to explore the needs and experiences of children and their families. A national random sample of families who had attended the paediatric services of the NRH within the six year period prior to January 2002 were chosen to take part in this study. The sample was stratified according to the cause of the injury, with approximately 60% of the children acquiring their brain injury through road traffic accidents and 40% through other causes (e.g. stroke). The study adopted a family-centred approach, whereby children, parents and their siblings were invited to take part in an interview. Each family was also asked to nominate a teacher and a health professional within the community who were familiar with the child with ABI. Twenty-seven families took part in this research, with 96 interviews and 2 focus groups carried out in total. The total number of participants in this study was one-hundred and sixteen.

Findings

Impact on child with ABI

- The children had a broad range of perspectives on their adjustment back to home and community life after a period in the NRH.

- Both children and parents identified numerous changes in the child with ABI following the trauma. Children tended to focus on changes in physical functioning and limitations in activities.

- Many parents identified difficulties in peer relations as a significant feature of ABI in children and young people. Parents felt their children often experienced social isolation, a loss of friends and a difficulty making new friends or finding a peer group to which they felt they belonged.

- While negative reactions were experienced by a substantial number of children, many children and parents recognised the presence of supportive friendships as a crucial factor in the child's adjustment post-ABI. A number of teachers also identified the benefits of placing children with their friends upon their return to school.

- Both children and their parents depicted the acquisition of a brain injury during the period of childhood or adolescence as a negative emotional experience for the young person.

Impact on family members

- Family members experienced significant emotional turmoil, stress and frustration in the aftermath of the child's injury. For some, this occurred in both the short and long-term.
- The separation of families during the intensive and long periods of hospitalisation was a particular difficulty for all concerned.
- For some siblings, parental absence during the period of hospitalisation and the lack of contact with the ill sibling

were stressful aspects of their experience. Some parents perceived that the intensive care-giving which the child with ABI often required, both in hospital and at home, resulted in the neglect of their other children.

- Parents experienced significant role-changes following their child's illness or injury. The burden of care following the child's return home typically fell on parents, frequently resulting in a restriction of social activities and a lack of time for themselves.
- Parents had many concerns for their child's future. These concerns typically related to the well-being of their child, their ability to cope with secondary school or their vocational and residential situation following the completion of school.

Health care experiences

- Reports of parents and professionals suggested one of the over-riding problems within community health services was the lack of resources and services to meet the comprehensive needs of children with ABI and their families.
- Many parents reported receiving a lack of follow-up services within the community and feeling a sense of abandonment following their discharge from the NRH.
- Professionals within the community reported little experience of working with children with ABI. A primary need of professionals within the community was the need for training and more information.
- Both NRH professionals and parents themselves, viewed parents as playing a key role in pursuing services for their child with ABI and managing their child's care needs.

- Community health professionals highlighted the inadequacy of communication amongst the various providers of health services and identified the need for more formal links between all stakeholders in the child's care network.
- Professionals within the community identified the need for a team approach to provide a co-ordinated system of care to children with ABI.

Educational experiences

- Children experienced a variety of difficulties within the school environment. These included intellectual and physical problems, and for some, behavioural and social difficulties.
- Despite these difficulties, many teachers reported that the children adjusted relatively well to the school environment.
- Teachers perceived themselves as having little understanding or experience of ABI in children and felt they received little formal support or assistance from professional services.
- Teachers reported that the children had a strong desire to fit in and to feel 'normal' within the school environment.

Key recommendations

Policy issues

- To develop strategies to promote family-centred care and to foster family unity and support during the period of rehabilitation within the NRH.
- To consider the care needs and service requirements of young people with ABI and develop a strategy for the management and treatment of all ABI cases.

- To consider the place of ABI in future disability policy.

Information and training

- To provide information and training to professionals in the community to support and enhance their work with children with ABI.
- To promote public awareness and understanding of acquired brain injury and its impact on children and their families.

Provision of services

- To develop family-centred care within the community and to recognise the support and advice required by the primary caregivers of children with ABI.
- To develop measures to foster the well-being of young people with ABI and to support their social integration within family, neighbourhood, school and leisure activities.
- To provide support and guidance to young people with ABI prior to and during life transitions and development changes, (for example, from primary school to secondary school and secondary school to young adulthood).

- To promote a co-ordinated system of care that is responsive to the needs of children and their families, with adequate resources to provide a prompt service, as required.

- To improve communication between existing services and to allow for the consistent passage of information through the system thus incorporating the acute hospitals, the NRH and the community health, social and educational services.
- To develop a plan for preparing teachers in the community for the education of children with ABI.
- To develop a system for tracking and monitoring children's progress and changing needs as they move through the educational system.

Future research

- To encourage the development of longitudinal studies from a) the point of A&E onwards or b) community-wide epidemiological studies in order to account for pre-morbid factors.
- To initiate further research on the social experiences of different illness groups (e.g. stroke, traumatic brain injury etc) and to utilise observational methodologies to explore peer relationships and social adjustment.

Chapter 1

Overview of the study

INTRODUCTION

Advances in medical science have contributed to increased survival rates and improved outcomes for those who have suffered from an acquired brain injury. The current challenge facing our health and social services is to enhance the quality of the lives of these individuals by providing the necessary support and services to enable each individual to fulfil their potential. This challenge is increased when working with children and young people who have acquired a severe brain injury. The outcome of a given brain injury is difficult to predict, in both adults and children alike. With children however, acquired brain injury (ABI) occurs in the midst of a period of rapid change. During childhood, the consequences of an acquired brain injury may not always be obvious in the immediate aftermath of the trauma, but may only emerge as the child moves through the developmental trajectory. With children therefore, the challenge is to provide the optimum level of care that is responsive to their changing needs.

Various terminology is used in reference to Acquired Brain Injury. Examples include head trauma, brain injury, head injury, acquired brain injury and traumatic brain injury. Acquired brain injury has been defined as "... injury to the brain which results in deterioration of cognitive, physical, emotional or independent functions. It can occur as a result of trauma, hypoxia, infection, substance abuse, degenerative neurological disease or stroke" (Commonwealth Department of Human Services and Health, 1994, p26, cited in Department of Human Services, 2001). The term 'acquired brain injury', therefore, represents a broad classification, referring to both traumatic brain injury (e.g. road traffic accidents, blow to the head) and non-traumatic brain injury. Much of the social scientific research that exists focuses on traumatic brain injury as opposed to the broader classification of acquired brain injury.

From a research perspective, there has been inadequate investigation of the psychosocial impact of ABI during the period of childhood. To date, much attention has focused on the neuropsychological consequences that may arise from ABI, with a lesser focus on the social and behavioural effects of ABI. There has also been little focus on children's experiences of acquiring a brain injury with a view to understanding what it is like for children to undergo such a traumatic and life-altering occurrence. While in recent times, increased importance has been placed on the family context in which ABI occurs (e.g. Taylor, Drotar, Wade, Yeates, Stancin, & Klein, 1995), there has been an evident neglect of the stress and demands placed on siblings in the event of ABI in the family.

From an Irish perspective, the lack of empirical studies impedes our understanding of the experiences of families following ABI in a child. Understanding the current situation which families face in the community following a period of rehabilitation in the National Rehabilitation Hospital (NRH), is a necessary step in the identification of long-term service needs and resource requirements.

PRESENT STUDY

The present research uses qualitative interview techniques in an effort to understand the experiences of children and their families following an acquired brain injury. The main focus of the study is on the experiences of children and their families following discharge from the NRH and their re-integration into their home communities. The emphasis on post-discharge experiences allows one to look 'beyond the doors of the rehabilitation hospital' to the

real life contexts and situations which families may encounter (Janus, Mishkin, & Pearson, 1997). The study also seeks to identify the service and support needs of those who have been affected by an acquired brain injury, with a view to making recommendations for enhancing future service provision.

The following research questions are targeted within the present study:

- What are the psychosocial and educational experiences of children and their families following an acquired brain injury in a child family member?
- What are the special support needs of parents in parenting a child with an acquired brain injury?
- What is the impact of ABI on the family unit as a whole?
- What is the nature of existing service provision for children and their families in the community following discharge from the National Rehabilitation Hospital?
- What are the needs of community professionals in working with children who have acquired a brain injury?

The initial idea for this research originated within the social work team in the NRH. The Children's Research Centre, Trinity College Dublin, was subsequently commissioned to carry out this research on behalf of the hospital. The National Rehabilitation Hospital were the primary funders of this study but were supported by the National Disability Authority, the Eastern Regional Health Authority, the Katherine Howard Foundation and St. Vincent de Paul Holy Cross Conference/South Dublin Area County Council

The research project was supported by an advisory group comprising of members of the research team, professionals from the NRH, professionals from the disability sector and service planning and a parent representative. The role of the group was to provide advice and guidance throughout the study. Members of the group, which was chaired by Mr John Collins, Department of Health and Children, were:

- Prof Robbie Gilligan, Director & Professor of Social Studies, Children's Research Centre, Trinity College Dublin;
- Dr Caroline Heary, Post-doctoral Fellow, Children's Research Centre, Trinity College Dublin;
- Dr Diane Hogan, Lecturer in Psychology & Senior Research Fellow, Children's Research Centre, Trinity College Dublin;
- Sr Stella Lambert, Sister of Paediatric Ward /Claire Conway, Acting Ward Sister, The National Rehabilitation Hospital;
- Rosaleen Maguire, Head Medical Social Worker, The National Rehabilitation Hospital;
- Diane Nurse, Service Planner for Physical Disabilities, Eastern Regional Health Authority;
- Anne O'Loughlin, Senior Medical Social Worker, Paediatric Team, The National Rehabilitation Hospital;
- Patrick Pierce, Parent Representative;
- Dr Mike Timms, Senior Psychologist /Dr Anne Good, Senior Researcher, The National Disability Authority.

RESEARCH APPROACH

This research adopted an innovative approach to understanding the needs of young people with an acquired brain injury, through its inclusion of the views of multiple stakeholders. The study explored the views of children themselves, their

siblings, parents and professionals who work with children with an acquired brain injury. As such, the research participants are regarded as experts in terms of their roles and experiences, and have an important part to play in identifying the current situation that exists for children and families in Ireland.

To date, inadequate consideration has been given to understanding the views of children and young people on what it is like to live with an acquired brain injury. In an effort to comprehend the true impact of an acquired brain injury during childhood and adolescence, it remains crucially important to invite young people to take part in this exercise. The evident move towards a more child-centred approach in research, practice and policy, highlights the need to explore children's subjective experiences and give them due consideration. In addition, the National Children's Strategy (2000), with its emphasis on the development of quality services for children and the quality of life of children in Ireland, provides an impetus to place the child at the centre of all our efforts.

Overall, the inclusion of multiple stakeholders in this research project will provide the first comprehensive evidence on the lived experiences of young people and their families following an acquired brain injury in Ireland, and can potentially contribute to the future development of service provision. An additional positive aspect of the current study is that the families who took part in the interviews constitute a random national sample. They were therefore dispersed throughout the country and are likely to represent a cross-section of the overall population of children who have suffered severe head trauma in Ireland.

A whole-child perspective is adopted in this study in an attempt to understand the impact of ABI on children and young

people. In doing so, it acknowledges the potential impact of ABI on a child's emotional and behavioural well-being, their physical functioning, their intellectual processes, their sense of self and their relationships with others. In addition, this research encapsulates a family-centred approach. It recognises that an acquired brain injury during the period of childhood and adolescence represents a family affair, with consequences for all those who are part of the child's social world.

In exploring the phenomenon of ABI, it is also important to acknowledge the considerable diversity in the causes, nature and consequences of an acquired brain injury. No two children are the same and no two families are the same. Each family's journey in the aftermath of ABI is a unique one. It is not the aim of this report to tell the story of each individual family. Much emphasis is given to the common experiences which families face and the common struggles they encounter. However, the study also focuses on diversities in families' experience, by revealing the variety of views that emerged.

STRUCTURE OF THE REPORT

This report is set out in eleven chapters. Chapter 2 provides a brief overview of acquired brain injury and outlines current policy and service provision in Ireland. In Chapter 3, an overview of the study design and the procedure followed in undertaking this research is outlined. Chapter 4 follows with a profile of the children attending the NRH with an acquired brain injury and a profile of the interview sample which was randomly selected from the overall client base of the NRH. In addition, three case-studies are provided to illustrate some common features of ABI in children. Chapters 5, 6, 7, 8, 9 and 10, focus on the respective views of each group interviewed, namely children and young people with acquired brain injuries,

parents, siblings, teachers who have worked with children with ABI in the community, community health professionals and NRH professionals. The final chapter summarises the emerging trends of this research and identifies the implications of these findings for future service provision. Based on the empirical findings of this study, recommendations are made for the future delivery of support and services to children with ABI and their families.

Throughout the chapters that report on the research findings, quotations from the participants are provided, thus illustrating some of the views that emerged in the interviews. Given the moderate number of families who took part in this study and the diverse characteristics of these families, the authors chose to omit details regarding the age and gender of those whose quotes are provided in order to protect their identity. Furthermore, in an effort to ensure the confidentiality of those who participated in this study, the names of all participants have been changed.

The abbreviation ABI will be used in place of Acquired Brain Injury, throughout the report. The terms 'children' and 'young people' are used interchangeably throughout the report. One of the criteria set for the inclusion of families in the interviews of this research study was that the young person with ABI would be less than 20 years 11 months. However, in all cases, the individuals with ABI were under the care of the *Consultant Neuro-Paediatrician*. Therefore, it generally seemed appropriate to use the aforementioned terms.

Table 1.1 Main points of study

- The main focus of the study is on the experiences of children and their families following discharge from the NRH.
- The aim of the study is to understand the experiences of children and families living with ABI, and to identify their needs for services and support.
- The views of multiple groups – children, siblings, parents, teachers & health professionals – are included.
- The study adopts a whole-child perspective and a family-centred approach.
- The families participating in this study were randomly chosen from a nationwide sample.
- The study was supported by an Advisory Group.

Chapter 2

Background

INTRODUCTION

Acquired brain injury represents one of the most significant causes of morbidity and mortality amongst young people, both in Ireland and internationally. At present, the precise number of children who have acquired a severe brain injury in Ireland is relatively unknown. A recent epidemiological study in Ireland found that head injury represented 26% of all unintentional injury hospital admissions over the period 1993-1997 for children under 5 years, and 28.1% of all unintentional injury hospital admissions over the period 1993-1997 for children 5-14 years (Scallan, Staines, Fitzpatrick, Laffoy & Kelly, 2001).

Within the UK estimates of the prevalence of brain injuries amongst children are likewise unavailable. However, a recent study provides information on the incidence of traumatic brain injuries in children in the North Staffordshire region (Hawley, Ward, Long, Owen & Magnay, 2003). The results of this population-based study indicate that each year, 280 per 100,000 children are admitted for ≥ 24 hours with a traumatic brain injury, of these 232 will have a mild brain injury, 25 moderate, 17 severe, and 2 will die. These figures are generally higher than previously estimated. From a review of several studies, Kraus (1995) identifies the average incidence of brain injury in children as approximately 180 per 100,000 per year. Estimates of the broader diagnosis of acquired brain injury are generally unavailable.

THE NATURE OF ACQUIRED BRAIN INJURY

A unique feature of ABI is that its effects are often hidden or not readily apparent. A child may appear well on the outside, but they may have suffered extensive damage to their cognitive and social functioning. The true consequences of a child's brain injury may only become evident in the context of verbal

exchanges, academic situations or social interactions.

A further point worth noting is the diversity that exists in terms of the cause, impact and ultimate outcome of ABI. As Furlonger and Johnson (1989) note, "head injury is not an all or nothing phenomenon, but occurs along a continuum of severity, causing commensurate changes in cognition and behaviour, with parallel needs for help" (p. 147).

Many argue that the issues that confront families that have a child with an acquired brain injury vary quite significantly from those with congenital disabilities (Warzak & Anderson, 2001). The very nature of an acquired brain injury is its sudden acquisition, which frequently distorts the normal developmental trajectory leaving significant emotional, cognitive, language, behavioural and physical consequences. These consequences may be temporary or permanent, subtle or pervasive.

CAUSES, MECHANISMS AND CONSEQUENCES

Brain injury is typically categorised by the cause of the injury as well as the severity of the injury. Statistics clearly reveal that the predominant causes of *traumatic brain injury* vary with age. Infants and toddlers typically sustain traumatic brain injuries due to falls or abuse, 4-12 year olds commonly sustain brain injuries due to falls, sporting events and road traffic accidents, and the most frequent cause of brain injuries for adolescents is road traffic accidents (Fletcher et al., 1995). Overall however, road traffic accidents represent one of the most common causes of severe brain injury amongst children and young people (Dunn, Thurman & Alverson, 1999).

Measures of initial brain injury severity are typically applied in the case of *traumatic brain*

injury, with the three primary classifications being mild, moderate and severe. These classifications are typically indicated by the depth of coma (Glasgow Coma Scale [GCS]), the duration of coma, the length of post-traumatic amnesia and the type of injury (Midleton, 2001). However, there is not necessarily a direct linear relationship between the severity of the head injury and the child's long-term outcome. Individual cases of remarkable recovery have been found amongst those with severe head injuries, while, conversely, there have been some examples of children classified with mild head injury who have shown a poor long-term prognosis (Midleton, 2001). Overall, much variability exists in terms of the cause of a child's injury, the nature of their injury and the actual outcome of their injury. Consequently, there can be considerable heterogeneity in the care needs of children and their families.

The consequences of an acquired brain injury are numerous and complex in nature. Following a brain injury, deficits may arise in one or more of the following areas: intellectual functioning; language and communication skills; attention; memory; speed of information processing; academic achievement; motor abilities; sensory functioning and behavioural or psychosocial domains (see Middleton, 2001; Oddy, 1993 for reviews).

Much research has focused on the functional limitations of acquired brain injury and the neuropsychological consequences of head trauma. However, in addition, social and behavioural changes can be seen in some children following the head injury. Indeed, for some families, the emotional and behavioural changes produce the greatest stress amongst family members (Brooks, McKinlay; Lezak, 1978; cited in Waaland & Kreutzer, 1988).

A combination of factors interact to determine the final outcome in children. These include a variety of injury factors, such as the nature

and location of a child's brain injury and the severity of the injury. Such factors also interact with both child and family characteristics prior to the injury or illness and in the aftermath of the child's trauma (Kinsella, Ong, Murtagh, Prior & Sawyer, 1999; Rivara, Jaffe, Polissar, Fay, Liao & Martin, 1996; Taylor, Drotar, Wade, Yeates, Stancin & Klein, 1995; Taylor, Yeates, Wade, Drotar, Klein & Stancin, 1999).

ACQUIRED BRAIN INJURY DURING CHILDHOOD AND ADOLESCENCE

An acquired brain injury at any age is a traumatic event. However, such an injury during the formative years of childhood and adolescence represents a significant obstacle in the development of a child's potential.

Traditionally, the notion of the developmental plasticity of the brain emphasised the protective effects of a young age in the acquisition of a cerebral insult. According to this view, the acquisition of a cerebral insult at a younger age results in fewer behavioural and cognitive deficits. This arises due to the ability of children to compensate for brain damage acquired through brain re-organisational processes. While there is some evidence to support the greater capacity of the brain for repair following brain injury in children, there is increasing evidence to suggest that is an over-simplistic notion (Chapman & McKinnon, 2000; Dennis, 2000). Dennis (2000) points out that the time since injury does not necessarily equate with the enhanced recovery of a child. While some abilities may improve over time, others may decline and others may remain stable.

Due to the changing nature of children, certain deficits may not become apparent until further on in the life cycle, when the young person is confronted with new challenges and increasingly more complex tasks and information. As the child progresses

therefore, it may become evident that certain higher abilities have been significantly compromised by the head trauma (Christensen, 1997). It has been hypothesised that children with certain injuries may "grow into" the deficits acquired as a result of the trauma (Chapman & McKinnon, 2000). This clearly depends on the nature of the injury, the developmental stage of the child and the ability or outcome being assessed.

An acquired brain injury during childhood has the potential to disrupt normal maturational and developmental processes. Thus children may be more vulnerable to problems in the aftermath of ABI. For some individuals, following the onset of an acquired brain injury, it may be more difficult to learn new information than to recall previously learned material. As children generally have an incomplete knowledge and skill base, there is concern that some younger children may become doubly disadvantaged in the acquisition of new material if the brain injury has an impairing effect on this process (Janus, Mishkin, & Pearson, 1997).

Childhood represents an important period in a person's life, in that the basic building blocks for the child's social, emotional and physical development are laid down during these formative years. As such, it remains crucial that optimum growth and development are fostered and nurtured during this stage of life. A long-term perspective is required in assessing the impact of ABI on a child's development. Children have different developmental needs at different stages of the lifecycle, and require ongoing monitoring and assessment. Consequently, the content and focus of any rehabilitation programme must be tailored in accordance with the child's needs and abilities at a given point in time.

ACQUIRED BRAIN INJURY AS A FAMILY AFFAIR

A child's injury or illness occurs within the context of a family. According to Lezak (1987), acquired brain injury is a "family affair". The onset of trauma or illness is likely to have a systemic effect, impacting not only on the child with the injury, but also on family members, acquaintances and friends. Research has identified that the family environment both affects and is affected by the occurrence of an acquired brain injury. Financial difficulties, occupational adjustments, family strain, emotional and behavioural changes in the child and parental psychological symptoms are but some of the issues which parents may have to cope with (Kinsella, et al., 1999; Osberg, Kahn, Rowe & Brooke, 1996; Osberg, Brooke, Baryza, Rowe, Lash & Kahn, 1997; Taylor, et al., 1995; Wade, Taylor, Drotar, Stancin, Yeates, 1998; Zinner, Ball, Stutts & Philput, 1997). In addition, pre-existing coping strategies, family stressors and other family factors have an influence on how families adapt to the stressful nature of head trauma (Kinsella et al., 1999; Max, 1998).

MODEL OF REHABILITATION

Given the impairing effect of a head trauma, there frequently is no medical cure for a child's condition. Instead, medical and social services attempt to rehabilitate affected individuals to their optimum level of functioning. Rehabilitation may be defined as "development of a person to the fullest physical, psychological, social, vocational, avocational, and educational potential consistent with his or her physiological or anatomical impairment and environmental limitations" (De Lisa, Martin, & Currie, 1988, p.3; cited in Michaud, 1995). The rehabilitation process is typically facilitated by an interdisciplinary team which may consist of the following professionals: physicians; nurses; occupational therapists; speech and language therapists; physiotherapists; dieticians; psychologists; social workers; vocational

counsellors and special educators (Eames, Turnbull & Goodman-Smith, 1989; Michaud, 1995). Each rehabilitation programme consists of individualised target goals that are tailored to an individual child's needs and abilities.

The ideal continuum of care for those who acquire a brain injury spans from the initial acute trauma period to the rehabilitative phase, and right through to the period of reintegration into the community. According to Waaland and Kreutzer (1988), this process should begin with intensive care in the hospital setting and end with successful academic, community and vocational integration. In the long-term, schools and families provide much of the needed support for children during their developmental years (Savage, Pearson, McDonald, Potoczny-Gray & Marchese, 2001).

While families frequently experience severe distress, chaos and a whole range of emotions when initially faced with the prospect of their child's survival or non-survival, for those who acquire a severe brain injury this emotional roller-coaster can continue for some time into the future. Lash and Scarpino (1993) identify a "second crisis of injury" in the period after discharge from a rehabilitative facility or a hospital environment. Frequently, this is a period during which health professionals become less involved and families become the primary caregivers. The consequences and changes brought about by the injury or illness become more readily apparent during this time, and the burden of responsibility in caring for the child typically rests with the parent(s).

It is important to highlight at this point that research indicates that not all individuals with a severe brain injury are referred from an acute care facility to an appropriate rehabilitative setting or institution (Emanuelson & Wendt, 1998; Hawley, Ward, Magnay & Long, 2002). It appears that a sizable number of children who suffer from a severe acquired brain injury are discharged from the acute medical facility to their home

environment. Therefore, the care continuum and the consequences that arise for these children and their families may be fundamentally different.

POLICY IN IRELAND

There is currently no specific national strategic plan or policy dedicated to acquired brain injury in Ireland. Until recently, ABI has remained on the fringes of the national health agenda and has not been targeted as a serious health issue from a national policy perspective.

However, within the recent health strategy (Department of Health & Children, 2001) certain broad principles have relevance to ABI. Part of the underlying vision of the health strategy is the development of a health system that will support people and empower them to achieve their potential. The strategy embraces the notion of holistic health, and recognises the wider implications of illness and disability on the family, community and society. As such, it adopts a person-centred approach, with the aim of placing the individual in need of care at the centre of all health care endeavours. In addition, maximising the quality of life of individuals is identified as a primary objective of the health system. As part of the move towards enhancing the quality of life of individuals, the Irish government has set a target for the development of an action plan for rehabilitation services, with the aim of setting out a programme for tackling inadequacies in services and the integration of specialised facilities with local community based services. This action plan is currently in preparation.

At a regional level, there has also been some recognition of the need to develop strategies relevant to those with ABI. For example, within the Eastern Regional Health Authority (ERHA) initiatives are underway towards the development of a rehabilitation strategy. While this strategy will be dedicated to meeting the

needs of people with disabilities in general, it will undoubtedly have implications for the planning and provision of support and services for young people with ABI.

With regard to the area of disability per se, one of the key documents in the area of disability is the equality strategy that was formulated by the Commission on the Status of People with Disabilities (1996). Within this document, those with head traumas are identified as a vulnerable group who receive inadequate care provision. One of the primary recommendations of this report is the introduction of a Disability Act to safeguard the rights of those with disabilities in society. In addition to the principle of equality, further key principles of this document are the maximisation of participation amongst those with disabilities and the need to foster independence and choice. This report also recognises the need to adopt a needs-based approach to the delivery of services, thus providing an individualised system of support and care to those who require it.

Legislation in the area of disability is currently in a state of flux. The Disabilities Bill proposed in December 2001 resulted in a public outcry in reaction to what was perceived as emphasis on the duties of public bodies, as opposed to the adoption of a rights-based approach as outlined in the Commission on the Status of People with Disabilities (1996). Moreover, much dissatisfaction has been expressed with Section 47 of the Disability Bill, which contains a clause purporting to remove the rights of people with disabilities to seek judicial redress if any of the Bill's provisions are not carried out. This Bill was subsequently withdrawn in February 2002 and a new round of consultations was initiated. These consultations have just been completed.

With regard to the area of education, the Education for Persons with Disabilities Bill was introduced in March 2002. Amongst its many aims, the bill aims to enhance the rights of children to avail of an appropriate education

that will allow them to lead socially and economically productive lives. It outlines the need to establish a register of children with special needs and the preparation of an education plan for children placed on the register. However, the NDA (2002) in their response to the proposed bill argue that there must be a statutory right to the assessment of a child's need at the earliest possible time and the provision of a statement of need should arise from this assessment. The introduction of legislation in this area is currently awaited.

A further policy with relevance to the current research is the National Children's Strategy (2000). This strategy aims to enhance the status of children in Ireland, and to enhance the quality of children's lives. It represents the first co-ordinated governmental policy that directly addresses the multiple needs of children. It is noteworthy for its emphasis on the importance of seeking children's views on matters of importance to them, and on the need for the development of structures that facilitate the views of children to be heard. In addition, it aims to enhance the quality of services for all children. In relation to children's health and well-being, it recognises the challenge that Ireland's health and social services face in responding to children with multiple disabilities. It also envisages the establishment of a programme for adolescents in the area of accidents and injuries.

Overall, existing policy provides a broad framework for providing children with the support and services they require for the fulfilment of their potential. There is recognition of the need for integrated and co-ordinated services for those with complex health needs, and the need to ensure that those with disabilities have equal opportunities for participating in social, educational and economic life (Department of Health & Children, 2001; Government of Ireland, 2000; Commission on the Status of People with Disabilities, 1996). Regional developments are underway in some areas in addressing the needs of those with ABI and the government

has made a commitment to developing a rehabilitation strategy in the near future. However, up until the present time there has been no national concerted action or initiative to specifically recognise the difficulties children, young people and their families experience when faced with a head trauma.

SERVICE PROVISION IN IRELAND

In examining the needs and experiences of children and young people with acquired brain injury in Ireland, it is important to outline principal service providers. At the outset, all children will have spent a period of time in an acute hospital facility. Those who are deemed to require rehabilitation are generally referred to such a facility. At present there exists one primary rehabilitation centre in Ireland, covering both adults and children alike. The National Rehabilitation Hospital serves patients from all over the country. In relation to children, it provides comprehensive rehabilitation for those who have sustained acquired and traumatic injury, as well as those with spinal cord injuries, limb absence, spina bifida and other neurological disorders. The focus of this report is on those who have acquired a brain injury. As stated previously, this includes those children who have acquired a brain injury as a result of a traumatic injury (e.g. fall, road-traffic accident), a malignancy, infection (e.g. empyema, meningitis), or a stroke-related illness. Children are typically referred to the NRH from a neurosurgical team, a paediatrician or a GP.

Once discharged from the NRH, children and their families typically return to their home environments and further rehabilitation generally takes place close to the child's place of residence. Community-based facilities are provided by the local health board or by a local branch of a voluntary organisation. The main function of the health board is to provide health, community care and personal social services to the people within its area.

For those with disabilities, the health board may provide services such as basic health services, assessment, rehabilitation, income maintenance, community care, home support, respite care and residential care.

Two further organisations at a national level which are pertinent to the area of acquired brain injury are the National Disability Authority and Headway¹. The National Disability Authority is an independent agency established under the aegis of the Department of Justice, Equality and Law Reform. Its principal functions are: to assist in the co-ordination and development of disability policy; to undertake research for the planning, delivery and evaluation of disability services and programmes; to monitor the implementation of standards and codes of practice for programmes and services for people with disabilities; and to liaise with service providers and other bodies in the development and implementation of appropriate standards.

Headway is a national voluntary association for acquired brain injury. This organisation aims to enhance understanding of acquired brain injury amongst the public and political representatives. In addition, Headway aims to promote and provide services for those with an acquired brain injury and their relatives. Counselling services are available to parents of children with an acquired brain injury. However, Headway does not provide services for the direct benefit of children.

A new development that is currently underway is the formation of Brí, the Acquired Brain Injury Advocacy Association. This is a national organisation which in partnership with others, strives to ensure that individuals and their carers who are affected by ABI have the best possible quality of life. The formal launch of this group in June 2003 will provide a forum for individuals who are affected with ABI to express their views and attempt to overcome any inequities or inadequacies encountered in service provision.

¹ Information acquired from the organisations' website

<http://www.headwayireland.ie>

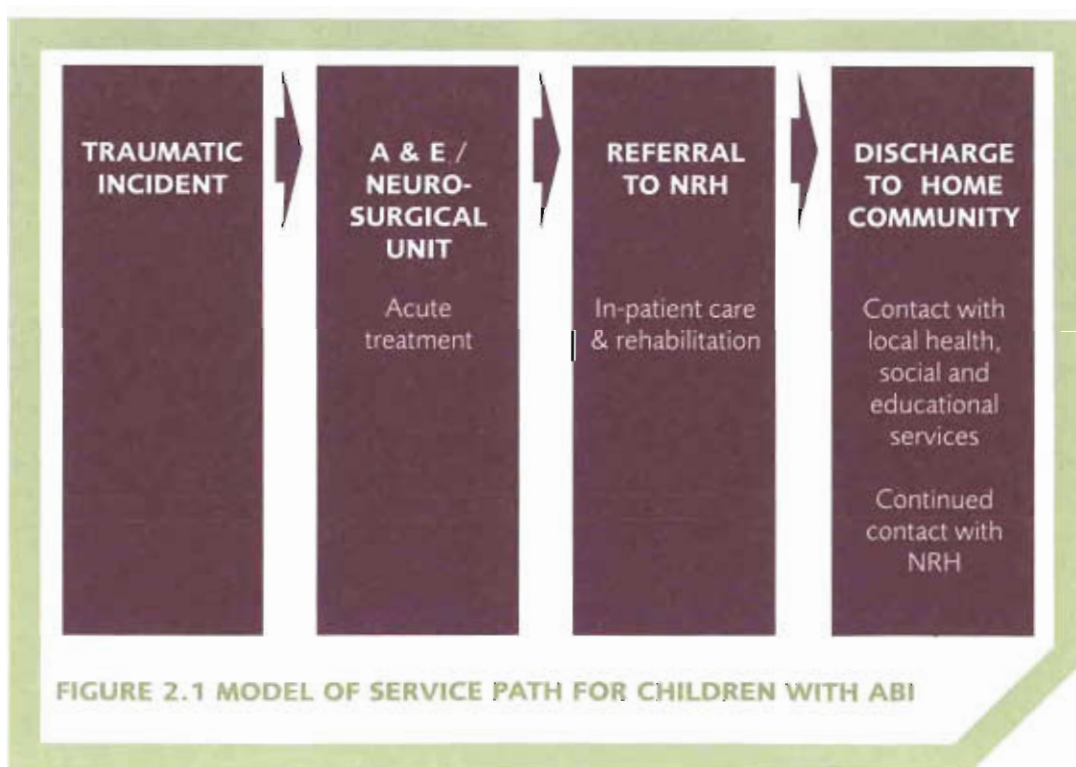
<http://www.nda.ie>

On a more local level, a variety of additional organisations dedicated to those with disabilities exist throughout the country (e.g. Enable Ireland). Such organisations are typically providers of services for those with congenital disabilities, yet may offer their services to children with acquired disabilities. Specialised services for those with an acquired brain injury at a community level are uncommon. However, it would be inaccurate to say no such services exist. For example, the South Eastern Health Board has established a unique service that involves a rehabilitation planning team for those with ABI, an outreach programme and a transitional living unit for people with ABI aged 16 to 45 years. The ultimate goals of the transitional living unit are to enable greater independence in the home and community, to enhance productivity in an education or work setting and to reduce the impairments acquired as a result of brain injury.

Furthermore, in the Midland Health Board, a project team has been established with the aim of developing services dedicated to people with ABI.

This section has attempted to briefly outline the principal services and supports that may be available to young people with ABI and their families (see Figure 2.1 for an overview). However, it is important to state that this is not an exhaustive list of all the agencies or organisations which families may have contact with.

It is likely that all children will have received some form of care in an acute care or neurosurgical setting. At present, it is unknown what proportion of children with an acquired brain injury are referred to the NRH for rehabilitation services. International research suggests that a significant number of those with severe brain injury are not referred to such a facility (Emanuelson & Wendt, 1998;



Hawley et al., 2002). Headway and Bri are examples of bodies that are specifically dedicated to the needs of those with ABI. The former typically provides support and information and the latter aims to provide advocacy. Within the community, specialised services for those with ABI are few and far between. While such settings specifically dedicated to ABI are rare, recent developments provide exceptional examples of individual community initiatives.

CONCLUSION

Overall, research in the area of paediatric acquired brain injury lags behind that which has been carried out on adults (Taylor, et al., 1995).

The uniqueness of acquiring a brain injury during childhood must be given sufficient consideration, and caution must be exercised in over-generalising research and clinical findings that pertain to adult samples. The significance of ABI to a developing child warrants further research in order to identify the long-term impact on children, and to identify the consequences of ABI for individual family members.

Children with ABI are a heterogeneous group and their needs are likely to be complex in nature. At present, there is no national strategic plan for specifically dealing with ABI in Ireland. The findings of this study may therefore contribute to future policy and service developments within this area.

Table 2.1 Key points in understanding ABI in children

- The consequences of ABI are multidimensional.
- There is great variability in the experiences of children and families following ABI.
- A number of special considerations are required in managing and treating ABI in children.
- There is a need to recognise ABI as a family affair.
- The needs of children and families are likely to change over time. This has implications for service provision.
- The ideal continuum of care spans from the acute period of rehabilitation to re-integration in the home community.

Chapter 3

Research design and methodology

RESEARCH DESIGN

The study design consisted of two main phases. In Phase 1, a census of NRH cases within the past six years was carried out in order to develop a profile of the paediatric clients of the NRH who had acquired a brain injury. Examination of the data accrued from this census provided important information on the characteristics of the young population of Ireland who had attended the NRH for the purposes of rehabilitation following an acquired brain injury. This phase of the study subsequently informed Phase 2 of the study, namely, the selection of an interview sample. Phase 2 involved using a qualitative approach to explore the views and experiences of family members and those who worked with the family. The total number of interviews conducted was 96, plus two focus groups with NRH personnel. One hundred and sixteen individuals were interviewed in total. The precise details of both study phases will be outlined in due course.

PROCEDURE

The procedure to be followed in carrying out the census, and the subsequent selection of families who would be invited to take part in an interview, was decided upon following consultations with the research team, the NRH Ethics Committee and the Advisory Group of the research study.

Census

At the commencement of this study there was no existing database within the NRH containing client information such as socio-demographic characteristics and illness characteristics. In order to interview a representative sample of families in Ireland, it was felt that it would be important to establish a sampling frame of the overall NRH client base, which would subsequently inform the selection of an interview sample. All medical records of children under the care of the Consultant Neuro-Paediatrician, who were either first time

admissions or re-admissions in the past six years, were reviewed and the relevant information was extracted. The information extracted included the child's age, date of birth, health board region, cause of injury, date of injury or illness, diagnosis and GCS score (if provided).

The research team however, did not have direct access to the medical records. This information was extracted by members of the social work and nursing teams in the presence of a researcher, and was subsequently relayed to the researcher in a non-identifiable manner. 128 records were reviewed in total. Chapter 4 presents the results of the census.

Sample selection

Following the analysis of the census data, a random sample of 30 families was chosen from the overall census database. One record was removed from the sampling frame following completion of the census, as NRH staff felt that the family circumstances were such that it would be inappropriate to invite them for an interview. Therefore, one family was excluded from the selection of a random sample. Full details of this random selection process are given in Chapter 4.

Access to families

All families that took part in this study had a child who attended the NRH for rehabilitation purposes. Families were therefore recruited with the assistance of the NRH. All census information that the research team held was in an anonymised format. The research identity numbers of those selected in the random process were conveyed to members of the social work team in the NRH. This allowed members of the social work team to identify the families by name. The Consultant Neuro-Paediatrician sent a letter from the research team to the families selected, outlining the research study. In addition, a consent form was enclosed for families to complete if they gave permission to the NRH to release their name

and contact details to the researchers. The provision of permission for the release of contact details by the NRH to the research team constituted the first stage of the consent process.

Those parents who signed this initial consent form were subsequently contacted by a researcher to provide them with further information, address any concerns they had, and arrange a time and location for an interview if a parent wished to do so. Parents were the only point of contact at this stage. However, parents were informed that the research team would like to speak to siblings, the child with the injury or illness, a teacher and a health professional who would be familiar with their child. Parents frequently spoke to their children prior to the researcher's visit, requesting if they would like to meet with the researcher. However, the child's consent was not obtained until the researcher met with the child during the visit to the home. Some parents did not wish their child with ABI to be involved. The primary reason given by these parents was that the child had moved on with their lives and parents felt it was not appropriate to ask them to recall this stressful life event. In addition, some children, when asked, did not wish to take part in the study.

The consent process

Both parents and children were informed of the purpose of the study, the rationale of the study and what the study entailed. All potential participants were informed of the confidentiality of the information provided. It was also important to inform participants that the researcher was not a member of staff of the NRH, but part of an independent research team, and only summary information would be provided to the NRH in an anonymised manner. In addition, participants were informed that if they wanted to take part in the study, they could still withdraw at a later point if they wished. Adherence to these principles during the consent process was important in facilitating individuals to exercise their choice regarding participation in the research and to enhance their understanding of what was involved.

Individual consent was obtained from each family member that wished to take part. However, for children, parental permission was required prior to approaching the child. In addition, access to teachers and health professionals was discussed with parents and the child with ABI (if the researcher had access to the child). Parents were asked to nominate an individual teacher and a community health professional that they would like the researcher to approach to invite them to take part in an interview. This formed part of the consent process for both the children and the parents. Overall, 27 parental interviews were carried out. In addition, 13 interviews were carried out with siblings and 18 interviews were carried out with children and young people with an acquired brain injury.

Family support

Given the sensitivity of the research topic, it was felt that it would be important to provide families with the contact details of the social work team in the NRH in the event that they may wish to speak to someone after taking part in an interview. The provision of follow-up support however, was at the discretion of the individual family. During the conduct of the interviews, the researcher was sensitive at all times to the emotional nature of the material, and paced the interviews accordingly.

Access to professionals

Those professionals that were nominated by families were approached and informed of the study. The same principles as outlined above were applicable to the process of seeking the informed consent of professionals. In addition, it was important to emphasise that the disclosures made during an interview were not passed on to other interviewees associated with the child. For example, the health professional would not be informed of the parent's view of the service and vice versa. Twenty-two interviews were carried out with teachers and 17 interviews were carried out with community health professionals. The community health professionals were from a diversity of backgrounds. The results of these interviews will be provided in Chapter 8 & 9.

In addition, two focus groups were carried out with NRH staff who had experience of working with children with ABI in the rehabilitation setting. Participants were recruited with the assistance of a member of the social work team within the hospital. Further details of these focus groups will be provided in Chapter 10.

DATA COLLECTION

The fieldwork was primarily centred around the use of semi-structured interviews to explore respondents' views and experiences of ABI in young people. The focus of the interviews for each respective group will be outlined accordingly.

Interviews with young people with ABI

Semi-structured interviews were used with children to explore the following topics:

- Description of injury or illness
- What it is like to be a young person with ABI
- Perceptions of being in the NRH
- Experience of returning home following their initial period of rehabilitation
- Perceptions of support received and desired following ABI
- Experience in school
- General life changes following ABI

A flexible approach was adopted in carrying out the interviews with children. The approach taken depended on the developmental stage of the child, the time available to the researcher and the abilities and interest of the child.

A variety of stimulus materials was used with the children. These included a 'wish list' which probed a child's perceptions of things they would change if they got a chance, a 'life snake' which allows a child to fill in important things that happened to them as they grew up, and a

'five field map' which allows exploration of the support received from immediate and extended family, health services, school and friends.

Interviews with siblings

A similar approach was used with siblings. However, the primary emphasis of the siblings' interviews was on the impact of a brother's/sister's ABI on the life of the sibling. The following topics were explored during the interviews with siblings:

- Experience of the time of their brother's or sister's illness/injury
- Experience of the period of hospitalisation and their brother's or sister's return home
- Perception of life changes
- Perceptions of support received and desired following their brother's/sister's ABI

Interviews with parents

Parents completed a family background questionnaire which contained details such as family composition and socio-demographic variables. In addition, parents took part in a semi-structured interview. This was a comprehensive interview that focused on the impact of ABI on parents, their child and the broader family network. It also explored service contact and usage. More specifically, it covered the following topics:

- Description of child's injury/illness
- Health care experiences
- Educational experiences
- Impact on family
- Support needs of parents
- Social and psychological experiences of child with ABI

The parents' interview schedule was piloted with a parent prior to its use in the main study.

Interviews with professionals in the community

The primary emphasis of the interviews with both teachers and health professionals in the community was their perception of the needs of the child with ABI and their perceptions of the needs of professionals working with children with ABI.

Focus groups with NRH professionals

The topic guide of these focus groups was primarily focused on the consequences of ABI for families, service provision and service need in the community.

DATA ANALYSIS

All interviews with participants were tape-recorded with the permission of the participant and were subsequently transcribed. Content analysis was used to analyse the emerging themes of the interviews. The views of each respective group were analysed separately and their views are presented in Chapters 5 to 10. Further analysis focused on the themes emerging from the overall sample of participants. The final chapter thus integrates the primary themes emerging from the overall dataset.

ISSUES TO CONSIDER

It is important to emphasise that the selection of families for this study was through the NRH. Therefore, the sample of families that took part in this study had received some level of rehabilitation at the NRH. However, it is conceivable that some children may have not been referred onwards to the NRH, despite the potential to benefit from its rehabilitation programme. The findings of this study, therefore, pertain to those who have attended the NRH. There may be some children or young people with ABI who warrant rehabilitation, but who have never attended the NRH. The stories of these children are therefore untold.

A further issue to consider is the response rate of the study. While the number of those who responded to the invite to take part was relatively high (69%), there was a number of families who chose not to take part in this study. The circumstances of these families are not known. In addition, a small number of parents did not wish their children to take part in a research interview, as they felt it may be disruptive to the child's effort to move on with their life. For those who chose to take part in the study, many had a willingness to tell their story for the benefit of helping others. It appeared, therefore, that the desire to help others and improve the situation for the future was a strong motivator for participating in this study.

Table 3.1 Summary of research methodology

- Two-phase study design.
- Phase 1: Census review of NRH paediatric clients.
- Phase 2: Random selection of interview sample of families.
- Parents, children with ABI & siblings were invited to take part in an interview.
- Families were asked to nominate a teacher and health professional who were familiar with the child with ABI. The researcher subsequently invited these individuals to take part in an interview.
- Semi-structured interviews were used to explore the needs and experiences of each respective group.

Chapter 4

Profile of NRH paediatric clients with an acquired brain injury and interview sample

INTRODUCTION

This chapter contains three different sections. The first section presents the results of the census, thus providing a profile of the children with an acquired brain injury who have attended the NRH since 1996. A random sample of families was selected from the overall census database. These families were subsequently invited to take part in an interview. The second section of this chapter presents a profile of the interview sample, highlighting the characteristics of the children who form a core part of this research study. Finally, three brief case-studies are provided to illustrate some pertinent issues that may arise for children and families following ABI.

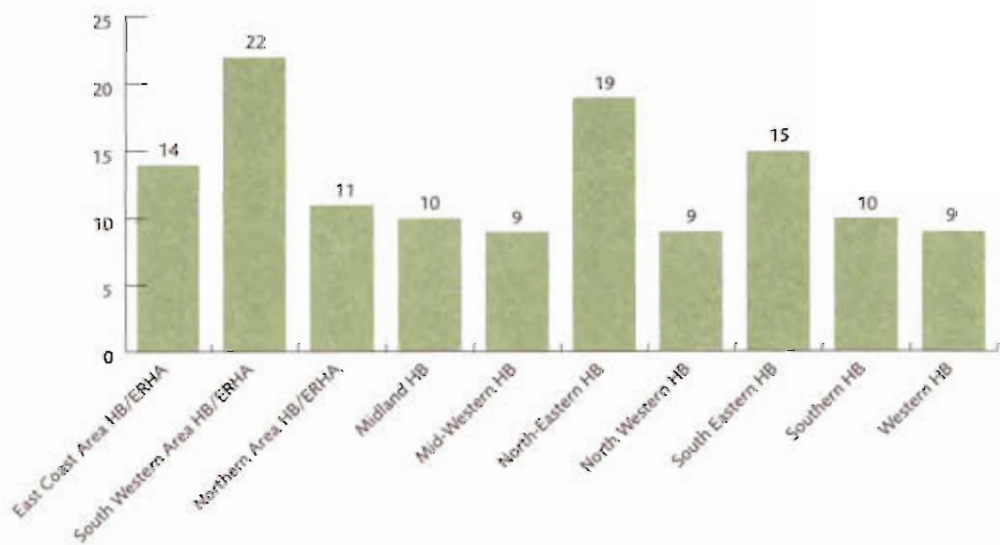
PROFILE OF NRH PAEDIATRIC CLIENTS WITH AN ACQUIRED BRAIN INJURY

The census took place from January 2002 to March 2002. This constituted Phase 1 of the study. All children who were under the care of the Consultant Neuro-Paediatrician, and who were either seen as inpatients or day-patients in the NRH within the previous six years, were included in the census review. Both initial admissions and re-admissions were included in the census review. The total number of records reviewed was 128.

Socio-demographic factors

The age range of the children was from 3 years 7 months to 23 years. The average age of the population as a whole was 15 years. 60% of the group were male and 40% were female. The average time since illness or injury

Figure 4.1 Health Board distribution of paediatric clients with ABI ² within the NRH



² HB = Health Board

was 5½ years (range = 6 months to 15 years 5 months). The age at which the illness or injury initially occurred ranged from 1 year to 15 years 10 months, with the average age at the time of the incident being 9 years 6 months.

The children and young people were residing in a variety of different health board areas. Figure 4.1 illustrates the number of children in each health board, respectively. Examination of the distribution of children residing in the various health boards, revealed that the South Western Area Health Board had the highest number of children and young people with an acquired brain injury who had attended the NRH (17.2% / n=22), followed by the North Eastern Health Board (14.8% / n=19).

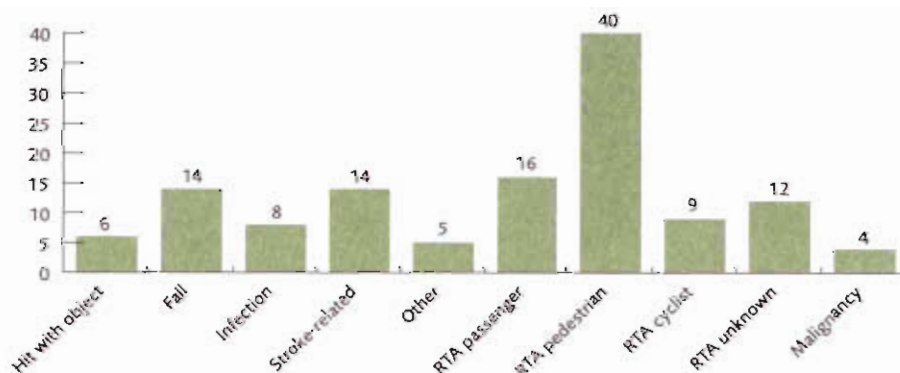
Injury/illness characteristics

The Glasgow Coma Scale (GCS) is typically used to assess the individual's depth of coma, and provides a measure of brain injury severity (Teasdale & Jennett, 1974). However, there is some debate over its application to the paediatric population (Bruce, 1995; Fletcher et al., 1995). Within the current population of NRH children, there were no GCS scores recorded within the files for

almost 44% of the sample. Approximately 53% of the NRH clients scored less than 8 on the GCS, which typically indicates a severe brain injury. 2% of the sample population had a score between 9 and 12, which may indicate moderate brain injury, and just 1% had a GCS score greater than 12, which typically indicates a mild brain injury. The danger of relying on these scores, however, is that much variability exists in the timing of the assessments. For many of the ratings provided, there was no indication of the timing or the stage at which the assessment was carried out. Frequently, there was also no indication of whether the GCS rating provided was the lowest score the child obtained over a period of assessments, or merely a one-off assessment. Thus, it is difficult to compare these indices, due to the inconsistency that prevails. However, while GCS scores are an important indicator of brain injury severity, it is often used in combination with other injury indicators.

Examination of Figure 4.2 reveals a variety of underlying causes for the children's acquired brain injuries. Road traffic accidents were the primary cause of acquired brain injuries in

Figure 4.2: Predominant causes of ABI for paediatric clients of NRH³



³ Infection refers to empyema, meningitis, etc.

Stroke-related illnesses include A.V.M., an infarct, embolism, etc.

RTA refers to road traffic accident.

young people, with 60% of the overall population falling into this category. Within the road traffic accident group, the most common form of accident was with child pedestrians. The remaining 40% of the population of children with acquired brain injuries was made up of a variety of underlying causes. The two most common causes outside the road traffic accident group were stroke-related illnesses and falls (e.g. falls from heights or moving objects).

SELECTION OF INTERVIEW SAMPLE

Procedure

Following consultations with the advisory group, the parameters were set for the interview sample. The upper age limit for inclusion in the interview sample was set at 20 years 11 months. Such a broad age range allowed the researchers to capture the experiences of those who had grown up with an acquired brain injury and were now entering the period of young adulthood. The research therefore sought to be inclusive as opposed to exclusive by focusing on the diversity of experiences of children and young people who acquired a brain injury.

As the focus of the research was predominantly on the experiences of children and families following discharge from the NRH, it was deemed appropriate to only include those who were at least one year post-discharge from the NRH. In addition, one individual was removed from the potential pool of participants due to personal circumstances, following the recommendations of NRH staff. A random sample of 30 individuals was chosen from the remaining pool of participants, with the intention of inviting them to take part in an interview. This sample was stratified according to the cause of the injury. Therefore, 60% of the sample had acquired a brain injury as a result of a road traffic accident and 40% through non-road traffic accidents. This was in

accordance with the distribution of causes in the overall census database.

PARTICIPANTS

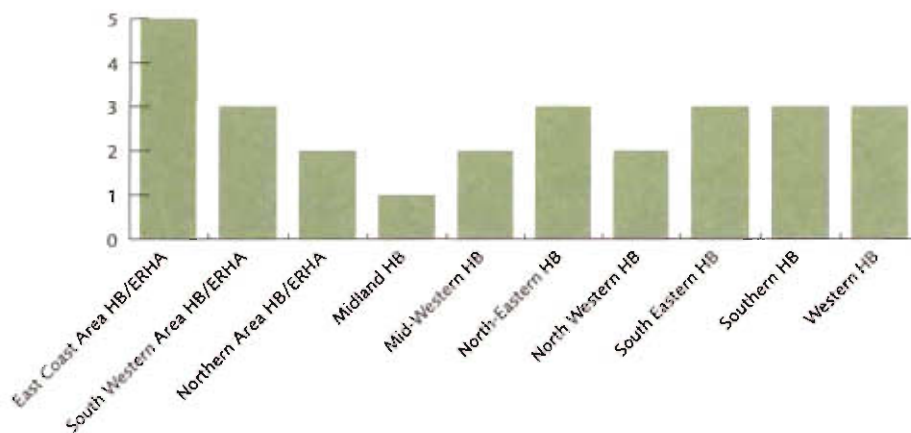
Over the course of the research, a number of families did not wish to take part in the interview process. Replacement families were randomly chosen from the census database. In total, 39 families were invited to take part in this research. 33 consent forms were received in response to the initial approach, thus allowing the NRH to pass on the contact details of these families to the research team. Of these 33 families, 27 subsequently took part in the research interviews. The remaining families did not take part, due to family or work commitments or a lack of interest. This represents a response rate of 69%.

The characteristics that will be described here pertain to the overall sample of 27 families that took part in this research. Within these families, at least one parent was interviewed. A sibling or the child with the illness or injury was not interviewed in every case. Therefore, the profile presented here is not relating to 27 children who were interviewed, but to 27 families where at least one family member was interviewed.

The average age of the children who were the focus of investigation within this study was approximately 13 years (range = 5 years 4 months to 20 years 11 months). The average time since these children's illnesses or injuries was 4 years 9 months (range = 18 months to 9 years 5 months). The average age at the time of injury or illness was just over 8 years (range = 1 year to 15½ years).

The families of 17 boys and 10 girls with acquired brain injuries took part in this research. In accordance with the census results of Phase 1, the children were dispersed across a variety of health boards, thus enhancing the representativeness of the study sample. See Figure 4.3 below for the distribution of children across health boards.

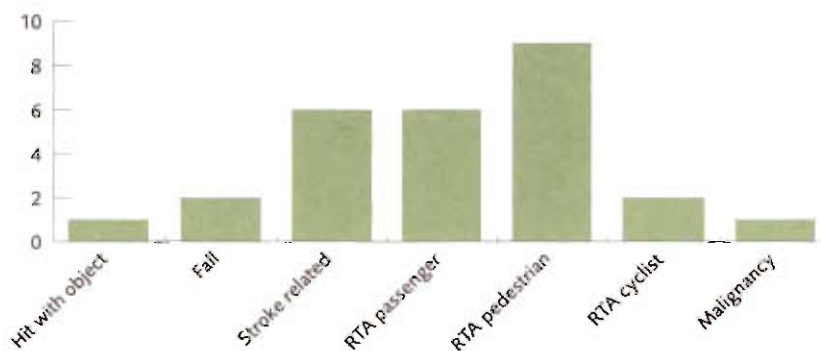
Figure 4.3 Distribution of interview sample across health boards ⁴



The underlying causes of the children's acquired brain injuries were diverse in nature. Approximately 63% of the interview sample had acquired their brain injury through road

traffic accidents, while the remainder acquired their injury through a variety of other means (see Figure 4.4).

Figure 4.4 Predominant causes of ABI in interview sample



CASE-STUDIES OF CHILDREN WITH AN ACQUIRED BRAIN INJURY

Three case examples are provided in this section to illustrate the potential consequences of acquiring a brain injury during childhood. These case-studies do not represent individual children or families but are a composite from a variety of different individuals, based on the views that emerged during interviews with children, parents,

siblings, teachers and health professionals. These case-studies are not exhaustive in nature. It is merely hoped that they will serve to illustrate the range of issues associated with the phenomenon of ABI during childhood. This section is particularly likely to be useful to those readers with little background knowledge in the area of ABI.

CASE EXAMPLE 1

Prior to her illness, Sinead was regarded as 'academic' yet outgoing, and was extremely popular with all of her classmates. She also had a keen interest in sports and had captained her school's camogie team in a county final success.

At the age of 8 years, after returning home from school one day, Sinead complained of headaches while doing her homework. Her mother advised that she lie down, but later when she checked on Sinead, she found that her daughter was pale and unresponsive, though she appeared to be semi-conscious. Upon examining Sinead, the family GP had her transferred immediately to Beaumont hospital where she was diagnosed as having suffered a stroke. Sinead spent three weeks in Beaumont, before being transferred to the National Rehabilitation Hospital in Dun Laoghaire, where she spent the following six months learning to re-use her right arm and leg. Her speech had also been affected by the stroke, and during her stay at Dun Laoghaire she received intensive speech therapy.

Her mother and father visited as much as possible, but as they were from the Munster area and had three other children, all younger than Sinead, it was difficult to be with their daughter all of the time.

When Sinead returned to her local community, she was gradually eased back into school. She still had difficulty walking and talking, but she was making steady progress. Her school had been briefed regularly by Sinead's parents, and all were delighted to see her on her return.

Six months after returning to school, Sinead was similar to the happy, go-lucky person she had been before the stroke. However, whereas before she had been in the top 10% within her class, she now struggled to keep up with her classmates. She no longer plays on her school's camogie team, but is a regular attendee at all their matches. She is as popular as ever with her classmates, who make a special effort to walk with her at all times, as her pace is slower than that of her peers since she had her stroke, and her speech, though improving, can sometimes be hard to follow.

CASE EXAMPLE 2

After the initial 100,000 units of production, the company's production volume is expected to increase to 150,000 units in the second year. The company's management is considering two different production strategies for the second year. The first strategy is to produce 150,000 units in the second year, which would result in a total production of 250,000 units over the two-year period. The second strategy is to produce 100,000 units in the second year, which would result in a total production of 200,000 units over the two-year period. The company's management is trying to decide which strategy is the best for the company.

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1. *Journal of the American Medical Association*, 1997; 277: 1039-1043.

CONCLUSION

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The present study aimed to develop a profile of paediatric patients within the NRH from 1996-2002. This data provides important indicators of the more common causes of severe acquired brain injuries amongst the young population in Ireland, and the dispersion of these cases nationwide. To date, such data has been unavailable.

The higher incidence of ABI amongst males found for this population supports previous research both in Ireland and abroad (O'Brien & Phillips, 1996; Kraus, 1995). In addition, examination of the external causes of acquired brain injuries reveals that transport and falls are the more common causes of an acquired brain injury among young people. This is in line with international research as reviewed by Kraus (1995).

The results of the present study suggest that the South Western Area Health Board holds a particularly high proportion of the population of children with ABI. The health board with the second highest level of young people with ABI is the North Eastern Health Board. Previous research in the Beaumont Neurosurgical Unit has revealed that the greatest number of its referrals from peripheral areas comes from County Louth (North Eastern Health Board). This may be partially explained by the fact that Louth experiences the highest rate of road traffic accidents on a nationwide level (as indicated by the ratio of accidents per registered vehicles and per population) (O'Brien & Phillips, 1996).

This census provides key descriptive information on the characteristics of our young population who have acquired a severe brain injury and have attended the NRH. Such information is vital if we are to plan, at both a national and regional level, for the long and short term needs of our young population. However, the absence of information on injury indicators for each individual (e.g. GCS, post-traumatic amnesia) precludes analysis of injury-related variables in the current population of ABI cases.

The interview sample chosen from the larger population represents a nationwide random sample of children and young people with a severe acquired brain injury. The in-depth qualitative research that took place with the sample of families provides a comprehensive understanding of the experiences and needs of young people with an acquired brain injury in an Irish context. The random selection of families and its nationwide focus are strong methodological features of the study, and as such will allow us to generalise the findings obtained in this study to the broader community of those who have acquired a brain injury during the period of youth.

The case-studies highlight some common features of ABI that may be experienced by children and their families following ABI. As such, these case-studies provide a brief descriptive profile of the potential consequences of ABI during childhood.

Table 4.1 Summary of census review

Criteria for inclusion:

- All cases had attended the NRH as either in-patients or day-patients at some point since 1996.
- Both initial admissions and re-admissions were included in the census review.
- All children were under the care of the Consultant Neuro-Paediatrician.

Results:

- The total number of cases reviewed was 128.
- Results revealed a gender distribution of 60% males to 40% females.
- The primary cause of ABI was road-traffic-accidents with pedestrians.
- Road-traffic accidents accounted for 60% of the overall causes of ABI among NRH paediatric clients.
- The children were dispersed across a variety of health boards; the health board with the highest proportion being the South Western Area Health Board.

Table 4.2 Characteristics of interview sample

Inclusion Criteria:

- The upper age limit of paediatric participants was 20 years 11 months.
- All young people were at least one year post-discharge from the NRH.

Results:

- The total number of families included was 27.
- The average age of children was 13 years.
- The average time since illness or injury was 4 years 9 months.
- The gender distribution of children was 17 boys, 10 girls.
- 63% of the sample acquired a brain injury through road traffic accidents.
- Families resided in a variety of health board areas.

Chapter 5

The perspectives of
young people with an
acquired brain injury

Eighteen young people with an acquired brain injury participated in these interviews. The sample of young people was diverse not only in terms of age but also in terms of ability. They ranged in age from 9 to 21 years. However, they clearly differed in terms of their insight into and understanding of the consequences of acquiring a brain injury for their own personal selves and those around them. In addition, some individuals were limited in their ability to articulate their thoughts and feelings. However, a number of others were cognisant of the changes they experienced and recognised the differences brought about by their illness or injury. On the whole, the views expressed by the young people were inherently influenced by their developmental levels and their comfort in speaking to a researcher who they had not previously met. Yet despite the barriers faced within such a research context, there is much to be learned from listening to the views of the young people who chose to take part in this research.

This chapter presents an overview of the issues which were raised by the young people during a short individual interview. These interviews could be characterized in terms of differences and divergences. Frequently, no one theme dominated the responses of the young people. Instead, numerous ideas and responses arose in relation to the questions asked. As such, these interviews can function to raise awareness of some of the potential needs, desires and experiences of young people following the acquisition of a severe brain injury.

EXPERIENCE IN NRH

The young people had mixed reactions to their experience as patients in the NRH. Some of them experienced difficulties recalling their time in the hospital, due to the time lapse since their stay in the NRH or alternatively

due to cognitive difficulties in recalling past events. The young people were primarily asked to identify the positive and negative aspects of staying in the NRH for a period of time.

The more positive aspects identified were the facilities or activities available, the friends the young people made during their time there and the individuals they worked with during the rehabilitation process. The quotes that follow exemplify some of the more positive views that the young people held of the activities they encountered and the sports they played:

[Was there anything that you liked about the hospital when you were there?]

"The breakfast that you get in the morning was nice. The supper. The relaxation down in the relaxation room. The music."

"There were a lot of sports when I was in rehab. It was fun and I enjoyed it. It was everyday and you would receive a medal when you did well and I had fun."

A small number also recalled the professional help they received and the benefits they obtained from their time in the NRH.

"I was glad to be going there because I know how well they work with people. I know that they can do so much for you, that was reassuring."

Other positive comments that arose included reference to being in the NRH school, being pushed around in a wheelchair and seeing how the other patients improved over time.

Some negative comments were also expressed by the young people about their stay in the NRH. "Spooky", "bleak", "repetitive", "scary" and "horrible" were some

of the adjectives used by the children to describe their view of the NRH. Some children expressed a general dislike of the NRH. Others had more specific concerns relating to the issue of hospitalisation itself. These included such factors as the distance of the NRH from home, their separation from their families, the treatments and procedures they underwent and the organisation of the day. Some expressed dislike with concrete aspects of the hospital environment such as the nature of the building itself and the food provided within the hospital. The following comments illustrate some of the negative views of the young people:

"Being away from home was tough."

"You travel this entire journey and you come to this building and it is all bleak."

"(You're) not allowed to go outside ... Play football, see your friends."

"It is very quiet I suppose, and you have physio at 9.30 a.m. and then you go again at 2 o'clock. I think it is too much of a space, you are in there all day. I think it could be better."

Overall, a mixture of positive and negative comments arose regarding the young people's period of rehabilitation in the NRH. While some of the young people appeared to welcome the help received, the friends they made and the facilities available, they also encountered aspects which they disliked such as features of the hospital environment and removal from their natural home environment.

THE RETURN HOME

The young person's return home following discharge from their initial intensive period of rehabilitation appeared laden with both positive and negative experiences. While

many of the young people expressed delight at returning to their home environment, some of them also experienced difficulties in adjusting back to life at home. The following quotes illustrate some of the more positive views expressed concerning their return home:

[What was it like when you left there and finally came home for the first time?]

"It was great, I was ready to get out of there."

[So then you came home fully, what was that like?]

"It was nice."

[Yeah? What was nice about being back?]

"I could do what I like."

A number of the young people relished the idea of getting back to normal, seeing their family and friends and doing things that they normally engaged in. The following quotes are two such examples:

"I could see my family and my room and my dog."

"I was very happy"

[Were you... what made you happy?]

"To see my family and friends again."

Three of the young people mentioned the welcome home they received and the party that was thrown for them upon their return home. For these individuals this was a memorable event in their recall of the transition from the rehabilitation facility to home.

The following quote from one young person highlights her experience of the difference between the NRH environment and her more local surroundings:

[Was there anything else hard about getting back home and getting back to school?]

"It was different, very different."

[What was different?]

"I was going to school with people who weren't disabled or whatever and they didn't think of me as that disabled either, because I don't look that disabled really. It was okay though."

However, the transition from the NRH to the home environment was not always an easy one for children. A variety of difficulties were encountered. These included physical limitations such as having difficulty getting about in their home and being unable to participate in work about the home. Illness-related problems, such as having difficulty sleeping and feeling very tired, were also identified as problematic by a small number of young people. Two young people spoke about the communication difficulties that they encountered. Specifically, they identified the difficulty they experienced in understanding others, or alternatively, the failure of individuals to understand them.

[What was hard about it?]

"'Cause they all knew and I couldn't understand when they talked to one another."

[What did you find was hard for you when you came home?]

"Well, the fact that nobody understood me..."

Services were identified as a bone of contention by one young person. The following quote reveals the perceived lack of services within the home community to meet this young person's needs following ABI:

[What was it like when you finished in all the hospitals and you came home to Mom and Dad?]

"That was worse! ... nothing happened. No one was helping me."

While on the whole, it appears that most of the young people were happy to return home, some experienced specific difficulties

during the re-adjustment period. In contrast, the following quote reveals an overall negative view of the move home from the perspective of one young person:

[What was it like when you left the hospital?]

"Really bad."

[What was bad?]

"I just didn't feel right that's all."

[Leaving is it?]

"Yeah I didn't really get used to living at home anymore."

[It was hard to come back was it?]

"Yeah, thinking about it, definitely."

While such comments were rare, it illustrates that the return home may not be a smooth transition for some young people.

CHILDREN'S PERSPECTIVES ON THE IMPACT OF AN ACQUIRED BRAIN INJURY

All of the young people were asked to describe what it was like for a young person to suffer a brain injury. The language and terminology used by the interviewer was tailored to each individual. The researcher often attempted to check with the parent prior to the interview to identify what term the family used to describe the child's illness or injury (e.g. head injury, brain injury, accident). During the interview, each young person described their injury or illness in negative terms. Words such as "strenuous", "hard", "shocking", "annoying" and "sad" were used. There was a clear consensus about the impact of acquiring a brain injury among these young people, as illustrated in the following comments:

[If you were to describe what it was like for a young person with a head injury, how would you describe it?]

"Boring, sad, all you do is twiddle your thumbs and sit down ..."

"I missed a lot of days in my life."

"It changes everything for you."

"I can't do as much things as other children."

The young people identified a number of things that were hard for them after they acquired their injury or became ill. Over a third of the young people identified their physical limitations or sensory problems as their primary difficulties.

[Could you tell me what things have been like for you since you were in the accident and you hurt yourself...?]

"It's ... it was hard at first ... but then it was all right"

[Researcher: Do you want to tell me what were the hard bits?]

" ... learning to talk again ... walk again ... and all that ... and using my hands ..."

Being confined and limited and having to re-learn the basic functional abilities and skills proved challenging for some. In addition, a small number of young people mentioned medical-related problems such as seizures and headaches as difficulties they endured.

A few children also mentioned the difficulties they experienced in understanding or assimilating the reality of what had happened to them.

"If ... when they woke up ... if they were told, ... they wouldn't actually believe it ... it would take them time to get over it."

Two of the young people also realised that it took a considerable amount of time to get back into their normal routines and to return to their old self again. These individuals identified the general difficulties that can be experienced in getting things started again

following their return home.

"The hardest thing would be coming home from the hospital and trying to get back into everything ... trying to get everything started again."

Other difficulties encountered could broadly be classified as social issues. The perceived lack of understanding from other people and problems in peer relationships were acknowledged by a minority of participants. The inability to engage in activities and the lack of things to do was a further difficulty mentioned by a small number of young people.

[What has been the hardest time for you since your injury?]

"Making friends."

It is important to note that a minority of the young people had difficulty identifying or articulating the impact of ABI on their lives during the encounter with the researcher.

Changes in their lives

The young people were also asked to identify things that might have changed in their lives following their ABI. This question was difficult for some to answer as a small number of children did not have memories or insight into life before their ABI. This may be due to their chronological age, their cognitive disabilities or a combination of both. Interestingly, the young people more commonly identified physical and functional changes in response to these questions.

"My hand doesn't work any more."

"I can't go up into heights, because I will get dizzy."

"I just couldn't do anything when I came home."

In addition, many young people identified limitations in activities as a result of their injury or illness.

"Well I can't do the things I could do before. Like running because I might trip and even walking I might fall down."

"Like now I'm not able to swim and I was a great swimmer ..."
 [... and how do you feel about not being able to swim?]
"... I feel a bit sad ..."

It appears the young people identified more readily those more concrete aspects of their lives that had changed, such as changes in activities and motor behaviours.

In comparison, changes in relationships and social or behavioural changes were less frequently mentioned by the young people. While at times the young people didn't directly identify friendships as something that had changed significantly in their lives, over the course of the interview over a third of the young people cited friendship problems or the lack of friendships as an inherent part of their experience post-ABI. The following quote illustrates the adverse reactions from a peer which one of the young people experienced:

"I had this friend and she would come and visit me ... and she was very upset about it. But when I went back to school she turned everybody against me. That was very tough because she was my friend you know!"

In addition, a significant number of young people reported that they were the subject of bullying or teasing or staring from others at some point in time. Some of these young people were clearly able to identify how they were picked on as a result of the visible consequences of their injury.

"They call me (names) because I talk real slow ... My brain just doesn't function really fast, it's not like everyone else."

The remaining young people who were subject to bullying or teasing did not identify the context or reason for the bullying behaviour. While a number of children experienced adverse reactions from individuals in their peer group, many of the young people also identified peers who appeared to display positive behaviours and attitudes towards them. The supportive nature of these relationships and interactions will be discussed in a subsequent section.

Apart from the bullying behaviours of peers, further changes were also noted in the responses of others to the individual with ABI. A significant group of individuals mentioned how people treated them differently in some instances. This had both positive and negative implications for the young people concerned. Two young people mentioned teachers "going easy" on them in school and were pleased about this. A number of young people also noted that people went out of their way to help them. The following quote illustrates some of the practical assistance which young people may receive at times:

"They look after me a lot better ... they always make sure I'm all right when I'm crossing the road because of the vision thing."

While, at times, such efforts were welcomed by the young people, a small number of young people also highlighted times when they found the help of others to be unnecessary or overbearing.

In addition, one teenager mentioned how the attitude of her parent towards exams changed, thus placing less pressure on her to achieve results than would otherwise have been expected. On the other hand, at least

three teenagers identified their parents or caregivers as being over-protective and consequently restricting their freedom. The following quote illustrates the impact of this over-protectiveness on the life of a teenager.

"I am a teenager and I am ordinary except for the few things wrong with me. But I should be treated the same as everybody else."

Overall, only a few young people noted that they had experienced behavioural or personality changes. Two young people, however, identified a change in their outlook or approach to life.

"I have become braver."

"You feel glad that you have achieved something, that you have survived."

Only three young people identified notable differences in their behaviour or their perceptions of their behaviour. One participant claimed to fight more with his brother and another participant claimed he was getting into fights in school. In addition, the following quote from a child provides an example of how the child's behaviour was interpreted by others and was subsequently incorporated into their own self schema:

"I was good ... before the accident."
 [Okay ... and since the accident you're ...]
"Bold" ... Yeah! That's what Mam says."

It is important to note that a considerable number of young people identified no changes in their personalities or their relationships with family members. This may be due to various reasons. Those who perceive themselves to have recovered from their ABI may perceive few residual effects in their lives. Some individuals may have difficulty recalling pertinent changes in their lives during the research interview. However, it is also important to recognise that some of the changes reported may not be due to the

ABI per se, but to normal developmental changes of childhood, or indeed the interaction between these developmental processes and the sequelae of ABI.

When the young people were asked if they experienced any changes in their school life, a variety of different responses were received. Five of the young people identified changes in their educational setting. For some, this included repeating a year and joining a new class, and for others it involved joining a new school. For some of these children, they found it difficult being removed from their friends and joining a new class of peers.

[Was there anything different in school after your crash?]

"No, ... only like I stayed back and I was unhappy about that."

[Why?]

"Because all my old friends from the other class went on."

A small number of children also mentioned that they no longer participated in certain subjects in school as a result of their illness or injury.

The young people had varied opinions about the demands placed on them in school following their ABI. Approximately, one third of the respondents felt that their illness or injury did not affect them in school. However, about a third of the children also expressed that they found school work difficult and demanding. Two children specifically mentioned how prior to their illness they were top of the class, but this was no longer the case.

"I would like to be top of the class again and that is hard for me."

Furthermore, there were a small number of children who felt that following their initial return to school after their illness they experienced much difficulty but this had

dissipated over time. For some of these children, their lengthy absence from school resulted in them missing considerable amounts of work, thus contributing to the difficulty they experienced upon their return.

Thus overall, there was much diversity in the children's educational experiences, with some experiencing more problems than others.

COPING AND SUPPORT

Support received

The young people were generally appreciative of the support provided by family, relatives, friends, school and services, during their time in hospital and following their return home. When the young people were asked to identify the support that the immediate family provided them with, a number of individuals mentioned a variety of tangible activities or tasks which family members assisted with or engaged in. Interestingly, some young people did not refer to the intense care-giving they frequently received from their parents and family.

[What about your family? What did they do that helped you?]

"Come up to visit me and brought me home and ... Had a party in my house and that was good ..."

"My brothers and sisters played with me, and my mother and father ... were helping me ... taking me up to the hospital."

[What did your family do that helped you?]

"They cooked, well my mammy and daddy cooked me dinner."

Others were clearly aware of the vital role that family played in the therapeutic process.

"They practically did everything for me."

"They got the people's attention for me."

[Do you want to tell me what Mum did to help?]

"Everything, I couldn't do anything myself."

Overall, there were very positive perceptions of the help and support received from the immediate family.

Friends and neighbours, with few exceptions, were also identified as important sources of support. Once again, general suggestions were provided as to the nature of help these individuals offered. These included the provision of general assistance when required, coming to visit the individual following their return home from hospital and keeping them company or playing with them at times.

The support provided by relatives was also recognized by the young people. The assistance they gave included providing general support when needed, coming to visit, giving presents and cards and helping with homework.

One individual also noted the role of her aunt in keeping her spirits up. In addition, two individuals mentioned the role of relatives in supporting other family members. The following quotes show how these young people valued the broader role which relatives played during their time of need:

"My auntie ... she probably supported my mum as well, mum had to deal with everything."

"Well sure, they helped my little brother, because my aunt and uncle took my little brother everywhere ..."

Services were also identified as an important source of help that the young people

received following their ABI. The young people readily identified the role of therapists in assisting them with the development of their functional abilities and motor skills.

[What did they do that helped you?]

"Helped me walk, helped me talk and helped me write."

The following quote from a teenager reveals her conception of the powerful role which the health services played in her life:

"Well they got me back to this. The doctors saved my life, the physios got me back walking and they're still trying to get my hand working again, nurses looked after me in hospital and occupational therapists got me back to living after school. They basically helped me recover."

While many of the young people identified specific benefits accrued from their work with therapists ("did exercises with me"; "made me walk quicker"), a minority talked generally about how they "fixed me up" and "helped me get better".

The final source of support that had a significant impact on the lives of the young people was the support received in school. At least half of the young people identified the beneficial contributions of their teachers in the aftermath of their ABI. In addition to the general kindness and helpfulness of teachers, more specific aspects of support which were identified as helpful included being allowed sufficient time to complete the work to be done, setting work which was within the child's capacity and having the teacher take down the homework for the student. In addition, two young people specifically identified the importance of the support received from their care assistant, while a further two individuals identified the benefits of individual or small group tuition they received outside of the main classroom.

Approximately a third of the young people also mentioned the role of peers in providing assistance in the school environment. The quotes below highlight the supportive role that peers can play in aiding the child's transition to school and assisting the child during times of uncertainty.

"All the other children helped me on ... gave me a little boost."

"Some of my friends said, 'I'll tell you what you have to do'."

Overall, the young people identified numerous sources of support and supportive behaviours that were clearly important to them in dealing with the outcomes of their ABI. It was notable that many children and young people found it difficult to pinpoint the precise role that close family members such as parents, had played in their lives since their ABI. Perhaps it is easy to overlook the value of those closest to us, in that the support they provide is so pervasive that it does not stand out. The young people clearly recognised the role of therapists in aiding the restoration of their lost skills and abilities. It is possible that this is due to the visible results that the young people identified as emerging, as a result of the professional and formal sources of assistance they received. These professionals were recognised as having a specific function, and therefore, more readily came to mind.

Support needs

The predominant sources of support and help which the young people felt were required in the event of an ABI during childhood or adolescence was the receipt of professional services and therapeutic interventions. The specific therapies identified as important by the young people were physiotherapy, occupational therapy, psychological services and speech therapy. The quotes that follow pinpoint the perceived benefits of therapeutic work from the perspective of some of the young people in this study:

"If they can't walk, someone to make them gradually ... even on their hands and knees ... like crawl."

"I have a good suggestion of what children should get. They should get two physio a day, two speech and two OT (Occupational Therapy) because they're the only three that helped me."

One young person also identified the benefit of having the therapist attend the home instead of having to travel continuously to the therapist's place of work.

It is interesting to note the large number of respondents who mentioned the role of therapists, as an essential requirement in recovering from an ABI. Most notably, the young people frequently referred to the role of physiotherapy and speech therapy, occupational therapy occasionally, and psychological services only rarely. Perhaps the service needs identified by the young people are the services they had personally availed of or received at some point. Therefore, those services which they have had prior contact with, might be more readily identifiable and recognized as an important part of the therapeutic process. It is also interesting that the services identified typically relate to the functional abilities and physical deficits of the young people, with less recognition of the need for psychological support services emerging from the interviews.

Other needs identified by the young people interviewed included general support and having people there for them, the need for support from friends or indeed assistance to get more friends and the need to prevent or stop children from being bullied. In addition, individual suggestions which arose included the need for others to pray for them, having assistance in the home with daily living activities and the need for rest following an ABI.

In relation to school, a few children mentioned the role of teachers and the benefits of small group sessions or individual work with teachers away from the main classroom environment. Two teenagers also identified the need to inform teachers about ABI so as to prepare them for what to expect. One young person also mentioned that the nature of the child's complaint or illness could be explained to peers or classmates. This participant felt that peers didn't understand or realize the true nature of her limitations or illness.

"It should probably be explained to them that it is not necessarily visible and that if you can't see it, it doesn't mean people are faking it ... If I had come in with a bandage on my head, they would have said, 'Ok that's fair enough, at least she has a bandage on her head, she's not well'."

Further suggestions of help required in school included teachers taking the time to examine the student's work, giving the student homework that was easy to complete, the availability of aids such as laptops and also lifts to facilitate easy access to other parts of the school building.

Overall, a variety of suggestions emerged from the young people's responses. The young people thus recognised the potential utility of support from many individuals and recognised them as a vital part of their recovery process.

CONCLUSION

These interviews give insight into the ideas and experiences of young people who have suffered the trauma of an acquired brain injury. The findings of these interviews reveal the complex pathways which many of these young people follow in the wake of an acquired brain injury. It is also fundamentally clear how the journey of the young people post-ABI was very variable and highly individual. From the time the children left the NRH to return home, they were faced with a combination of positive and negative emotions and experiences.

Their readjustment to their familiar surroundings was not always a simple process but could be tempered by factors such as their newly acquired limitations, the time spent away from home and the availability of support to ease this transition. The young people recalled many changes in their lives following their ABI ranging from changes within the self to changes in the way others treat them. Clearly, they depended on many individuals to provide both formal and informal levels of support to help them deal with the challenges they faced.

Table 5.1 Key points in young people's perceptions of their lives following ABI

- The young people's memories of adjusting to the NRH and adjusting to the home environment following discharge from the NRH had both positive and negative elements.
- Young people's descriptions of ABI depicted a negative emotional experience.
- Perceptions of changes in their lives following ABI typically focused on physical and functional limitations and changes in the responses of others.
- The young people had varied opinions of the difficulties and demands which school imposed on them.
- Support was provided to these young people with ABI from a variety of sources, ranging from the more formal to the more informal sources of support.
- Therapeutic interventions and professional services were identified as significant needs of young people with ABI.

Chapter 6

Parents' perspectives on having a child with an acquired brain injury

This chapter presents the results of 27 parental interviews. During three of these interviews both parents contributed to at least part of the interview, resulting in up to 30 parents being consulted in total. The profile of the children of these parents has previously been presented. Examination of the characteristics of the children and their families reveals that this sample of parents is a diverse and heterogeneous group (see Chapter 4). Many factors are likely to contribute to the variety of individual differences in the coping and adjustment of families, and in the long-term outcome for all. Such factors may include the child's age, gender, residential location, socio-economic status, family composition, type of head trauma, time since trauma, age at onset of trauma and the consequences of the trauma for all concerned. The aim of this chapter is to explore the diverse experiences of families, and also to highlight the common factors which many families may have experienced.

It has been identified that over the long-term, parents become the primary support for children following a brain injury (Ylvisaker, 1998). In addition, Ylvisaker (1998) claims that parents become the primary providers of long-term rehabilitation services. Thus, parents appear to have a crucial role in the aftermath of their child's trauma.

Within the present study, parents represented core informants on the impact of an acquired brain injury and the needs of children and their families. The parents' interviews ranged from approximately 1 to 2½ hours. These interviews were comprehensive in nature, as parents had many stories to tell. The researchers specifically targeted the following areas in their investigations: impact on family; health and social service usage; educational experiences of the child; psychosocial well-being of the child and the support needs of families.

Emotional experiences

The devastating impact of the child's illness or injury was one of the most striking issues emerging from the parental interviews. Many of these interviews were emotional in nature, with parents frequently being upset at recalling certain traumatic memories or incidents. Parents used words such as "shocking", "stressful", "hard", "torture" and "sad", when describing the impact of their child's illness on the family as a whole. The following quote described one parent's feeling of sadness for her child:

"You're looking at your own child every day and the way he is, and you know the way he was. It's just heartbreaking every day. You'll never get over that, you'll never accept it. You feel so sorry for them as a parent and a mother."

For a small number of parents, their sadness was such an overwhelming part of their experience that they described it like a death or a grieving process. For these parents, the severe changes which their child and family experienced, represented a loss of the child they once had, and a fundamental change in their family unit as a whole. For some individuals, the sadness has receded into the past; for others, however, this sadness has lingered on.

The sadness that families felt had many dimensions to it. The parent themselves can feel so much sadness, not only for their child, but for others who have been affected, yet they may also experience a whole range of distressing emotions directly themselves. The following quote summarises the difficulty that families can experience in attending to the emotions of others:

"We were all so taken up with our own grief and I felt so sad that this had happened. I

was sad for my child and those things were difficult for her, yet I was in so much pain myself emotionally ... It kind of splits everything, in that everyone is going through their own little grief and the pain of it all, and none of the family are relating to each other."

Some parents also experienced such a high intensity of emotion that at times they found it difficult to cope.

"My energy levels were so low and my morale was totally rock bottom ... I was more worried about cracking up and feeling very vulnerable to everything and trying to keep everyone going."

"I have highs and lows the whole time now."

"The behaviour thing just got so bad. I was just losing my tether with the whole thing. There were days I just felt like walking out that door. I couldn't cope with her."

Overall, the vast majority of families experienced an intense emotional roller-coaster of a journey following their child's trauma. For many, there was also a perception of feeling lucky, in that their child could be worse, or a sense of gratitude that their child was alive. Yet despite this, a lot of the families experienced many overwhelming emotions and many challenges of a diverse nature. At the time of the interview, many families were able to report that things had settled down, but for others the struggle continued.

Family-wide effects

An acquired brain injury during childhood or adolescence appears to have wide-ranging effects within families. It was evident from the parents' interviews that each family member was potentially affected by this stressful life event. The lives of siblings, grandparents and other family members were not immune to the

trauma that families endured. It caused much chaos, turmoil and upheaval in family life.

"Our whole family life was totally beyond recognition ... Our family life totally ceased with it, totally. It was (like) living in a hospital. Even at home was like living in a hospital, it was totally non-normality ... (that's the) only way I can describe it, totally unnatural."

Not only are immediate family members deeply traumatised, but extended family members can also be adversely affected. One parent even mentioned how her child's injury had a huge effect on the wider community.

Role of parent/parenting challenges

Some parents reported fundamental changes in their lives as a result of their child's injury or illness. Such changes included a changed outlook on life, changed life circumstances and changes within themselves. The following quotes illustrate the upheaval and life-altering transitions which some parents experienced:

"... our life is changed completely."

"You change a lot as a person and live a different life completely."

"My whole world fell apart for me and there was no sunshine at the end of the road for me."

It is important to emphasise that for many families, their child's injury or illness did not occur in isolation. They frequently struggled to meet and cope with the multiple demands and stressors which life brought. Life events, such as illness in other family members, bereavements, care-giving of other family members and other such demands, can occur in addition to the challenge of coping with a child who acquired a severe brain injury. In addition, daily life stressors are an important factor to consider. Parents frequently had more than one individual to care for in the

there was a sense of feeling completely responsible for their child. The following quotes indicate the perceived feeling amongst many parents of being left on their own:

[What has been the most stressful aspect of being the primary caregiver?]

"All the decisions being left up to you. And sometimes there would be times when I honestly wouldn't know what to do. That is hard."

"It's really the parents at home that's doing the work. Well in my eyes, it's the parents. We're left to cope and do it ourselves."

Despite this sense of responsibility which many parents experienced, there was also a sense of uncertainty amongst some of the parents about what they should do, what was best for their child, and how they should go about achieving it. Parents were experiencing something new. They frequently didn't know what to expect. They were faced with the medical and professional world which, for some, was a daunting prospect.

"It was very hard at first ... you're raising a different child in your house. All the lads are healthy ... there's no handicapped children ... and we were dealing with something like that, that we never dealt with before. He depended on us at that time."

A small number of parents had doubts about decisions made by health care personnel (e.g. termination of treatment); however, because this may have been unknown territory for them, they may not have pursued the matter further. A larger number of parents took it upon themselves to fight for their child's rights and their entitlements, an issue which arises again in the section on health care services.

From speaking to the parents, it was evident that they invested an enormous amount of time

and effort in their injured children. Apart from the normal care-giving activities which in and of themselves can be time-consuming, these parents often faced intense work in rehabilitating their child, and attending hospitals and appointments. Many parents reported being constantly on the road, going to and from services or hospitals. For those parents who lived some distance from the capital, they frequently faced long trips to the National Rehabilitation Hospital or other such national facilities. When parents are requested to carry out work for each of the therapies their child is engaged in, the time invested in all these activities becomes substantial indeed. In addition, a small number of parents experienced problems in getting their young child to adhere to their exercise regimes.

"Oh my God, (it was) something else, I used to take work from all the therapists, occupational therapy, speech therapy, physiotherapy and when Rob took the break from Dun Laoghaire, I'd get work from all of them. I had to cope with all of that. I had to do my level best to do all that work, when he'd come home it was desperate. You feel guilty then if you didn't do it for the child, as a parent."

Parents frequently become their child's tutors, teachers, therapists and confidantes, all on top of their normal parenting roles.

There also appeared to be changes in the nature of the child-parent relationship. About one-third of the parents spoke of the increased dependency of their child on at least one of the parents following the head trauma. Some children became quite attached and clingy to their parents. The intense period of time which parents spent with their children following their illness or injury, and the role of the parent in fulfilling the child's needs, are likely to contribute to this enhanced dependency. In addition, over a third of the parents reported adopting a more protective stance towards

their child. This was related to the parents' fear for their child's safety.

"Every time he goes out you're wondering is he all right. Even when he goes upstairs, I'm terrified of him coming downstairs, in case he's going to fall, things like that, you know. It's there everyday, really, isn't it? No matter his accident is over years, it never leaves you."

"Even though he's a good child, very happy, very good like that, sits back. I'm the one who worries about him (the), one that's stressed out and worried sick about him if he goes outside the gate."

Having a child with special needs placed limitations on some parents in terms of the activities they engaged in and the manner in which they spent their time. They spoke about difficulties finding someone to look after their child, the inability to leave some older children alone in the house, and the need to consider the injured child's needs during any family activity or outing. Over half of the parents spoke about restrictions in their social lives and a reluctance or inability to leave their child in the care of someone else. The following three quotes illustrate this theme:

"Your whole social life, I suppose, is changed in the way you go about things during the day and all. A lot of it is based around him, because you have to be here for him, that kind of way."

"We don't leave him now, ... we'd be all the time with him."

"I don't have a life."

The difficulty in getting someone to look after the child in the parents' absence, which approximately one-third of the parents

reported, was partly due to the dependence of the child on the parents, and partly due to the difficulty of getting someone who would be capable of attending to the child's needs. The following quote illustrates the latter point:

"Maybe it's wrong but because my child has special needs, she needs special attention. I don't know who you'd turn to for that."

The restrictions on a parent's life ultimately depends on a variety of factors, such as the child's age, their stage of recovery, the time since the accident, and the extent of the child's special needs. A small number of parents mentioned the need to make a concerted effort to make time for themselves and do things they enjoy. These parents perceived having time for themselves as a crucial coping strategy that was critical to their well-being.

A minority of families spoke of the pressures placed on their marriages or relationships with partners following their child's illness or injury. The comments that follow highlight the stress a marriage may endure following the child's illness or injury:

"It was a big strain on us all, I suppose when you do have an accident, it either brought people together or it divides. Because it was going on for so long, it actually divided us."

"I nearly lost my marriage over it, do you know? Because we were trying to cope so much on our own and we just exploded one day. There was war here, I nearly lost my marriage over it."

The lack of time for each other, the different coping mechanisms which individuals can adopt, and the overwhelming stress which people are under, can contribute to marital strain.

Overall, it is evident from these interviews that

parents frequently face extensive changes in their lives following their child's trauma. In fact, parents frequently appear to become 'supermums' or 'superdads'. Parents seem to carry much of the responsibility for their child's welfare and at times this may be to the detriment of their own welfare. While many displayed a fighting spirit in their efforts to secure help for their child, there was much evidence of the trauma and strain that parents and families had endured.

Impact on siblings⁵

For those parents with other young children, the difficulties faced by siblings of the ill child featured as a common theme during the interviews. Parents reported that siblings suffered from a whole range of emotions following the trauma their brother or sister endured. Parents repeatedly acknowledged the upset, torment and stress experienced by the other children. In addition, for those children with ABI who were injured in road traffic accidents, parents reported that some siblings who were in the vicinity of the scene of the accident experienced a sense of blame or guilt relating to their brother's or sister's injury. For a minority of children, this resulted in long-term psychological problems requiring professional intervention.

A large number of parents spoke about how their non-injured children were neglected for a period of time, and how these children frequently lost a parent, both physically and emotionally, for some duration. Parents were frequently absent for long periods during their child's hospitalisation and subsequent rehabilitation. In addition, upon the child's return to the home environment, the care they require is frequently all-consuming and constant for at least some duration of time, with the result that other siblings can sometimes feel neglected and by-passed.

"You do, you kind of forget you have other kids, really, you do kind of forget. It's amazing but you just see one child, constantly see one child."

Parents spoke about devoting the vast majority of their time to their ill child. Given the potential long-lasting consequences of an acquired brain injury, this sense of absence or reduced quality time with their other children may last for a long period of time.

"At the end of the day I kind of missed out on a year, a year and a half, of my other child's life, and he missed out on me."

Parents can find it particularly hard leaving their other children behind if they have to spend a long period of time in hospital with their sick child. The following quote highlights this difficulty with one such parent:

"Well they (siblings) coped but I still feel that they lost out. They were in different houses and I wasn't there. They lost out, you know. It was a hard time for them. To this day, if I am going somewhere, I will make sure to take them with me. I would never leave children again."

As time progressed, a small number of parents realised the negative impact their absence or devotion to one child had on the other children. The increased attention which some parents had to offer to their ill child resulted in jealousy, attention-seeking behaviours or long-term emotional effects in some of their other children. A small number of parents reported how their other children who were very young at the time of their sibling's illness, subsequently became clingy due to the parent's absence for a long period of time.

"We were with the child that was injured and we thought he needed us. He needed us all right but they needed us here at home too. I was gone for years, years with Hugh and even when he would come home (from hospital), I was looking after him, he was so helpless, he was a full time job. That young

⁵ Some siblings were interviewed and their experiences and perspectives are presented in Chapter 7

little child (other sibling) was watching me with Hugh all the time, getting mum's attention and everybody's attention was to Hugh, we didn't realise it."

Over a third of the parents reported how their other children had increased responsibility following their sibling's illness or injury. Siblings frequently took on a care-giving role and assisted the parents in therapeutic regimes, supervised the child or young person in the absence of the parent, and looked out for the child during school and social events.

Overall, it was evident that a number of parents felt that the siblings of the ill child also had important needs that needed to be attended to. However, given the severity of the ill child's condition, this was frequently difficult, if not impossible, for parents to rectify. In many ways, siblings appear to be the neglected individuals within this trauma. According to parental reports, few siblings appeared to receive support or assistance from health or social services. For those who received formal professional assistance, it appeared to arise following a crisis in the child's emotional well-being some time after the trauma. The provision of general support on the part of professionals to all siblings following the trauma, did not appear to be a regular part of service provision.

The following quote from a parent summarises aptly the need to support children who have a sibling who has acquired a brain injury.

"The other children in the family needed as much support as I needed to give John. You need to have children provided with stability."

Family coping

When parents were asked to describe how their family coped with everything that they faced, the most common answer that was given was the need to "get on with things", to "take it

day by day" and to "keep going" as much as they possibly could. There was a strong sense from the parents that they knew they had to keep going and they had to be there for their child. It was not a choice for people, it was a necessity.

"You know, we probably feel sorry for ourselves, and you feel sorry for him but, at the end of the day, you just have to get on with it."

"You just have to pull together. You get strength from some place, you have to, for the sake of the kids. I don't know. On a daily basis, we just got on with it."

"You know you can't stand still and you can't bring it back ... At this stage, there was no one left to pity me. So I just got up and got going again"

Upon reflection, many responded that they were not sure how they did it or where they managed to get their energy from, but they somehow managed to pull through it. The perseverance, determination and willpower of individuals, appeared to be the common factor that pulled many families along.

"It's like you have to adopt (an) 'I can do everything syndrome'."

Social support was an important factor for most families in the aftermath of their child's illness. However, the issue of social support is a complex one. There is not necessarily a direct relationship between the needs of individuals and the provision of help from others. Within this study, family, friends and neighbours were all identified as potential sources of support. These individuals frequently provided tangible services or supports, in terms of gifts, food, transport, babysitting and money. In addition, parents spoke about people being there for them and

calling in to see them. Emotional support appeared to be much less frequently cited.

The paradox of social support, is that frequently during times of stress, people do not know what to do; they may feel too frightened and alienated to be of help and, at times, they are unable to be there for those who need them. This was evident amongst some of the descriptions which parents provided.

"They were all there, they didn't want to be pushing their help because they didn't know what to do ... they were all more traumatised than we were."

"I had great friends that wouldn't come to visit because they didn't know what to say and they were upset. They might send a box of chocolates or flowers but the one thing that you need, they don't give at all."

A further paradox in understanding the nature of support provided by significant others is that a small number of families discovered something new about people that they hadn't anticipated. Some people were there for families when needed, yet others felt let down by people for whom they had higher expectations.

"You have no idea how good people are, until you are in trouble ... they are absolutely brilliant."

Some parents recognised that significant others provided support in the initial days and months, but, over the long-term, recognised that people had their own lives to lead. Thus, there frequently is a time limit to the provision of social support.

"People that you thought were friends who came and visited us in hospital for the first month ... we had great backing ... but when something goes on for three, four, five

months, they don't, it's too long, it was then we lost a lot. Then you find out who your real friends are."

For other families, there were limits to how much they wanted from extended family and friends. Some families were self-reliant; they felt it was good to have support when needed, but otherwise wished to manage alone. A smaller number of families were negative in their evaluations of the support provided by significant others. For these families, they felt people were too busy looking after themselves.

In addition, a small number of people felt they coped by talking to others about their experiences and their feelings, while others felt they could share the responsibility of the care-giving with their partner. Some felt the need for hope or optimism with regard to the future was a necessary life-line in the struggle to recover, while others identified the need for time out, either through social or occupational activities, as vital for their well-being.

A factor that is likely to influence the level of support received by the family is the level of understanding of significant others and individuals within their support network. A number of parents identified the lack of understanding of others as a problem they contended with.

"They think that they understand but they don't. They look at that child and they think that he is perfect but they only look at him for one day."

"One or two friends, I found, they stopped treating Donal as an equal child, suddenly he wasn't included, and that I found definitely with one or two people and, for that reason, I turned off them."

A number of parents reported that because their child looked 'normal' that people had little conception of the impact of the ABI on the child and family. They underestimated the stress the family experienced and the care the child required.

Over the course of the interviews, many parents reported that they did not have an outlet in which to express their emotions and seek support. There appeared to be an unmet need amongst many individuals for emotional support. Many parents expressed the benefits of talking to other parents who themselves had children with acquired brain injuries. Such contact would facilitate identification with others and foster support and communication amongst people who had a high level of similar personal experience. Although parents frequently met other such parents in the NRH, this contact often did not continue thereafter.

A large number of parents also identified the need for counselling and family support as a primary need for the child who suffered the trauma, the siblings (particularly those who witnessed a sibling's accident), and for parents themselves. Some parents suggested it would have been helpful for them to have someone to talk to during the initial stages of acute hospitalisation, while others suggested that later on down the road it would be beneficial to receive counselling to help them cope with the immense stress and turmoil they experienced. Overall, from the parents' perspectives, there appeared to be little professional emotional support provided to families following the trauma.

PSYCHOSOCIAL EFFECTS OF AN ACQUIRED BRAIN INJURY ON CHILDREN

Emotional effects of ABI

Parents identified many emotional disturbances in their child in the aftermath of their illness or injury. Few children appeared to avoid negative emotional experiences at some point in their recovery. Over half of the parents spoke about the depression, the frustration and the anger

which their child experienced at some point in time. The quotes below portray parents' perceptions of some of the emotional experiences of children with ABI:

"I can't see the temper getting any better, because he'll get frustrated 'cause he'll see ... and he does see the boys who started national school with him ... And now he's not the same, and they don't want to be bothered with him ... and he cannot go out the same as them ... he's sort of stuck here, he's confined to this wee space."

"In 6th class, she cried a lot all right and was giving out about the disability. She locked herself into the room and she is still very distant."

Parents differed in their assessments of whether they felt their child had a realisation of the extent of their problems. Some felt the child had got used to their situation and didn't realise they were different, while others felt they had a clear understanding of the extent of their disability and its impact. The majority of parents identified their child as persistent and determined in their efforts. The perseverance that parents observed amongst the children, was regarded as a crucial factor in the children's progression and recovery.

"Even though she's a great mixer and she doesn't hesitate ... when her walking was bad, she still went out. It wasn't that she didn't realise it, I knew she realised it, she just didn't give a damn for it. 'To hell with 'em,' she said, she was going out walking and if they didn't like it that was their business."

There was a sense of admiration amongst many of the parents for the manner in which their child coped with all the obstacles they met. However, despite the determination which many children showed, a number of the

as a peer and they don't see him as part of their group. He doesn't see himself as being part of the disabled world. I see him as being right in the middle of a group that he wants to be with, but who don't see him as being like them. That is the most difficult thing. I will try and find a social group that he will like to be part of and keep it normal."

A further difficulty which some parents felt their child endured was the teasing, bullying and name-calling of others. Children's vulnerabilities were often identified and made fun of. A minority of parents also felt that their child was being led astray and taken advantage of by others.

Yet the converse of this is that a minority of parents stated that their child had never experienced any bullying or teasing following their illness or injury. Furthermore, many parents identified the positive, helping and prosocial behaviours of some peers and classmates towards their child. While some children lost their old friends, others had individuals who helped them re-adjust to their home and school environment.

"His friends in the school made it very easy for him. We were lucky in that sense that there were children there who were very supportive of him. They were coming up to see him and they helped him in school, so his friends were great in that sense."

According to parents, a large number of children were restricted in some way from partaking in activities or events. A combination of physical limitations, speech difficulties, and behavioural problems impacted on many young children's social activities. For some children, activities such as sports, music and social outings were difficult to participate in. Other parents spoke about their child not being able to keep up with other kids, always being picked last for teams, and having limited participation in social events.

"She wouldn't be able to hop or anything. I don't think she'll ever cycle a bike, she'll never get up on roller skates, do you know, that kind of stuff? It's stopped a lot of things ..."

"He should be going to discos, girlfriends and that, it's not really happening for him. Neil wouldn't be able to go off to a disco because of his balance and his speech, little things like that ..."

For children who used to enjoy or excel in certain activities, parents felt it can be frustrating for them if they can no longer avail of these opportunities.

"He can't play soccer like he used to ... he can't play ... he'd fall over ... and then he stopped going to school on a Friday because of this ..."

The development of peer relationships is a primary need for young people. Friendships can function as an important source of security and support, while also providing a context in which one learns about oneself and the world around them. Friendships can also lay the foundations for the development of relationship skills such as intimacy and reciprocity (Hartup, 1992; Schaffer, 1999). Consequently, the absence of peer relationships represents a significant obstacle to the integration of these young people in society.

Once again, it is important to state that there were some parents who felt that their child took part in activities, were included by others in events, and were not held back from partaking in activities or events. While the outcome was not negative for all concerned, there was a significant proportion of parents who identified their child as experiencing social difficulties and, as such, required attention.

For a parent, their child's social isolation and victimisation is harrowing to observe and difficult to remedy. Some parents were exasperated at the lack of social outlets for their child with ABI. There were a small number of parents who felt their child was exclusively dependent on their family for social activities or social engagement.

"That is his greatest loss, you know, his social life is so limited and he can't meet people."

"Socially would be the big thing, that's something you never hear about in any hospital. It would be the big thing. And if I ever had to meet a parent I would say, 'Don't worry about the medical side, that will all follow.' It's the social side of things nobody prepares you for and any parent will tell you that."

Future concerns

The concerns that parents expressed during the interviews were frequently not only rooted in the past and present, but also in the future. Parents expressed many future worries for their child with ABI.

"I pray to God every night that he will have a good future and that he will find a job that will suit him. That is all that I am worried about is his future."

For those parents with primary school age children, they frequently worried about the period of adolescence and the transition to secondary school. The teenage years were a concern for many parents, as they envisaged it would bring new challenges for both the child with ABI and themselves to cope with.

"She is ok right now, but it will get tough in the next few years with her being a teenager."

Many parents, however, had broader concerns about where their child would end up, who

would look after them, and how they would survive in the outer world.

"When he hits 18, there is nowhere for him to go. And he does need, as I say, all the support services..."

Some parents feared their child would never work or live an independent life. For those parents whose child with ABI was older there were concerns about where they would go and what they would do after they finished school.

"I can't see where his place in the world will be. I wonder if he will get into a unit and have some type of assistance and somewhat independence ... I don't know what there is for him, but I would love for him to be able to work at something on the computer, you know, that he has a place in the world and an occupation to work at."

Thus for many of these parents a level of uncertainty exists about what the future holds.

Overall, according to parental reports, children and young people face many obstacles in growing up following an acquired brain injury and have many support needs as they grow and develop.

"They need so much confidence to cope with growing up with disabilities or their injuries."

Those children with more severe disabilities are particularly at risk from exclusion from their peer group, and parents face many challenges in finding appropriate settings and activities for these children.

This section explores parents' perceptions of the services encountered from the time of rehabilitation onwards. The acute care which children received during the initial stages of their illness or injury was not explored in the present study.

Perceptions of NRH

This research was not directly concerned with the experience of families in the NRH. Instead the focus of this study was on the post-discharge experiences of children and their families. However, a number of comments were made about the NRH service:

There was an overwhelmingly positive reaction from parents to the work undertaken in the NRH and the value of the rehabilitation process in which their child participated. Parents frequently recognised the benefits of the rehabilitation their child received in bringing them along the road to recovery, in enhancing their functioning, and in recognising the needs of their child. There was a remarkable sense of gratitude to those within the NRH for the way they moved their child forward.

There was also recognition amongst parents of the value of the co-ordinated and comprehensive team approach that was adopted within the NRH.

Community health and social services

Approximately three-quarters of those interviewed felt they received insufficient help and support from their local community services. A variety of problems were identified by the parents. The primary problem was the perceived inadequacy of the intensity and frequency of therapeutic intervention. Many individuals felt their child was not receiving enough physiotherapy, occupational therapy, speech and language services and psychology services. Parents frequently felt their child did not receive the ongoing rehabilitation which they required. Few individuals were happy that their child received appropriate, consistent, and on-going assistance. The following quotes demonstrate the global dissatisfaction which some people expressed

[To what extent do you think the health services are meeting Jenny's needs?]

"Absolutely not. No way, I don't think they are at all, at all. Because if they were, they should give more time to kids in her position. It's ridiculous. I know there may not be too many around that are ... who've had strokes ..."

[Do you think the current health service provision is meeting John's needs? Do you think it's reasonable?]

"Badly. The point of view is that he should have more physiotherapy. He hasn't had any occupational therapy since he came home."

Many parents recognised that staff in local services were heavily burdened, that they had a variety of clients to work with, and had insufficient time to devote to individuals. In addition, a number of parents faced problems of staff shortages and unfilled posts which, at times, resulted in the unavailability of a much-needed service in their area.

A large number of parents felt they were abandoned and neglected following their return to their home community after a period of rehabilitation in the NRH. A common problem which parents perceived was the lack of follow-up support after children had been discharged. Indeed, many recognised a discrepancy between the care they received in the NRH and the care they received from their local health services. The team approach, the specialised knowledge and expertise of staff within the NRH, and the intensity and appropriateness of interventions in the NRH, were seen as a stark contrast to the level of care or, for some, the lack of care they received in their home communities.

"After all that they had done, and how far that they had brought him, and then home to nothing."

"The awful thing about head injuries is that we thought that we would never get to Dun Laoghaire and then, when we got to Dun Laoghaire, we were so excited about it ... that we were going to get Jason back. We were very naïve, really, and I felt that the day Jason left Dun Laoghaire, I thought that all my prayers had been answered. Everything would work out fine, but I was sent home in kind of a limbo with Jason. There were no services of any kind and I was just left to carry on by myself."

"Once he left rehab, that's it, just drop him into a black hole, basically. He's gone from the system and he doesn't have the care that he does need."

Many parents were exasperated at the constant struggle to obtain services for their child. Over half of the parents spoke about having to actively fight for their child's rights and the fulfilment of their child's needs.

"Oh you have to fight, there's things worth fighting for ..."

"You shouldn't have to fight for these things when you come back. This is my home and always will be. Why should I have to stay up in Dublin for another 6 months when he can get the treatment at home? Why can't they cope with the needs of my child? It is just unbelievable."

In addition to the struggle to obtain services, when services have been obtained, it frequently falls on the parent to co-ordinate such services, monitor the child's progress, and provide vital information to service providers. A number of parents identified the need for a middle-person to act as a communication link between the NRH, the hospitals and the community services.

"... If they had one person that could come in and convey information back to the various bodies ... you need someone to see the situation in these homes and they would follow up and go back ... and go to somebody and tell them that this is what is needed in this house."

Having a 'Case Manager' or a middle person to monitor the child's needs and negotiate amongst the various service providers was identified by a number of parents as an ideal way of assessing the child's progress and identifying priority needs.

A further difficulty which almost half of the parents faced was the lack of experience and understanding of the nature of acquired brain injury amongst many professionals. For some, this resulted in inadequate assessments of their child, inappropriate expectations of their child and an uncertainty about what to do with the child.

"The impression I was getting was they really didn't know what to do with him because they didn't seem familiar with a head injury at all."

"It's just an accident happened ... you get a brain injury. They don't ... I think they just think it comes back to normal after a certain amount of time which I don't think is the case ..."

According to some parents, there also appeared to be a lack of information and a break down in communication within the health services. A small number of people reported finding out some time later that they were entitled to receive certain allowances or grants. For some of these parents, they only discovered this information from speaking to other parents. Parents also reported communication problems amongst health care personnel. A number of parents reported poor communication amongst services vis-à-vis the

parent. For some parents, they frequently experienced a lack of follow-up to their enquiries, with the result that they were left feeling confused and uncertain about the continuation of services. A communication problem noted amongst a small group of parents was the lack of information provided in the acute and specialist centres regarding what to do in the event of problems arising, or what to expect from their children at a later point in time. This proved bewildering for parents at times, and reduced their sense of control over events.

A significant group of individuals spoke about the costs which accumulated as a result of their child's illness. Travelling up and down to hospitals, paying for accommodation during their time in the NRH, and paying for childcare while parents were away, added to the burden which some parents faced. Further costs were endured by those who resorted to private services in an effort to obtain the help their child needed.

"We have paid a fortune for the physiotherapy – £70 pounds a week – and the health board need to do something."

A small number of individuals reported going into debt as time progressed. For those who had a court case pending, if their child was in an accident, the length of time which parents waited for their settlements to come through was a crucial factor in alleviating or aggravating their financial situation. In addition, a small number of parents noted receiving assistance from the NRH or the health board during their time in the rehabilitation facility, in terms of transport or financial assistance, which proved very beneficial.

A further ongoing difficulty, which about one-third of the parents emphasised, was the extensive travel they had to engage in to get their child to services and therapies. This was particularly a problem for those who lived in rural areas. For those who had no transport of their own, this was a difficulty if the majority of services

were not within walking distance of their home, or if a good transport system was not available.

"It's just, you have to travel for everything, and it's not just that you mind travelling, it's just that the child is tired, and hot, and cranky ... Stressed."

"I would like someone to come into the house and take over with Jessica and give me a break, instead of driving all the time."

Extensive and regular travelling to appointments can be disruptive for children and their families. Some parents spoke about being on the road a lot, and being absent from the home, during the time when their child may have been engaged in multiple therapies.

Overall, a variety of problems were encountered amongst many of the parents. However, it is important to emphasise that a small number of parents were generally happy with the services they received. Some of the more positive aspects of services which parents encountered included the delivery of prompt and appropriate services and aids, and a co-ordinated team approach.

It appeared that those children who attended multidisciplinary clinics, or resided within a care setting in which they had access to various professionals, fared better in terms of their receipt of services. While some parents may have felt dissatisfied with the level of intervention received within these services, others received a co-ordinated team approach and regular input from professionals. However, the availability of professionals and services within these organisations or settings varied from place to place, thus affecting the overall satisfaction levels of parents. In addition, for those with a limited availability of services, the remaining care needs of children and their parents may have been neglected. Furthermore, some parents debate the appropriateness of multidisciplinary clinics that primarily deal with congenital disabilities for

children who have acquired brain injuries. On the whole, however, those who had the opportunity to avail of such services tended to have a greater range of services and professionals available to them.

A number of people spoke about specific individuals who had a positive effect on their child, self or family. Personality factors and the perceived helpfulness of professionals clearly played a role in parents' views of services. Parents frequently spoke about a specific individual such as a physiotherapist, speech therapist or psychologist to whom they were grateful for the service provided and the compassion they displayed. A minority of parents had regular and ongoing visits from a public health nurse, following their child's return home from the NRH. For those individuals who received this service on an ongoing basis, there were many benefits in having a person come to the home, and provide advice and a friendly listening ear. However, the vast majority of parents reported not seeing the public health nurse or seeing very little of them. GPs also featured prominently in the positive assessments which some parents provided. The positive aspects of GP services included their understanding of the parents' concerns, the provision of a friendly listening ear, and their response to the child's health-related issues. A small number of individuals also spoke positively about knowing that a particular individual was there for them if they needed their services or advice. This provided parents with security and reassurance. Finally, it is important to emphasise that a number of parents praised the care they received in the acute hospital following their child's trauma, or subsequent to the trauma, in the event that the child had to return for further treatment or care.

Overall, it is clear that the provision of health and social services to children and their families was a contentious issue. There appeared to be many unmet needs and many gaps in service provision for those whose child had suffered a head trauma. Inadequate availability of services, poor co-ordination of services, the absence of a

support, advice or information resource for families, and a lack of family support to help cope with the trauma, appear to be the primary difficulties which families face. The failure to provide such services evidently increases the burden on families, hinders the progress of children and impairs the families' ability to cope.

EDUCATIONAL EXPERIENCES AND EDUCATIONAL SERVICES

The challenges children face

Parents perceived their child with ABI to face many challenges in the school environment. They identified a variety of academic difficulties which the children encountered in relation to their school work. Most notable was the time it takes a lot of children to complete their school work, both in school and at home. In addition, if children do not get sufficient time to take down their work, they are at a further disadvantage. According to parents, children's slowness in writing, reading difficulties and the time it takes for some children to organise themselves and physically get the necessary materials, all contribute to the lengthy time children invest in their work. Some children appeared to struggle with particular subjects more than others (e.g. maths and Irish). Other parents reported general memory, concentration and learning problems, which added to some of the children's difficulties.

In addition, parents reported added problems of missed time from school due to hospitalisation and repeat appointments. Some parents chose to keep their child back a year, while others felt it was best to return their child to their original classmates.

The question of where to send the child to school was a concern for some. For those parents who faced the choice of full-time special education versus regular mainstream school, this was a difficult decision. In addition, it was difficult for some parents to find an appropriate special school for their child if this was the route they chose to go. Some parents experienced a level of uncertainty regarding

the appropriateness of the setting in which their child was placed. The following quotes are examples of such uncertainty:

"It is a good school, education-wise but to me, it is for dealing with cerebral palsy children, you know? Maybe I am wrong but I don't think that it is the right place. Paul hasn't got cerebral palsy, you know, and most of the children down there are in wheelchairs."

"I think it wasn't the right place, but it was the best place. It is very different being a head injury person than somebody who has been disabled all his or her life."

It is also important to emphasise that, for those in mainstream schools, even if they may benefit from special assistance or extra resources, there are other factors that may impinge on these decisions. A small number of parents emphasised the need for their child to fit in and feel 'normal'. Receiving special assistance may result in some young people feeling different; however, others may cope with it quite well. At the time of the interviews, six of the 27 families had children who attended a special school for much of their education.

One of the more crucial factors in the parents' perceptions of the role of the school in meeting their child's needs was the supportiveness and interest of the child's teacher or principal in working with both the child and the parent. About half of the parents were positive in their assessments of individual teachers or school principals. Parents spoke about certain teachers or principals being helpful in securing extra resources for their child, being approachable if the parent had a concern or worry, and supporting their child in a variety of ways. The following quote is one such example:

"She got great help in school and her principal was a great help ... He would bring her out in the wheelchair and he would put

As the following parent identifies, the response of a teacher can have a significant impact on a child's satisfaction and comfort within the school environment.

A number of the parents also mentioned their child's school was accommodating, flexible and willing to do whatever they could for their child. The following quotes illustrate some of the efforts that parents appreciated within the school environment:

My son's school is very flexible. They have a lot of things that they can do for you. They can give you extra help, they can give you extra time, they can give you extra resources. They can give you extra support. They can give you extra help. They can give you extra time. They can give you extra resources. They can give you extra support. They can give you extra help. They can give you extra time. They can give you extra resources. They can give you extra support.

There were, however, some parents who felt their child received insufficient help and support within the school environment. While a number of parents had positive perceptions of individual teachers, a small number of parents also observed a lack of teachers' acceptance or interest in their child. Two parents spoke about the reluctance of a class teacher to facilitate or allow a classroom assistant to be present in their class. While this is, indeed, a small number, it may have significant implications for the particular child's progress and adjustment. Other parents spoke about the negative attitude that some teachers displayed towards their child. This is illustrated in the quotes below:

Some of the parents also felt their child needed more home tuition, while others felt there was a need for more one-to-one tuition or small group tuition during the class day. There was a clear perception of the benefits of resources such as home tuition, resource and remedial teaching. Over a third of the parents had a desire for more help of this nature. In addition, some parents felt the general class teacher was not attending to some of the children's needs within the larger class setting.

The school represented another context in which some parents had to fight for services. At times, they also faced long delays in receiving much needed assistance. A significant number of parents experienced difficulty in accessing resources or aids for their child, with a number of parents identifying the need to fight for resources for their child.

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Some parents also mentioned that they had to fight for resources for their child.

"You drop in 500 stones and only one might appear, you know. I don't know whether it was the County Councillor that arrives on my door and I told them..."

A further problem which some parents encountered was the lack of understanding and experience of teachers of acquired brain injury or disabilities in general.

"... It was the first time they are seeing a child with a head injury coming into them. They wouldn't have a clue how to deal with that child. They just did their best to accommodate him, but it was no good really."

"Schools should be aware of what's available and pass the information on. There should be a person with responsibility for dealing with children with disabilities."

Some parents advocated the need for further training of teachers, improved communication between the NRH and local schools, and the need to prepare teachers for the consequences of an acquired brain injury and appropriate teaching methods for children with special needs. In addition, three parents specifically identified the need for a professional to speak to the child's classmates to prepare or inform them about the child's injury or illness and the consequences of it.

"...a professional should have been sent into the classroom to explain to the other children because the word 'head injury' meant nothing to them. She was still the same to them, but was Darina with the messed up brain."

For those parents whose child with ABI was in primary school, approximately half of them were concerned with how their child would cope with the larger and more complex environment of secondary school. Many of these children were in small rural schools and thus there was greater familiarity amongst the children and the teachers.

"The older she gets, the more worried I get, because I can't imagine her going to secondary school. To see her coping from one classroom to the other ... Remembering to take her books, remembering this and that, taking notes down from the blackboard. She can be quite slow writing, you know. Takes a long time to do her homework, so it's going to take her quite a long time"

Many parents felt their child was more protected within the confines of primary school, and worried about the obstacles and challenges that secondary school would bring.

CONCLUSION

In many ways, it is difficult to provide a concise summary of the issues that arose during these interviews. The complexity, intensity and pervasiveness of the impact of ABI is clear. The parents' reports revealed that many parents were engaged in a continuous search for the optimum level of care they could attain for their child. Yet they faced repeated obstacles in their quest to secure a better future for their child. Overall, there appeared to be many hidden victims in the aftermath of ABI. Parents frequently became so engrossed in the plight of their child that they did not attend to their own needs. In addition, the siblings of ill children experienced many fundamental changes in their lives, and they were often hidden victims within this trauma.

The tables that follow summarise some of the more pressing issues which emerged from the parental interviews.

Table 6.1 Key points in parents' perceptions of the impact of ABI on family members

- An intense emotional trauma is often endured by individual family members.
- Intensive care-giving and responsibility often lies with parents, and consequently many restrictions are placed on their lives.
- Families often feel a sense of abandonment following discharge from the NRH.
- The impact of parental absence on siblings was commonly identified.
- Significant psychosocial sequelae are experienced by children with ABI.
- There is a sense of determination, perseverance and motivation among families and their children in an effort to live their lives in the aftermath of ABI.

Table 6.2 Key points in parents' perceptions of their community-based care experiences

- Parents perceived a lack of follow-up care following discharge from the NRH.
- Inadequate service provision and insufficient resources were common problems encountered.
- Parents often had to actively seek services and fight for optimum levels of support for their child and family.
- A lack of experience and understanding of ABI was observed amongst community health professionals.
- A lack of co-ordination between services and service providers was encountered by families.
- Poor communication / lack of information regarding service availability was a further problem noted.
- Practical implications of service provision for families (e.g. cost and travel) were important considerations for families.

Table 6.3 Key points in parents' perceptions of their child's educational experiences

- A variety of academic difficulties were experienced by the children.
- The perceived helpfulness / unhelpfulness of specific teachers or principals had a significant impact on the child's educational experience.
- There was much variability in the ability of schools to accommodate a child with special needs.
- Parents experienced some difficulties in accessing resources or aids for children with special needs.
- The lack of experience or knowledge of ABI amongst school personnel was commonly found.

Chapter 7

Siblings' perspectives
on having a brother or
sister with an acquired
brain injury

INTRODUCTION

Research has shown that an acquired brain injury changes the life, not only of the child concerned, but of the family as a whole (Taylor, et al., 1995). The focus of this chapter is on the impact of an ABI on the other children in the family, the siblings of the injured child. Here we draw on interviews with thirteen siblings, ranging in age from 10 to 35, six males and seven females.

In Chapter 6, the parents' perspectives on the impact on siblings were presented. Parents highlighted the impact that the injury had on their whole family, with all family members experiencing increased stress in the period surrounding the injury and in its aftermath. Parents in the present sample spent long periods of time away from the family, with the result that they had less time to spend with their other children. Parents' accounts also revealed the high degree of adaptation that is made by families to accommodate the needs of an injured child on his or her return from hospital. For example, parents spent a great deal of time in the rehabilitation of the child, such as with physiotherapy.

Some of the siblings had been too young at the time of the injury to recall the immediate events around the illness or trauma, and found it difficult to talk about how the injury had affected their own life or the life of their brother or sister with an ABI. The majority of siblings interviewed, however, gave accounts of the time around the injury and initial hospitalisation of the injured child, and of the aftermath of the child's home-coming, that resonated with the parents' own accounts.

FACTORS INFLUENCING IMPACT ON SIBLINGS

It is important to bear in mind that the injury to a child in any family occurs within a context, including factors such as whether

there was any other significant loss as a result of the incident causing the injury. Some siblings had been hospitalised themselves following car crashes and some had lost other family members in car crashes. One such sibling found it difficult to disentangle the impact of the child's brain injury and the death of a parent:

"Well everything changed, my whole life flipped over so it's hard to say how like Paul in particular changed, because everything was changed."

The context also includes such factors as how close and resourceful the family is prior to the injury, the number of children in the family and their ages and individual needs, and the location of the family home in relation to national treatment and rehabilitation centres. It is important to bear in mind that this considerable diversity in individual and family circumstances shaped the experiences and perspectives of those interviewed.

THE EMOTIONAL IMPACT OF THE INJURY

Reactions to the initial trauma or illness

Several of the siblings recalled the trauma or illness with some distress, becoming upset during the interviews when they talked about what had happened and how they had felt at the time. Their distress signified that the initial event represented an important emotional period in their lives, marking the beginning of a period of turmoil and change for the whole family. Siblings recalled the initial shock and uncertainty, and the anxiety that surrounded it. They also recalled the ensuing relief for all the family when their sibling survived the trauma or illness.

"It was a shock and it was frightening for the time that she was sick."

The period of hospitalisation

The period of hospitalisation for the child with ABI was typically lengthy, and was a stressful period for siblings, on a number of levels. Siblings' first encounters with their injured brother or sister after the ABI, occurred in the hospital setting. These encounters were experienced as being upsetting for siblings, who found it extremely difficult to see their brother or sister in the hospital, particularly if they were unconscious or were not able to speak. Several recalled their struggle to manage their own emotions when they first encountered their injured sibling in the hospital:

"Well you go, like, stop, stop, trying to stop, trying not to cry ... when Julie was awake and she didn't know where she was, like, and I started telling her where she was, what happened and all that. It was kind of sad when she couldn't talk to me, like ..."

"Well I thought he was dead ... so far as I was concerned he was dead and gone. And then it turned out that he wasn't really ... it was kind of, I don't know, I couldn't come to terms with it ... when I saw him I just, couldn't be in the same room as him."

Their emotional reaction to their injured brother or sister was shaped, in part, by their expectations about how the child had been affected by the brain injury. Some children were surprised to find the child able to talk and laugh, even if there was a clear difference in speech and other abilities. Other children, however, were shocked and upset to see for themselves how their sibling had been affected by the illness or trauma, and the recollection of this experience caused them to become upset during the

interview.

[What was it like seeing him?]

"Disappointing."

The most difficult aspect of the injury for many children was the lengthy separation from their parents during the injured child's hospital stay. Parents' absence from the home was experienced as more difficult in the context of children's own worries about their injured sibling, or in the context of another loss.

[What was the hardest thing for you?]

"Not seeing your mum and your brother."

"(It was) annoying really ... staying with someone else that you don't really know much."

The distance of the family home from the NRH had a bearing on the extent to which children felt isolated from their parents and injured sibling. Those living at further distances typically did not visit the hospital frequently, and parents spent long periods of time travelling. Siblings recalled this as a period when their mothers were absent a great deal, and when people other than their parents, typically looked after them. Several siblings missed the whole family being together to share daily family life.

Siblings also recalled the period of hospitalisation as a time when their parents were upset and worried, and it was difficult for them to see their parents struggle to cope.

"Well for my parents, it was a big crisis. They were going around in circles I felt."

Siblings typically saw quite little of the child with ABI during this lengthy hospitalisation period, particularly if they were young children themselves at the time. Many missed their sibling a great deal, and some found that it was difficult to pick up the

threads of their relationship again after such long periods of separation.

"In a way it was (difficult to see him again) because, I don't know, when he met me he wouldn't talk, he was so quiet, he was so shy 'cause he hadn't seen us for so long."

The hospitalisation period forced a separation of the entire family. As a result, the time in which the injured child was in hospital, stood out for siblings as a particularly difficult period in their lives.

The homecoming

The return of the child with ABI to living at home, represented another significant change in the lives of siblings. These changes were mainly described as being positive. The event of the homecoming marked the end of a long period of family separation and disruption for most siblings, and they remembered this, even if other details about this period in their lives were difficult to recall.

"I just remember taking him home for good."

They were relieved to be able to spend time together again as a family, even if there were many adjustments to be made.

"I couldn't spend time with them 'cause they had to spend time with Marie but once they came back, when Marie came back, me and (my sister and brother) can spend time with them again."

Many siblings acknowledged that while the homecoming brought relief, it also brought new adjustments as all family members tried to accommodate the needs of the child with ABI. In some cases, families encountered novel challenges as a result of their child's newly acquired disabilities. The use of aids, such as wheelchairs, may have resulted in access issues for some families. Many siblings were conscious that this period was

challenging for their parents and that it was a time of considerable anxiety.

"Yeah, I do remember relief like, you know, that he was finally home ... but things at home were fussy, fussy ... the biggest thing was his wheelchair."

SIBLINGS' PERSPECTIVES ON THE IMPACT OF THE INJURY

Impact on injured brother or sister

Siblings varied in their views of the impact of the injury on their sister or brother and the knock-on effect of these changes in their relationships with them. Younger siblings, particularly those still in primary school, recognised that there was some difference in both physical and mental capacities but found this difficult to articulate in the interview. Most felt that their brother or sister was now different from other children.

"Yeah he got a bit different. He's different from everybody else."

"Well he was like, he was this totally different person you know ... he was just like he was a non-entity you know what I mean like, he'd no speech, he was practically brain dead for a while, it was like ... taking Simon away and he was dead and there, there was this other, but it wasn't (him) ... I know it was, but it didn't seem like that to me."

"He is still the same person. The only thing that has changed is that he is a little quieter than he would have been all right."

Some of the younger siblings had a sense of having lost a playmate, particularly in terms of involvement in sports and other physical activities. One younger sibling said that if he had three wishes, one of them would be that his brother "would be good at sport."

Many siblings viewed their brother or sister as being more vulnerable since the accident or illness and adopted a protective role towards them. Like parents, they worried that the child was more susceptible to falls and were concerned about the impact this would have.

"I mind her ... if she falls I always go over and help ... I'd be afraid she'd hurt her leg with it."

Siblings were also protective in terms of their sensitivity to how others might react to the child when he or she returned to the community or to the school. Among this small sample of siblings interviewed, there was not a great deal of evidence that children with ABI had been teased or bullied, although there were a small number of accounts of this occurring. There was, however, a strong sense that if such teasing should occur, siblings were primed to respond in defence.

"Well, Mummy started putting her back in school, her leg was cramped and people started calling her names and I was standing up for her like."

On the whole, these interviews suggest that siblings were strongly motivated to ensure that their relationships with their injured brothers or sisters developed in a positive way, and that they put a good deal of effort into ensuring that this was the case.

Siblings' views of the impact of ABI on parents

Siblings of all ages felt strongly that their parents had experienced a major trauma and in some cases they found it difficult to witness such distress in their parents.

"The way you look up at your father and he is the one that looks after you and everything, but when you see him crying, it's a different story. But he was strong enough ..."

A number of siblings felt that their parents' lives were consumed, on an on-going basis, by the time they needed to spend caring for the injured child.

"Certainly Mum's focus has changed. She is completely devoted to Alan and ... doesn't have much time for anything else ... he takes up all of mum's energy and time really. I am not saying that in a negative way because that is what he needs."

There was evidence that siblings felt empathy with their parents, and that they had high levels of awareness that parents made choices about spending time with the injured child out of a sense of necessity. There was little evidence that siblings blamed their parents in any way for their absences from the home, and a great deal to suggest that these children and young people strove to help and support their parents in any way they could to deal with the adversity they were facing. They helped their parents more, for example, with household work, because they felt that this was necessary in the context of the changed demands on the family since the ABI.

"I had to do more stuff, I had to work harder."

"I use to help out in whatever way I could ..."

Impact on siblings themselves

There was some variation in siblings' views on whether, and how, the child's ABI had affected their own lives. Several siblings felt that the injury marked a dramatic negative change in the course of their lives, while others felt that although they had suffered through a terrible ordeal, they had come through it well, and even with some positive impact. Others felt that there had been no lasting impact of the injury. These different perspectives are illustrated in the following quotes from siblings:

"I was like completely changed. I just couldn't talk to people anymore."

"It has made me stronger as a person and in making decisions ... I feel better with people. I didn't know how well off I was actually, you know?"

"It is a consideration all the time ... he can't be left here on his own and so we work out ... who will take care of him. Everyday you are thinking about him or doing something for him."

"I am very strong mentally and it didn't leave any lasting emotional scars at all."

This diversity of reaction is to be expected, given the variation among this group in their family circumstances, age, the nature and extent of the brain injury and whether they or others in the family had been damaged as well as the brain injured child.

Impact on the family

There was also variation in siblings' views on whether the family had changed as a result of the injured child's trauma or illness. In some families there was on-going strain while in others the homecoming of the child marked an easing of the pressure on the family.

"Just that the whole thing saddened us you know. That we all have to deal with it and I can't say it brought us close because we were all very close anyway."

"Well I feel that it was a huge crisis and they were all afraid of everything and that has all changed since Alex is home."

"We wouldn't worry as much about the small things in life."

Some felt that the family had not changed in

any essential respect, although the experience had been extremely difficult. Many felt that the family had coped well with the ordeal and had learned from it. It appeared that some families had considerable resilience that was brought to light by this adversity.

"Well all I can say is all our lives are doing well ... like we're fine really. Well, we're not fine, you know, we all have baggage and stuff, but we're fine ... considering."

These differences in perspectives also reflect the diversity of circumstances of the families, some of which existed prior to the injury and some of which reflect differences in the outcomes for the affected children.

COPING AND SUPPORT

Experiences of support

For the most part, siblings felt that other people, such as neighbours, friends, and even strangers had responded with kindness and made efforts to be supportive. To a large extent they appreciated any positive gestures, such as teachers asking about their brother or sister or giving them more leeway with schoolwork. Other children however reacted quite negatively to the extra attention the family received.

"I didn't want anybody feeling sorry either. I just got on, I didn't say I had a sick sister ... I just got on, you know."

It appeared that most siblings did not actively seek sympathy or understanding from others, but appreciated kind gestures that others made in recognition of the strain they were under.

Siblings identified their extended families and schools as the principal sources of support. Relatives were viewed as having played a key role during the initial trauma

and the hospitalisation period, and many siblings who were young at the time the ABI occurred spent a great deal of time in the care of relatives. Like parents, however, some siblings, particularly those who were older, realised that the family could not rely on outside support indefinitely and eventually had to cope independently. Most siblings also felt that schools, including teachers and peers, had been kind and understanding and that this had eased their brother's or sister's return to the school environment.

Views about support needs

Siblings' perspectives on what *might* have helped them to cope better have much in common with parents' views. Many recognised that talking to a professional might have been helpful, but for the most part they had turned down any offers of help at the time of the initial trauma or illness. Some felt that the time at which the help had been offered had not been suitable for them, but that they would have been open to taking part in counselling at different times, depending on the circumstances. One sibling recalled that counselling had been offered to the family when his sister was in hospital, but he had refused it.

help with cooking meals and other work in the house. While some siblings had enjoyed spending time staying in relatives' homes, most appeared to value being able to remain in their own homes. It was evident, however, that the absence of their mothers from the home was a considerable psychological strain, in terms of the absence of the emotional support their mothers provided, and a strain in terms of adjusting to new care-giving arrangements, whether that was having to live elsewhere, having to adjust to different food, or other such changes. Some siblings also felt that their family would have benefited from having somebody to call to the home to check whether any help was needed once the child had returned home.

One sibling felt strongly that accommodation should be available for parents when a child is in the NRH. This would ease the burden on parents and thereby on the whole family:

He felt that if counselling had been offered at a later stage, maybe not at the time but maybe a month or two later he would have been more open to it.

Much of the focus of siblings' descriptions of support needs was on practical help to ease the strain on the family of having to provide high levels of on-going support to the child with ABI, while at the same time coping with the demands of daily family life. Several siblings felt that it would have been helpful to receive assistance in the home when their brother or sister was hospitalised. They felt that practical help was important, such as

Siblings in support roles

A key factor that shaped siblings' experiences was the role they perceived themselves to have played, either direct or indirect, when the trauma or illness occurred. It was evident that siblings wanted to play an active role in helping their injured sibling to recover.

*"I had to do stuff (when my sister came home). If she wanted something, I would get it for her, as before I would have told her to get it for herself."
[... were you feeling you had to?]
"Ah no, I did it all right. She was my sister. She would do it for me."*

Those who felt they had been in a position to take an active role to help their sibling or other family members appeared to have a more positive view of the outcome of the injury.

There was a great deal of diversity among the siblings interviewed, in terms of current age and age at the time of the illness or accident, and also in terms of the nature and severity of the injury. It was not surprising, therefore, to find considerable diversity in siblings' experiences and perspectives of the impact of ABI. There was, however, an underlying pattern of shared experiences and views. On the whole, siblings felt that the occurrence of the ABI brought significant emotional strain and daily stress to their lives, and their accounts of their experiences highlight the major adjustments that these family members made to adapt to the injury. They felt that their relatives and school played important support roles, but saw parents as needing a great deal of additional support, and felt that this support should be brought to the family home. These responses from siblings highlight the extent to which the impact of the injury reaches through the family system.

Table 7.1 Key points from siblings' interviews

- The period of hospitalisation of the child with ABI was extremely stressful for siblings.
- Lengthy separations from parents brought emotional strain and practical difficulties in daily living for siblings.
- Separation from the child with ABI added to the stress of siblings.
- Siblings had mixed views about the impact of ABI on the child affected, on their families and on themselves. All felt that the entire experience was very stressful, yet some appeared resilient in the face of adversity.
- Siblings demonstrated a commitment to the welfare of their families.
- Siblings saw relatives and school as the most important sources of support for the family.
- Siblings felt support should be provided to the family to ease the strain on the family of parents' absences and travelling during the child's hospitalisation.
- Siblings also felt that support should be offered to families when the child with ABI returned home from hospital.

Chapter 8

Teachers' perspectives on working with a child with an acquired brain injury

This chapter presents the views of teachers who have worked with children with ABI in their local community. Twenty-two interviews were carried out with teachers, with a total of twenty-five teachers being interviewed in total. These included teachers from primary schools, secondary schools and special schools. In addition, a number of special needs assistants, resource teachers and home tutors were also interviewed.

The transition from the medical or rehabilitation system to the educational setting is a critical phase in the child's recovery and rehabilitative process (Christensen, 1997). According to Christensen (1997), if this transition is unsuccessful, much of the previous work of the acute rehabilitation phase can become undone. Given that children spend much of their 'working day' within the school environment, the school represents the primary rehabilitative setting within the child's local community (Janus, Mishkin, & Pearson, 1997).

The teachers interviewed identified a variety of different needs and concerns for each child. Significant themes, however, emerged from the interviews which appear to apply to all or most pupils, regardless of their circumstances. There was also strong agreement amongst the teachers as to what their professional requirements and needs were if they were to provide the best possible post-injury education to children in their care.

There would appear to be four educational opportunities open to children following an acquired brain injury:

- Continue in mainstream education
- Continue in mainstream education while obtaining special needs assistance and/or resource teaching
- Attend a special school, but still avail of the mainstream educational opportunities for specific classes

■ Attend a special school only

This flexibility in the choice of options would appear to emanate from both the State sponsored educational system, the flexibility of schools, and importantly, from the teachers operating within this system.

The remainder of this chapter will identify the main themes identified by teachers concerning both the experiences of children with acquired brain injuries within the educational system and also the experiences of teachers themselves in working with these children.

ADJUSTMENT TO THE SCHOOL ENVIRONMENT

Teacher/child ratio

Issues concerning teacher/children ratios generate much debate amongst all stakeholders within the Irish education system, and it is no different in the case of children with special needs who are returning to mainstream schools. A number of teachers, particularly those in primary schools and special schools, specifically mentioned the benefits accrued to a child from being placed in a small class.

"So the fact the he was in a tiny class ... coming in made the transition very easy, you know coming to school." (Teacher in a mainstream primary school)

Some primary school teachers expressed reservations concerning the child's eventual move to secondary school where it was felt that the child might encounter the consequential difficulties of larger classrooms.

"...It would be very difficult for a secondary school to provide him with what we could provide him with because it is a smaller setting and it was a very familiar setting for him." (Teacher in a mainstream primary school)

Physical difficulties

The teachers' interviews revealed that children can experience a variety of physical difficulties as a result of acquiring a brain injury. These difficulties may emanate directly from the injury to the brain as in the case of a stroke, or they may be caused by additional physical injuries incurred at the time of an accident. The children's impairments ranged in severity from long-term physical limitations to short-term loss of movement or co-ordination. While such difficulties may be more common in special needs settings, in mainstream schools they can have consequences for others within the school setting. As one teacher put it:

"(He) holds up queues and everything like that at an enormous rate because he can't go any faster." (Teacher in a mainstream primary school)

Intellectual and academic difficulties

Intellectual and academic difficulties were, predictably, another common outcome for children who had acquired a brain injury. Each school teacher reported evident difficulties that children were experiencing in these areas. For example, in some cases where the child or young person was able to return to mainstream school settings, he or she required a special needs assistant to help them with their schoolwork.

"She would come in for the maths class. Say that I was doing addition; she would get out his counters for him because he wouldn't be able to get them out himself. She also had to get out his books first and she had to open the pages for him. Also get his pencil out for him and he was easily distracted. He would be in wonderland and she would be calling him back." (Teacher in a mainstream primary school)

While not all children required special needs

assistance, many children required resource teaching. It is not possible to say in all cases if this need was related to the ABI, because, in a number of the cases, the teacher had not known the child prior to their injury and consequently did not know whether this need for extra tuition was a post-injury or illness requirement.

"Her processing, her reading, her writing, her reactions to things you'd say were all (different)." (Teacher in a mainstream primary school)

"He would be behind his peers generally ... He would be behind in his reading, but not severely, and behind in his maths, probably two years behind. Problem solving wouldn't be his forte." (Resource teacher)

The most severe form of intellectual impairment resulting from brain injury necessitated the child moving to a special school. In such a setting, the young person was usually in the company of children with other intellectual difficulties, such as disorders on the autistic scale which differ not only in their aetiology but also because such impairments are not acquired. The following quotes illustrate some of the intellectual difficulties of children whose capacities were severely affected following an acquired brain injury:

"Peter (Teenager) is now operating at a Junior Infant's level and is unlikely to improve." (Teacher in a special school)

"Academically, he can basically write his own name now, but that's after three years." (Teacher in a special school)

An added difficulty in this setting is that, even in the most severe of cases, there appeared to be a recognition within some individuals that their abilities were not commensurate with

what they were before their injury, and that as people, they had changed. One teacher at a special school described praising one young person:

"I said, 'Wasn't that absolutely fantastic, wasn't that very good ... you're an absolute genius, I'll have you in university before long' and he turned at the door, he winked, and said, 'Ah (teacher's name), I wouldn't go that far.'" (Teacher in a special school)

Another teacher in a special school reported that the realisation of post injury difficulties can also be a cause of depressive episodes.

"He is resentful of his accident, and often comments, 'It changed my life, everything went wrong' ... it's like the realisation comes to them of what could have been and this colours so much of their pre-disposition to getting depressed." (Principal of a special school)

Behavioural issues

A further factor that some teachers identified as influencing a child's level of adaptation to the school environment was the presence of behavioural difficulties. Behavioural issues were identified by some teachers in both mainstream and special schools. Although such issues were mentioned by a minority of teachers, it was a sizeable minority. Terms used to describe such behaviour ranged from it being "volatile and explosive" to "inappropriate and immature". In one instance a teacher described how a child would realise – too late – that she had overstepped certain boundaries:

"She'd say things, and you'd know by her face when you'd correct her that she knew it wasn't appropriate." (Teacher in a mainstream primary school)

However, behavioural problems within the school environment presented difficulties, not only for the teacher but, also for the child.

"She's tolerated, they make allowances. If the class wasn't as tolerant she wouldn't be included as much." (Teacher in a mainstream primary school)

The personality of the child

The ability of a child to cope with challenges that they are faced with can depend, not only on the nature of the challenge but also on the nature of the individual. The personality of the child following an acquired brain injury emerged as an important theme in many of the teachers' interviews. However, where personality emerged as a factor, it did so in positive terms such as in the description of a child's approach to life, or their application to their work.

"... He was remarkable from the beginning. ... He seems a very happy kid at times ... he laughs easily and has a good sense of humour." (Home tutor to a child in a mainstream secondary school)

"(There's) no point in saying 'No, you don't need to do that', because she is going to do it anyway ... Very stubborn little girl, but that probably got her to where she is today." (Teacher in a mainstream primary school)

"...He's a very good student and works hard at what he's given to do ... He's not one to say 'I'm not interested in that' ... he'll give everything a go." (Teacher in a special school)

Overall, while teachers identified numerous difficulties which children with ABI encountered on their return to an educational setting, many felt that the transition was quite successful. However, it is probable that the teachers' perceptions were influenced by their knowledge of what the child had

experienced. Some of the teachers qualified their judgements of the child's school adjustment by taking into account the stress endured and the sequelae of their brain injury. The following quotes illustrate the factors that may influence the judgements of teachers:

"What we wouldn't be aware of is ... I suppose if he hadn't this, would he be a high achiever? But within the range that he's working, he's doing fine. And if he didn't have the injury prior to starting off maybe he'd be in a higher range of classes and so on. At the present time I don't know what his capability would have been without the injury. But as he's working here we have no problem." (Teacher in a mainstream primary school)

"He would be behind his peers generally, but he does apply himself generally better than teachers would be expecting him to. He compensates a lot." (Teacher in a mainstream primary school)

Many of the teachers were not aware of the child prior to their illness or injury and therefore their assessments of the child were based on their current progress and observed capability.

PEER-RELATED ISSUES IN THE SCHOOL ENVIRONMENT

Informing peers of ABI

Teachers were divided equally as to whether it was in the interests of an individual child for his or her classmates to be informed of the nature of the child's injury and the difficulties which they may encounter on their return to the school. Those not in favour of providing information to the class were of the view that it would serve only to draw attention to the child, while others believed it to be the job of parents rather than teachers to impart such

information. However, the opposing view was that such information could save a child a lot of discomfort upon his or her return to school. Teachers of this view believed that advance communication to a child's classmates may remove the necessity for a child to answer embarrassing questions from peers, and also, that it would help to alert other children to difficulties that their classmate may need assistance with.

"It helps other children to understand that behaviour which otherwise might be viewed as being odd or peculiar isn't – it's not anything to be afraid of." (Teacher in a special school)

One teacher was of the view that the children might benefit from being spoken to by a professional from outside of the school environment.

"I think that it would be a good idea to have somebody who is involved with disabled children come and speak to them ... it would answer some of the questions that are always on their mind." (Teacher in a mainstream primary school)

In some rural settings, where there was close community interaction, children appeared to learn, through parent or peer interaction, the consequences of a child's injury and their recovery progress. Circumstances such as these appeared to lend classmates an opportunity to support the injured child, through sending cards or other forms of communication, which in turn appeared to aid the child's eventual transition back into school.

"So when he came back, he was in a wheelchair and everybody wanted to wheel him. It was a great ... what would I say, it was a wonderful thing. I guess ... they would know the background of what

happened to him. I told them on a day that he wouldn't be in." (Teacher in a mainstream primary school)

Integration with peers post ABI

Successful peer integration post-ABI appeared to be dependent on a number of factors, including behavioural and intellectual issues related to the brain injury, the age of the child on their return to school, the personality of the child and the type of school environment that they had returned to.

According to the teachers interviewed, children with intellectual and physical difficulties post-ABI were accepted by peers in all school environments, but most readily in special schools. Teachers in these schools spoke of a willingness on the part of other pupils to accept individuals at face value. In special schools, there appeared to be no issue taken with any individual difficulty that a young person had – except where such a person's behaviour had consequences for the observer.

"With all the children, with all their diversity of needs, very accepting, very caring... You're part of the group as all of us, except if you're making a lot of noise, a lot of screaming or banging ... (they find that) slightly intimidating." (Teacher in a special school)

Teachers also felt that children returning to mainstream schools also seem to be accepted without any apparent issue. Children returning to primary schools appear to be openly received, and attract a lot of care and attention from both the teacher and classmates. Despite this, some teachers conveyed the point that while the child might be friends with everyone in the class, they might not actually have a friend as such. One teacher, who commented that academically and socially, a particular child was two years behind his peers, later remarked on the child's social skills:

"He's a very sociable child. But he's inclined, I've noticed in the yard ... he prefers to play with younger children ... and he's inclined to gravitate towards younger children ... children maybe two years younger than him." (Teacher in a mainstream primary school)

There is evidence that some young people in secondary schools either kept to themselves, or mixed with older children that they knew from outside school. A number of secondary school teachers commented on this:

"He hangs around out of class time with students who would be much older than him – because they've got the home connection" (Resource teacher in a mainstream secondary school)

"He does tend to gravitate to older students in the school ... I'm not sure that that's always the healthiest thing or the best thing" (Principal of a mainstream secondary school)

Sexual Issues

Two teachers, one of a young person in a special school and one of a young person in a mainstream secondary school, both reported concern with regard to relations with the opposite sex.

"(He) gravitates towards older students ... not so sure that's always the healthiest thing...he should be more in toe with his own peers as opposed to clinging on ... particularly to older girls." (Principal of a mainstream secondary school)

"He's experiencing feelings on issues of sexuality ... and there is going to be difficulties in dealing with that ... He said to me 'Miss, the women are causing me awful problems' " (Principal of a mainstream special school)

Issues related to one's sexuality are likely to arise for many young people as they move through the life-cycle.

Bullying

In contrast to parents, teachers claimed to have noticed very little evidence of bullying. One teacher however suggested that the bullying that did occur seemed to be a two-way process:

"There was some, but he definitely gave probably more than he got. He could be very scathing of other people's disabilities somebody may get a question wrong, and he would turn around and say to them 'Loser' ... He would usually pick on someone that would get very upset at being called a loser, he wouldn't tend to say it to someone who would just not take it on board." (Teacher in a special school)

Overall most teachers described a fairly consistent picture of children settling back into their educational settings without too much difficulty. However, a number of teachers highlighted the need for the child to be provided with social skills training. In some cases, teachers identified this as one of the most important needs of a child within the school environment. This need for social skills training was consistent across all educational settings.

Settling in – the need for normality

One of the strongest findings to emerge from the interviews of mainstream school teachers was that young people on returning to school post-injury had a strong desire to be treated like everyone else. This striving for normality emerged from a number of interviews.

"She works, she really works very, very hard. She probably works a lot harder than a lot of other children in the class because she tries to compensate for the fact that she is that much slower." (Teacher in a mainstream primary school)

One teacher commented on how one young child benefited from this normality – on this occasion as instigated by other students:

"I really did think that he improved no end being in with the ordinary children. You see, those children didn't take as much into account that he had a brain injury ... I might be saying beforehand that I wouldn't give him that because it was too hard but they wouldn't. I thought that this was very good for him. They probably stretched him a lot." (Teacher in a mainstream primary school)

Other teachers appeared to be aware of this need for normality, and considered decisions relating to the child on this basis.

"We could have withdrawn him from a lot of his regular classes, but it's a question of trying to find a balance ... he obviously will accept a certain amount of withdrawal ... but at the same time he wants to be part of the normal set up of the school." (Principal of a mainstream secondary school)

Evidence of this resilience in response to their circumstances can also be seen in the children's attempts to be involved in all non-educational school activities. Most of the teachers in both mainstream and special schools report that children are determined to pursue everything that other students do, but, inevitably, they are restricted because of their physical impairments.

"I have seen him on the basketball court, I have seen him tog out, I know he has been encouraged by the coach to have a go ... he has done his bit, but obviously he finds it quite difficult. He's quite restricted in his movement, particularly if you're talking about running." (Principal of a mainstream secondary school)

The role of friends

There was also some evidence that returning to a class of friends helped children to settle back in to the school environment.

"The children wrote to her while she was away and looked forward to her coming back. She knows that she's very special." (Teacher in a mainstream primary school)

Similarly in a secondary school setting, one teacher spoke of placing the young person sitting next to friends so they could act as a medium for communicating between the student and teachers, if any difficulties arose.

"He was specifically put with one or two friends from his home area and worked well with them. And we deliberately put him in classes like that ... so that he'd have support and contact, and he'd have a person that we'd have said (to)– 'Look it, if you have any problem, come down and tell us.'" (Teacher in a mainstream secondary school)

THE EXPERIENCES OF TEACHERS WHEN WORKING WITH A CHILD WITH AN ACQUIRED BRAIN INJURY

The concerns of teachers

A number of primary school teachers, working with children with acquired brain injuries, expressed concern regarding how the children would cope as they made their way through the school system. Particular concern was expressed with regard to the difficulties that the child might encounter in the transition from primary to secondary school.

"We were concerned about secondary school, because we had spoken to the Principal of the secondary school ... just to

fill him in on the assistance that he had got here, and what else he needed in terms of extra help." (Teacher in mainstream primary school)

"When she goes into the 'big school' she could become a victim of bullying, she is someone who will definitely need a special needs assistant in secondary school ... she won't find the same tolerance that she finds in the school she's in at present." (Teacher in mainstream primary school)

Extracts such as these help to convey the interest and concern that most teachers demonstrated with regard to the pupils in their care who had acquired a brain injury. However, there were also some examples of insufficient consideration being given to the needs of the child with ABI and a lack of understanding or ability amongst teachers to meet the child's needs accordingly. One contributor was of the view that his student received little support from teachers in his secondary school:

"(I have a) very strong impression that they weren't interacting with him. They did not know how to and they were not able to for whatever reason." (Home tutor to a child in a mainstream secondary school)

Many teachers reported increased demands and responsibilities that arose from having a child with special needs in their classroom. There were reports of alterations, or adjustments, that were made to their teaching schedule or the manner in which they organised their classes. One teacher spoke of the need to plan the teaching schedule each day in order to facilitate the child with an acquired brain injury.

"You see we had to look for everything. Nobody came with things and said, 'Well you have a brain-injured child and maybe this will help you and maybe that will help you'. Things that would have helped him and we didn't know (they) were available." (Teacher in a mainstream primary school)

"There should be in-service training as (for) a distinct group of students, as opposed to students with disability, it's all too easy to lump them together but they're not the same." (Teacher in a special school)

Where information was available to teachers, it usually came via the families, and not from any official source related to the child. This appears to be one of the areas in which families were supportive to teachers – in filling in their information deficit. But such individual, one to one, communication can have a cost for the other children in the class.

"You would have no other way to find out unless you were working closely with the parents and that takes a lot of time out of the classroom time. If she brought him for physiotherapy somewhere and then came in the next morning with him, well she would be a half a hour telling me how he got on or what might help him. Now, that half hour was gone and the rest of the children suffered. At the same time, I needed to know and I needed to work very closely with the mother." (Teacher in a mainstream primary school)

It is worth noting that, while all teachers identified specific shortfalls in training and, in some cases, resources, a number of them also commented that in their view the Department of Education and Science had improved significantly in recent years in providing

support to teachers working with children who required special assistance or additional resources.

"We have no problem in providing resources and, at the end of the day, resources have become reasonably well available from the Department also, if you make a case for special needs." (Teacher in a mainstream secondary school)

"To be fair, they have improved in recent years. You're not waiting as long as you'd be waiting five years ago." (Principal of a mainstream secondary school)

"(They are) very supportive ... 70 to 80%." (Teacher in a special school)

However, in contrast to this view, one special school principal spoke of the frustration concerning the lack of resources provided for children who had acquired brain injuries compared to other disability groups:

"When a group of parents of students with acquired brain injury decide to hit the courtroom, then you will find a response from statutory bodies." (Principal of a special school)

On the basis of the information provided by teachers, it would appear that most of the children in this study were assimilated into their old, or in some cases new, educational settings with a reasonable amount of success. In this context however, success is a relative term: while in every case it was apparent that the acquired brain injury had had a detrimental impact on the child's ability and performance in school, in most cases, teachers were of the view that the child was performing to the best of his or her ability.

Throughout the interviews it was notable that younger children – those in primary school – appear to attract more open expressions of sympathy and were described in more affectionate terms than their older counterparts. While this may reflect the positive perceptions of adults towards all young children, it suggests that children with ABI, in general, may return to a receptive primary school environment post-injury.

Teachers themselves faced many obstacles in working with children with an acquired brain injury. A deficit of knowledge, experience and contact with other

professionals frequently left them isolated in coping with situations that they had not previously encountered.

There appeared to be a belief amongst teachers that children, returning to the educational system post-injury, would benefit from some form of social-skills training to enable them to cope more successfully with their changed circumstances. A number of the teachers also expressed the view that classmates might prove more sympathetic to a child's situation if they were briefed in advance with regard to the difficulties that the child might encounter on returning to school. However, others had reservations about the value of providing such information to peers.

In conclusion, the teachers' interviews revealed that children, returning to a school environment, post-injury, encountered accommodating schools and enthusiastic teachers. However, inadequate teacher training, inconsistent departmental support and poor communication from healthcare professionals, emerged as outstanding problems for teachers that need to be addressed.

Table 8.1: Key points from teachers' interviews

- Children appeared to be assimilated into their respective educational settings with a relative amount of success.
- Social skills training would be of benefit to many children returning to school, regardless of the educational setting to which they return.
- Children returning to mainstream educational settings had a strong need for normality in the school setting.
- Inadequate training, limited resources and a lack of information sharing amongst professionals curtailed teachers' effectiveness.

Chapter 9

Community health professionals views of working with a child with an acquired brain injury

INTRODUCTION

Each of the 27 families that participated in this research were asked to nominate a community health professional who would be familiar with their child's needs, and whom they would like the research team to invite to take part in an interview. Seventeen community health professionals were interviewed in total. Some families were no longer in contact with health professionals in the community on a regular basis, either due to the termination of services, or due to the current unavailability of services or personnel in their area. In such cases, families did not feel there was anyone appropriate to nominate. A small number of health professionals who were nominated by families were uncontactable during the time period of this study. Those who were interviewed had a variety of different professional backgrounds. There were 6 physiotherapists, 3 GPs, 2 unit managers, 2 occupational therapists, 1 speech therapist, 1 psychologist, 1 alternative therapist and 1 nurse. The following sections will outline the results that emerged during the research interviews.

CHILD & FAMILY FACTORS

While many of the therapists and professionals were specifically involved in therapeutic interventions that focused on the child's physical and cognitive functioning, they frequently spoke about the broader implications of the child's injury or illness for their social and psychological well-being. Over the period of time in which the professionals had developed a relationship with the child, they had noted the broader implications of the child's trauma for issues such as their success in school, their integration with peers and society as a whole, and their psychological adjustment to their acquired disabilities. The factors identified mirror many of those that had been raised by the families, the young people themselves

and educational personnel. It is noteworthy that, despite the multiple disciplines involved and the varied foci which these individuals had, many specified a need for children to receive professional or peer support to help them cope with the trauma they endured. Thus, over time, these professionals appeared to develop an insight into the psycho-social effects that children with ABI experienced, and they recognised these children's unmet needs within these domains.

The success of professional intervention is dependent on a variety of factors. The involvement of children in their therapies and their adherence to the recommendations of professionals were challenges that many therapists faced. For a minority of therapists, the behaviour of the child and the child's willingness to co-operate had a detrimental impact on therapeutic progress. However, over time, these difficulties became less obvious for some individuals.

[In what areas do you think Bobby has made a lot of improvement, or quite positive gains since you've seen him?]

"I think a huge improvement in his attitude and his behaviour, big-time, big-time, which has an impact on everything else. Because at the beginning, as I say, it was a hard battle to even really engage with him, get near him. Forget any hands-on sort of stuff. He wanted to do what he wanted to do, and he'd really – to the point of – he would scream and shout and curse, and everything at you, even at the sight of you, if you hadn't said anything to him, he just did not want to be there. He's so much happier now, so much more relaxed, happy to come down to physio, to do anything, really happy in the class."
(Physiotherapist)

For other health professionals, the child's interest and motivation, their life stage (e.g. adolescence), and the level of support families gave to the work of the professional, had an impact on the consistency with which the child carried out the therapist's or professional's recommendations. The professionals recognised that as children grow, their insight could enhance their recognition of the need for therapeutic intervention. On the other hand, some professionals perceived that young people may feel that they are being 'singled out' by having to attend these services and may have a greater need to fit in and to feel normal.

Family factors may also influence the level of service usage. Over a third of the professionals interviewed mentioned the trojan work of a parental figure in obtaining much-needed services and assistance, and a similar proportion of professionals mentioned the supportive nature of families in a child's rehabilitative process. Yet, at times, the trauma the family has endured, the multiple demands on parents, and their general approach to life, had an impact on service attendance. Despite the difficulties encountered, many professionals praised families and children for the active role they played in a child's on-going rehabilitation.

EXPERIENCE AND UNDERSTANDING OF ACQUIRED BRAIN INJURY

In an effort to understand the experiences of those who are working with children with ABI in the wider community, it is important to explore their prior experience and understanding of ABI in young people.

Many of those interviewed had no previous experience, or very little previous experience, of working with young people with an acquired brain injury. Others had acquired some level of knowledge or experience with individuals with an acquired brain injury, either from an acute setting or from time

spent within a rehabilitative setting. For many of the professionals interviewed, the child with ABI presented new challenges to them. The following quotes highlight some of the issues raised:

[How much understanding did you have of brain injuries?]

"Very little, I would say, I had to read up quite a bit." (General practitioner)

[Do you have any concerns from a professional point of view?]

"My own inability, my own lack of experience in this area, possibly." (Physiotherapist)

"Being honest I am not quite sure what to offer them (the family)." (Psychologist)

Approximately 60% of the sample identified training as an important need from a professional point of view. Many would welcome the prospect of updating their existing knowledge and broadening their skill repertoire in relation to ABI.

"Because of his age and the nature of his injury, more training would be beneficial." (Speech therapist)

In general, the NRH was regarded as the ideal source of training, information and advice.

ORGANISATION OF HEALTH & SOCIAL SERVICES

A number of concerns arose regarding the organisation and delivery of health services. A whole system perspective was adopted by many participants, with many advocating a move towards more integrated services, more structured working relationships, and more organised systems of communication between and within the different layers of the health system.

On the whole, the expertise of the NRH was clearly recognised amongst the participants. Many recognised the benefits of contact and communication with specialists within the NRH for the delivery of care to their clients. Over three-quarters of those who worked as allied health professionals in non-residential settings expressed a need to enhance the follow-up support received from the NRH, following the child's discharge into community services. Those who worked within residential facilities tended to have greater access to other services and professionals.

There was much variability in the satisfaction of community professionals with the information received regarding the nature of intervention to be provided to the child with ABI and the nature of the child's condition at the time of their referral to community services. Many contacted the NRH to obtain advice and guidance regarding their work with a specific child. Some felt they would like more information, based on the child's long-term treatment goals, thus providing the professional with recommendations on how to further enhance the child's progress. Others expressed satisfaction with the quality of information received. The quotes below illustrate some of the views of respondents on the value of sharing information:

"(I) ... would have liked some support and although the Rehabilitation Hospital provided a good report, there was nothing else that followed after that." (Physiotherapist)

"We need to work on feedback from the special services in Dublin. There's a huge gap. We refer up, but we get nothing in return. It's very hard, we shouldn't have to work in isolation." (Occupational therapist)

"... well the only support you get is what you look for. You phone up the hospital in Dun Laoghaire and just say, 'What do you think I should do next?' or 'How have you found this

has worked out?' and 'Is this okay?' and it would be helpful to maybe have some form of regular conferencing, you know ... Just to be able to ask questions." (Physiotherapist)

"The communication with the NRH is obviously good, with regard to, say, the specifics of a certain child, or the expertise is there. I think that's something that should continue and grow." (Physiotherapist)

Even for those who were positive in their assessments of the support received from the NRH, there was a sense that this system of communication could become more formalised, thus facilitating the transfer of expertise down through the system.

"It's a bit too ad-hoc, you know, I'd like it to be more formalised." (Physiotherapist)

While the process of communication between all specialist centres and community professionals was alluded to in some way, more commonly people looked to the NRH for guidance, given that this was the source of referral, and given the high degree of knowledge and skill within this institution.

A small number of professionals stated they would welcome the opportunity to meet with personnel within the NRH to discuss their clients' needs, to familiarise themselves with appropriate techniques, and to cement the relationship between the different service providers. In addition, a small number of professionals argued for the need for more advanced discharge planning which would result in a more gradual transfer from the NRH services to community-based services.

Overall, the two-way transfer of communication between the NRH and service providers within the community would enhance the knowledge and confidence of those in the community, but

it may also enhance the familiarity of those within the NRH with community service provision.

A further need emerging from these interviews was the need for a team approach, to provide co-ordinated and comprehensive services to children in the community. A minority of professionals spoke about the value of the team approach that existed within their setting. Such a set-up provided support to the professionals themselves, while also enhancing the probability of a child having access to a range of professionals with complementary skills, thus facilitating the delivery of a more consistent service. However, in reality, many professionals worked in isolation, with little co-ordination amongst services.

One of the common obstacles many professionals face in the community is the inadequacy of services and resources to provide the comprehensive service that is desired. Many professionals spoke about difficulties accessing much needed services or the unavailability of certain services in their area. Staff shortages and the inability to fill certain posts is one factor responsible for such difficulties. The lack of health board support was another factor identified by a minority of participants. The inadequacy of services and resources can limit the scope of

some professionals' work, and result in some individuals fire-fighting in an effort to fill the gaps that exist.

A small number of individuals identified the benefits of having a liaison worker who would co-ordinate the necessary services, monitor the child's progress, update the various professionals accordingly, and function as an advocate for both the child and the family. This was identified as a difficult position for any practitioner to perform on an ad-hoc or informal basis. Therefore, a formalised system would have many benefits for both the family and the professional.

When the community health professionals were asked to assess the extent to which the current system in which they worked fulfilled the needs of their client, many professionals felt they, as individuals, provided as much as they could for the child, but recognised that on a broader level things could be improved in terms of the availability of more expertise and resources. Furthermore, when questioned about whether the current support and services available, fulfilled their own professional needs when working with children with ABI, only one professional provided a definitely positive answer. Some were very negative in their response, while others felt that some of their needs were met, but there was certainly room for improvement. Overall, the interest and desire to help the child with ABI, and their family was apparent among those interviewed. However, the professionals identified numerous areas for improvement which would ultimately enhance their capacity to fulfil their clients needs and their own professional requirements.

CONCLUSION

Table 9.1 highlights the main points to emerge from the interviews with community health professionals.

From speaking to these health professionals, the provision of services appears to be disjointed at many levels. Those professionals who worked on an individual basis, and did not work within a multi-disciplinary team, faced difficulties in providing a comprehensive service to children and their families due to the lack of support from colleagues and the absence of co-ordination amongst therapeutic interventions or alternative services. Furthermore, inadequate communication and co-operation amongst the various layers of the health system (acute, rehabilitative and community settings) further impeded the work of individuals within the community.

The two primary obstacles to the work of professionals within the community appeared to be the lack of training and information relating to ABI and the absence of a co-ordinated and integrated health service. The

fulfilment of these objectives clearly has knock-on implications not only for the type of service provided to families, but for the competencies of professionals and the functions they serve.

The interviews with community health professionals revealed much variability in service provision throughout the country. This is due to many factors, such as the role of the respondent, their location, access to other disciplines, the setting in which they operate, and other such factors. A minority of respondents were positive in their assessments of health board support, received adequate back-up support at a local and national level, had adequate staffing levels, and provided prompt delivery of a comprehensive multidisciplinary service. However, there remains a substantial body of participants who lacked these benefits. These interviews provide important insight into the views of those who work on the ground within local communities. It is vital therefore to attend to these views in our efforts to move forward.

Table 9.1 Key points emerging from interviews with community health professionals

- Community health professionals had a variety of outstanding training and information needs.
- The need for more structured working relationships between specialist service providers and local service providers was recognised.
- Follow-up support to those working with children with ABI on an on-going basis was identified as an important need.
- The need for a team approach within the community to provide a more co-ordinated and streamlined approach to children and their families was also identified.

Chapter 10

Rehabilitation
professionals' views
of the needs of
children with an
acquired brain injury

This chapter presents the views of 13 professionals within the NRH who had experience of working with children with an acquired brain injury in the rehabilitation setting. The views of these individuals were elicited during two focus group interviews. Participants were recruited with the assistance of a member of the social work team within the hospital. Individuals with a variety of different backgrounds were present at the focus groups. These included representatives from psychology, speech therapy, nursing, social work, occupational therapy, sports therapy, dietetics, teaching and physiotherapy.

The NRH professionals had much first hand experience of the impact of ABI through their direct work with children and their families. In addition, they had much indirect experience of the situations families face through their contact with professionals in the community and through ongoing contact with families following discharge. Their observations of the many children and families that come through the doors of the NRH provides insight into the potential deleterious effects of ABI and the manner in which individuals cope with it.

A variety of themes emerged from these focus group interviews. The participants identified the features of ABI and the challenges it presents to families. They also explored the effects of ABI on both the children and their families, the struggles family members face and the problems with service provision. In addition, they provided numerous suggestions for improvements within service provision. The topics covered give an overview of the journey families face from the perspective of rehabilitation professionals. These various themes will now be explored in further detail.

FEATURES OF ACQUIRED BRAIN INJURY

On repeated occasions the NRH professionals re-iterated the unique features of ABI and the

consequent challenges it presents to children, their families and the professionals who work with these families. The four primary features can be summarised as follows:

- unpredictability of ABI
- the diversity of ABI
- the developmental implications of ABI in children
- the hidden features of ABI.

The extensive experience which the respondents had acquired over time reinforced the wide spectrum of ABI that exists and the heterogeneity within children with ABI. Consequently, an individualised approach to the delivery of care was identified as an important need of children with ABI.

The unpredictable course of ABI results in a lack of certainty regarding the long-term outcomes which a family may face, according to the NRH professionals. This is a challenge for both the family and professionals alike. As the following quote states:

"With head injury ... you never really know when it's going to end."

There was a strong feeling amongst the respondents that in order for services to be capable of meeting the complex needs of children with ABI, they must attend to the unique aspects of each case of ABI. Therefore, services must be able to operate in a flexible manner and provide appropriate input as the need arises.

The possibility of newly emerging difficulties arising for children as they develop was expressed by a number of individuals.

"That particularly applies to the child who gets the brain injury when they are young and then at the early teenager years when the brain takes a further development normally,

... the executive function thinking part of the brain is not kicking into action because of the injury. The child becomes noticeably different. They have managed to sort of keep up and come along with their classmates and friends but then at 13, 14, 15 it just falls apart. The difference between the child and their friends becomes markedly different and that's very difficult to accept."

The respondents felt that the changing nature of children had important implications in terms of resource requirements and service demands. Regular and consistent input and assessment is required to monitor changes in a child's progress while also taking account of the general developmental changes which children experience.

In addition, many NRH professionals felt that the invisibility of some of the effects of ABI can result in a lack of understanding amongst the general public. The following quote highlights the difficulties those with ABI may face in gaining recognition and understanding from significant others:

"The whole big thing about brain injury is really not so much the physical thing, yes it stops them maybe going back to play sport and they might look different walking or whatever but it's the whole hidden thing to it, it's the conversation, it's the ability to learn, it's the behaviour. It's all those things that people don't see and don't have the insight into."

Furthermore, a small number of references were made to the differences between ABI and congenital disabilities. Some professionals perceived differences in public reaction to children with ABI as compared to other disabilities in terms of their understanding and sensitivity. In addition, some of the respondents felt that for those parents whose child may have changed fundamentally following their ABI, they may experience a contrast between

their "old child" and their "new child". This psychological conflict can be difficult for parents to acknowledge or resolve. It represents a significant challenge to their parenting role according to the NRH respondents.

CHILD & FAMILY EFFECTS

Impact on parents

The emotional anguish of parents which has featured strongly in the parents' reports (see chapter 6) was reinforced by the professionals' responses. They particularly spoke about the grief which they observed in parents as they focused on the comparison between who their child once was and their child subsequent to the acquired brain injury. The following quote highlights this issue and compares it to the view of the professional who has only known the child since injury or illness:

"They've lost their old child and they have to go through a grieving process and then there is this new child and they don't know... they have to learn ... Like I often find when a child is admitted I know the new child and that's all I know, it's much easier, when you're looking at how they make gains, ... But the parent is always looking back at who the child was."

Parents were identified as experiencing intense distress at various stages of their journey in the aftermath of ABI. The following quote from a NRH professional summarises the extremes of emotions that parents may feel:

"Immediately after the accident the parents will invariably have been told that the child may not make it and they have this child who is about to die and they pray like mad that the child will survive and the child does survive and they are so grateful that the child survived but then longer down the line they

The professionals interviewed also spoke in some detail about the difficulties with peers which some children experienced. The vulnerability of children, their susceptibility to bullying and their frequent loss of friends were all identified as experiences which some young people endured following ABI. The concomitant dependency on parents may emerge in the event of a child losing the support of their peers. The following quote by one of the professionals highlights not only the child's isolation from peers, but also the challenge parents may face in attempting to address this issue:

"The children come back to be reassessed and you sit down with the parent, usually the mam and you say to her and 'How are things?' and first of all she'll tell you 'Well things are not too bad, and a bit of a difficulty now with the Maths' and maybe 'English' and 'Irish' or whatever and then you'll talk about 'Does she go out to play?' or a 7 or 8 yr old or 10 yr old 'Has she friends?' Well it's as if you've just pushed the button and 9 out of 10 cases the parent will cry at that stage because (of) the social isolation,..."

Related to this issue of isolation from peers is the sense of difference children may feel. Indeed many NRH professionals noted that children may go out of their way to avoid being different as much as possible. At times the respondents noted that children may refuse much needed help because they may feel stigmatised or singled out if they attend such services.

Health Professional 3: "Parents will tell you that even though they might want support for their child, the child won't take it, because they don't want to be seen as different. They don't want to be going to the remedial teacher, they don't want to..."

Health Professional 4: "...or they don't want to be seen to be going to a counsellor or a psychologist, that's huge with adolescents."

In line with the views expressed by parents and community health professionals, these professionals also identified adolescence as a particularly vulnerable time. The potential emphasis placed on image and the desire of young people to fit in with their peer group may pose particular challenges during this period.

The professionals interviewed felt that children with ABI may suffer on many different levels as the following quote illustrates:

NRH Health Professional 6: "They may not look the same and maybe they have facial scarring or maybe a weakness or a weakness down one side. They're not going to excel at sports, they're not going to be the best... You know the way if they're not academic in school, (they) might be good at another area..."

NRH Health Professional 9: "but they're not"
NRH Health Professional 11: "these people would tend not to be good at those, so it's hard for them to find a niche and they don't."

SERVICE PROVISION

Numerous professionals acknowledged the variability that exists in community service provision depending on one's location and health board. There were many benefits identified in referring children at discharge to community services with adequately staffed teams, sufficient resources and a knowledge of working with ABI. However, these services appeared to be few and far between. Some of the respondents acknowledged the goodwill and support they encountered from professionals in the community, who frequently attempted to provide the child with what they could. Yet those interviewed felt that the

primary obstacle which community services may face is a lack of resources. Further difficulties in the community which the NRH professionals encountered at times were the lack of existing services or professionals to refer the children to in the community, staff shortages, unoccupied posts and long waiting lists.

A further problem recognised by these professionals is the lack of emotional or psychological support services for families. In their time of need, families may have no one to turn to for support and guidance. The need for long-term supports for families was recognised, as opposed to crisis intervention services, which typically was all that was available according to some of the respondents. The lack of outlets for children to express their inner frustrations was also identified as another gap in service provision. The noted absence of support to help young people to cope with and adjust to their changed life circumstance was also reflected in the perspectives of parents and community professionals (see chapters 6 & 9).

According to the NRH professionals interviewed, attempts to meet the needs of the child with ABI in the community are further complicated by the lack of experience of some community professionals in dealing with ABI and the large caseloads which these professionals may carry. The recognition of children with ABI as a priority by local service providers is complicated by these factors.

"Our children would often be considered quite good physically because they can walk, whereas a lot of the (other) children would be prioritised because they have never walked ..."

On the whole, the NRH professionals perceived that the provision of consistent therapeutic input on a long-term basis to children with ABI represents a major challenge to many services in the community. There was a perception amongst the respondents that the community health system currently did not have the

capacity to deal with the intensive input which some children with ABI may require.

"As an example, if you go to a community therapist, they expect to see maybe a child for 8 weeks, once a week, not maybe have a child on their books for possibly 10-15 years, in which case the service they can provide might only be once every 2 months, to monitor a (child's) progress, which is not adequate for the types of children we see."

SERVICE NEEDS

A variety of gaps in service provision were identified during the course of the interviews and those interviewed provided a number of suggestions for enhancing existing service provision. At a very broad level, the need for support to be provided to the family unit as a whole, on a more local basis, was a strongly identified need. This embraced practical support, emotional support and general advice and assistance. A number of practical measures were identified. These included home help, the availability of someone to mind the other siblings while the parent attended to the needs of the child with ABI, and financial advice for those faced with reductions in income or high health care expenses. Respite care was identified as a particularly beneficial support for parents. While the general lack of availability of this service for children with ABI was acknowledged, the respondents also identified factors which may affect the up-take of this service. They felt that parents can sometimes experience guilt or a reluctance to leave their child to be cared for in another setting. However, according to those interviewed, allowing the child to be cared for in such a setting can provide parents with a much needed break, while also facilitating the move towards a more shared-care approach.

There also appeared to be a consensus that

outreach or liaison services were required in order to relieve the burden on some families and promote the families' welfare. Varying dimensions of these services were explored. While there was some debate about the organisational structure that currently exists in terms of the centralisation of services and the viability of developing regionalised centres, there appeared to be a consensus around the need to provide services on a more local level. Many identified the need for a "Case Manager" or a central link person to function as the first point of call for families. Such an individual would function as a co-ordinator of services for each individual family or child and operate as a central source of advice and guidance for families. In addition, it was felt that it would be important for this individual to possess a knowledge of service availability and entitlements and to pass this information on to families as appropriate. Home visits were also identified as a potential part of this role.

The NRH professionals felt that the development of outreach services and the availability of multidisciplinary teams would result in a more co-ordinated approach to the provision of care to the child and family, thus providing the appropriate input that a family may need based on an enhanced understanding of the child's and family's situation. In such cases the respondents viewed having the NRH team meet with the community team as an ideal opportunity for sharing knowledge, while also representing an extremely efficient use of time.

The opportunity to meet other families was also identified as a beneficial support to families. While it was recognised that at present this may operate on an informal manner, there was scope for formalising this arrangement to enhance contact and communication amongst children and parents. The respondents recognised the invaluable benefits which some individuals

accrued from meeting with people in similar situations. Such contact can result in a shared understanding of the stress and dilemmas families endured, and function as an important source of practical information. In addition, it can reduce the sense of isolation which parents may feel in the larger community.

Social skills training and behavioural management programmes were two further identified needs for children with ABI. The shortage of behavioural management programmes at a national level was identified as resulting in little support being available to meet the needs of children with behavioural difficulties. Furthermore, in recognition of the social difficulties which some individuals may experience, social skills training was identified as a means of working with children to reduce problems of isolation and foster interaction amongst children.

Frequent references were made to the structure and organisation of services within the disability service system. On the whole, these services were regarded as being far more advanced than the current provision for ABI. Services such as behavioural programmes, respite care and the presence of agencies to facilitate case-planning were reported to be much more available in the general disability services. However, many of these services did not appear to be accessible to children with ABI. While many references were made to the unique aspects of ABI, it was also acknowledged that the general principles of working with children with disabilities were transferable in many cases. This gave rise to the question of

whether children with ABI could be integrated into the wider system of disability services already available.

Only a small number of points were made in relation to educational provision. This may have been due to the low numbers of educational personnel who were involved in the focus group sessions. One important suggestion that was made in reference to the school environment was the need for a visiting resource teacher, who would liaise between the NRH and the child's local school. Such an individual would provide a means of educating teachers and children and provide necessary support to teachers who work with the child in their local school.

CONCLUSION

The focus groups with NRH professionals provided a range of ideas regarding the impact of ABI, with many practical suggestions provided for meeting the needs of young people with ABI. The numerous families which these individuals have worked with over the years has given them insight into the plight of families affected with ABI. It also allows them to identify the gaps between service provision within a specialist rehabilitation setting and the broader community setting. As such, the views presented here provide valuable insight for the extension of rehabilitative efforts into the wider community. Table 10.1 provides a summary of the main ideas to emerge from the interviews with NRH professionals.

Table 10.1 Key points from interviews with NRH professionals

- The uniqueness of ABI during the period of childhood was recognised.
- The effects of ABI for children and families were multiple in nature.
- There were a number of discrepancies in service provision on a nationwide level.
- Family-centred care that focused on practical and emotional issues was identified as an important need.
- Outreach services and a central liaison person for each family was also identified as an important need.
- The need to develop links between families in similar situations to allow families to share their experiences and support each other was regarded as important.
- Behavioural interventions and social skills training for children with ABI were identified as important service requirements.

Chapter 11

Discussion & recommendations

Preceding chapters have highlighted the pervasive, complex and highly diverse consequences of ABI. In recognition of the manner in which ABI touches the lives of many individuals following its onset in children, this report sought to incorporate the views of children, family members and individuals working with these families on a professional level. Clear themes arose from the myriad of views encountered. These themes are explored in further detail within this chapter. Interestingly, different perspectives can emerge from different groups of respondents in relation to certain issues. For example, while bullying emerged as a common problem for young people in school during the parents and children's interviews, it was not such a significant issue in the interviews with teachers or siblings. This study, therefore, reflects the different contexts to which children belong, and the varying perspectives of individuals within and across these contexts. In doing so, it captures the direct and indirect experiences of those who interact with children, thus providing a more comprehensive picture of these children's lives. In the course of the research, 96 individual interviews and 2 focus group interviews were carried out. One-hundred and sixteen individuals were interviewed in total. It is the aim of this chapter to integrate the views of the multiple perspectives encountered, and to make recommendations for future service delivery.

PRIMARY THEMES

In recent times, survival rates following ABI have improved significantly. Yet living with the aftermath of an acquired brain injury reveals a much more bleak tale. Quality of life has been targeted for a number of years as a central tenet within the Irish health system (Department of Health & Children, 2001). Yet the evidence within this report suggests a neglect of the quality of life of many of those afflicted with ABI during the period of youth,

and a lack of support given to the families to which these young people belong.

The research evidence suggests that those services which families receive within the community tend to predominantly focus on the child's illness or injury, and the physical and language complications that may arise. Conversely, there appears to be much less emphasis on the psychosocial domains of ABI and the family context in which the child's illness or injury occurs. In general, parental reports imply that insufficient attention is given to the manner in which children and families cope with and adjust to the challenges they face following ABI. The lack of support services, as perceived by family members, suggests a neglect of the impact of a trauma on significant others and a disregard of the social context of illness. It is the view of the authors of this study that a biopsychosocial approach would be most appropriate to the long-term treatment and care of children and families who have suffered from ABI. The biopsychosocial model promotes a holistic approach to the delivery of health care. As such it highlights the need to focus on the biological, psychological and social aspects of illness and identifies the interaction amongst each of these components (Engel, 1977; Engel, 1980; Sarafino, 2002; Schwartz, 1982). This model essentially encompasses the multi-dimensional concept of health. Sarafino (2002) regards health as "a positive state of physical, mental, and social-well-being" (p5). Table 11.1 provides an illustration of some of the potential consequences of ABI across various domains and the potential services that could be provided to target these effects. As such it illustrates the application and utility of a broad holistic approach to a child with severe ABI.

Table 11.1 Application of biopsychosocial model to a hypothetical child with ABI**Examples of potential consequences of ABI**

Biological:	physical sequelae such as brain damage; limited mobility; balance difficulties; tremor in hand; epilepsy.
Psychological:	cognitive sequelae such as difficulties in speed of processing; poor short-term memory; limitations in sustained attention. emotional sequelae such as depression and frustration arising from newly acquired impairments and difficulties in partaking in age appropriate activities.
Social:	difficulties in peer relations; loss of old friends and difficulty in making new friends. Parental concern regarding the lack of appropriate activities for children with disabilities in the local region.

Examples of potential interventions or services that could target the various domains

Biological:	physiotherapy, neurology services. Attention to access issues in school buildings and other such settings (e.g. provision of ramps, lifts) and aids to facilitate functioning (e.g. laptops to facilitate writing).
Psychological:	family support; counselling services for individual family members; neuropsychological assessments for child with ABI.
Social:	peer support groups; development of regional recreational facilities for children with disabilities; peer education to encourage acceptance and understanding of children with special needs.

A multidimensional approach to the delivery of health care is typically applied within the context of the NRH. Yet frequently, once the child is discharged into community services and the true impact of the child's trauma dawns on the child and family, the evidence suggests a lack of support services for families, at the time when they may be required most. These children frequently require long-term monitoring, assessment and support, with a flexible approach to the provision of care and efforts to maximise the quality of life of both the child and their family.

Reflections on the sample of children

Prior to exploring the individual sub-themes of the research it is important to reflect on the composition of the sample as a whole and the needs of emergent sub-groups within the sample.

Comparisons between those whose illnesses were as a result of road traffic accidents (n=17) versus non-road traffic accidents (n=10) did not appear to be a useful exercise in this study. Comparing children in this manner proved extremely difficult as confounding factors such as age, ability and gender could not be ruled out. Even within the smaller group of children who suffered from stroke-related illness, there was some

variability in terms of needs and experiences and it proved difficult to identify issues specific to particular illnesses or diagnoses. Thus children with similar diagnoses did not appear to be homogeneous in nature. In this study it was therefore regarded as most useful to examine the sample as a whole and the commonalities and diversities within it.

However, there are a number of sub-groups that are worthy of mention. Those children who display severe behaviour problems appear to merit some attention in terms of their service and support requirements. For these children, there appeared to be few services available to provide support or intervention. The current research indicates that severe behavioural problems may create havoc in households, causing friction among family members, with frustration and anger potentially being directed towards the child with ABI. It is the view of the authors that consideration needs to be given to the development of services in this area or the integration of children with ABI into existing behavioural interventions in the disability sector.

A further group that seem to merit some attention according to the respondents are adolescents. The normal developmental trajectory for adolescents in Western culture, typically involves increased independence from parents, closer relationships with peers and members of the opposite sex, a search for life goals and the establishment of one's self identity (Santrock, 2002). The period of adolescence may bring new challenges for both the child and parent following ABI. The findings suggest that the care requirements of some young people with ABI may increase their dependency on family at a time when most young people become more autonomous. In addition, the many social difficulties which some young people may face, and the enhanced complexity of the social world which they encounter, pose many threats to those who have been severely challenged by head trauma. The

transition from primary to secondary school was a concern expressed by a number of parents and professionals, given the increasing complexity of the school environment which young people can be faced with. In addition, the completion of school and the future well-being of their child were concerns for many parents. For those parents whose child would be unable to live an independent life, there appeared to be an uncertainty about what their child's life circumstances would become. The on-going issues which many children and parents faced suggests the need for the development of support and services to meet the psychosocial, vocational and residential needs of these young people.

Thus there are particular groups who may have special support needs in the aftermath of a head trauma and as such may require extra consideration in the planning and provision of care. However, this research involved single interviews with participants at one point in time. The long-term outcomes for many of these young people and their families therefore cannot be predicted by the current research approach. The present study provides a snapshot of the experiences of families up until the present time. However, the methodological strength of this study lies in the selection of a nationwide random sample, which enhances the ability to generalise these findings to the larger population of children and young people with ABI in Ireland.

The following sections focus on the various sub-themes emerging in this research, with recommendations made accordingly.

THE REHABILITATION CONTEXT

Many parents reported that the NRH made a positive contribution to their child's progress and recovery. Parents identified the understanding they found amongst staff, and the intensive care they received, as vital

components in the well-being of their child. While many parents expressed immense gratitude to the NRH and the staff within it, some aspects of the NRH experience were also identified as stressful for parents and families.

One of the main limitations of the NRH service identified by family members was the lack of parental accommodation. International literature clearly identifies the positive impact of parental presence on the well-being of children during the period of hospitalisation (e.g. Lambert, 1984). Within the present study, some parents spoke about the upset they experienced while leaving their child behind in the NRH, while others vividly recognised the impossibility of leaving the child as an inpatient on their own, and were forced to travel daily from their home to the hospital as a result. In addition, the expense incurred by families who had to stay in alternative accommodation was an issue raised by some families.

An additional source of stress for families which can contribute to both short and long-term consequences is the artificial separation of family units, frequently for long periods of time. Many siblings reported not seeing their brother or sister for much of their stay in the NRH resulting in a loss of familiarity and a sense of alienation for the siblings at home. Simultaneously, many parents spent a large amount of their time away from the family home, which resulted in a double absence for those who remained at home.

A key recommendation to emerge from the current research is the development of strategies to promote family-centred care and to foster family unity and support during the period of rehabilitation. Such measures could include the following:

- The availability of family accommodation units within the NRH, thus encouraging the presence of families and preserving family ties;

- The facilitation of more contact between children and their families, which may 'normalise' the time spent within the NRH through its enhanced emphasis on a family friendly environment. Overall, this could reduce the stress families endure, while also smoothing the child's transition back into the home environment;
- The encouragement of parental presence in the hospital and increased parental involvement in children's care from the outset may allow a more gradual transfer of care from the rehabilitation professionals to parents prior to their discharge;
- The provision of support to assist families in spending time with their children during the period of hospitalisation. This support is particularly pertinent for those families who have children who spend long periods of time in hospital and for those whose family home is a long distance from the facility in which the child is staying. This support could include financial assistance for travel, accommodation and childcare.

These measures could enable the child's transition back to the home environment, help maintain family ties and facilitate the adjustment of families back to life in the community. A number of families identified the difficulties encountered in travelling to and from the NRH due to the distance of the NRH from the family home. Some children also found it difficult being so far away from their home and their family. Given this difficulty for some families, consideration could be given to the development of local step-down facilities or centres in which children could be cared for, in the event of continuing care needs which may not need to be fulfilled in specialist centres far from a family's home. This would serve to minimise the disruption and trauma to families and reduce the impact of family separation.

THE RECOGNITION OF ACQUIRED BRAIN INJURY

Service & policy context

All the children who participated in this study attended the NRH for specialist rehabilitation services following their ABI. Parental reports revealed that following discharge from the NRH, those children who received support or services within the community, typically were integrated into general health services or disability services. Families who participated in this study encountered a lack of services dedicated for children and young people with ABI in the community. It appears that those children and young people with ABI often fall between the gaps, in the sense that there is a lack of specialised services or support for those with ABI while, simultaneously, these children are not always fully integrated into disability services.

The issue of what is the ideal service model for children with ABI cannot be answered within this report. For those at the more severe end of the spectrum, the question arises of whether these children should be integrated into services for children with congenital disabilities. Such services are reasonably well established within Ireland on the whole. Some would argue that the principles of working with children with other disabilities can transfer to those with ABI; others argue that children with ABI may not always integrate into such a context. Within the present study, factors such as children's levels of insight into their former life, and their identification with the general disability label, appeared to affect the success of their integration. While clearly some practice from the larger disability arena can be transferred to children with ABI, many respondents spoke about the unique attributes of ABI. The sudden and unexpected nature in which ABI frequently occurs often brings many new challenges to children and their families. When children acquire severe impairments through ABI, families may grieve the loss of their "old" child, and have to learn to accept their "new" child. This was particularly an

issue voiced by the NRH professionals. While considering all sides of the argument, it is also important to keep in mind the geographical spread of those who have suffered severe ABI, and the small numbers that may live within any one geographical area in Ireland. This essentially has implications for the development of regional and local services.

From a policy point of view, the Department of Health and Children is committed to the development of a national rehabilitation strategy (Department of Health & Children, 2001). However, up until the present time there has been no national plan or policy for treating and managing individuals with ABI in the health system. In addition, within the Department of Education and Science there are a number of disability categories delineated to assist in the identification of children's special educational needs. At present ABI is not recognised as a specific disability with those afflicted having specific needs and service requirements. However, ABI may be subsumed under another form of disability. In contrast, in the US, *The Individual with Disabilities Education Act (IDEA) 1990* recognises ABI as a special education category. In addition, some states or countries have strategic policies or legislation for the development of services and the promotion of research on ABI (e.g. *Acquired Brain Injury Strategic Plan*, Victoria, Australia; *Traumatic Brain Injury Act*, 1996, USA). Such measures are absent in Ireland. While the process of categorising and labelling various forms of disability and allocating services accordingly can have potential drawbacks, the lack of recognition given to ABI up to the present time is likely to have contributed to the inadequate service provision and support provided to many families in their local communities.

There is clearly some debate on the issue of what is an appropriate setting in which to provide care for children with ABI. In light of

this issue, serious consideration must be given to where ABI fits into future disability policy and legislation and indeed in health care policy as a whole. While legislation in the area of disability is currently in a state of flux, the recommendations of the *Report of the Commission on the Status of People with Disabilities* (1996) are likely to be applicable to many of those with ABI. In particular, the adoption of a needs-based approach to the provision of care should have positive benefits for those with ABI.

One of the primary recommendations of this report is that due consideration must be given to the care needs and service requirements of children with ABI. Consideration must also be given to the place of ABI in disability policy. Options that could be considered as part of these developments include the following:

- The development of a national strategic plan for service provision for those with acquired brain injury, with special consideration given to the needs of children and young people. This would facilitate consistency in the delivery of care on a nationwide basis. As part of this strategic plan it may be important to establish a protocol for the management of ABI from the point of Hospital Accident and Emergency units onwards. Such a plan could also promote the recording and communication of standardised information that could be relayed through the various systems of the care continuum. Injury indicators (e.g. Glasgow Coma Scale) could be a key part of this process;
- The provision of enhanced recognition to ABI as a specific disability by the Department of Health & Children and the Department of Education & Science;
- The development of a database of children with an acquired brain injury to identify the morbidity and mortality indices associated with ABI. This would assist future planning for service provision and resource needs.

Prior experience and understanding of professionals in the community

The findings of this study illustrate that there is often a lack of understanding and experience amongst community professionals of ABI, and the resultant needs of a child that may arise from it. Only a minority of professionals were au fait with ABI and its implications for the child and family. The interviews with teachers and health professionals point to the challenges that individuals may face when confronted with a child with ABI for the first time. Many professionals expressed a lack of confidence and a level of uncertainty in working with children with ABI. A strong desire for information, advice, training, and support for their work in the area of ABI was evident during the interviews with professionals, both teachers and health care personnel alike.

A key recommendation of this study is to provide information and training to professionals in the community to support and enhance their work with children with ABI.

At present the specialist role of the NRH results in many professionals looking to them for support and advice. Therefore, a key source of information and training at the present time appears to be the NRH. Alternatively, the development of a dedicated resource centre would fill the gap that currently exists. The resource implications associated with the demands placed on any agency that takes on the role of training professionals who work with children with ABI within the community must be considered.

Public awareness of ABI

The current research also reveals a general lack of understanding of ABI amongst the public. The hidden nature of ABI represents a challenge to many families in gaining acceptance and understanding amongst their peers, relatives and wider community. The cognitive and behavioural sequelae of ABI, which may not be immediately obvious

during brief encounters with children, can lead individuals to dismiss the stress that a family may endure. Furthermore, for those who have acquired visible disabilities (i.e. physical or language complications) as a result of their trauma, there may be adverse reactions from others in terms of staring, teasing or intolerance. A number of children and parents identified the negative reactions of others as a significant factor in their post-ABI experience. This lack of public awareness and understanding appears to be a further obstacle that some children and families encounter.

A key recommendation of the study is the need to promote public awareness and understanding of acquired brain injury and its impact on children and their families. This could include raising awareness of:

- The possible causes of ABI (e.g. road traffic accidents, falls, stroke-related illnesses);
- The various sequelae of brain injury and its relation to brain functioning (e.g. understanding the origins of behavioural issues) and the potential non-visible effects of some brain injuries;
- The diversity of outcomes from ABI;
- The latent effects of ABI which may not emerge until some time later in a child's development.

Such information could be disseminated to parents during the time in which their child is in the NRH. It could also prove useful for schools, relatives, carers, professionals and others in contact with the child. Written information is recommended so as individuals can pass this information on to others who may be in contact with the child.

ACQUIRED BRAIN INJURY AS A FAMILY AFFAIR

One of the most consistent findings arising from this research is the wide-ranging impact of the condition, and the knock-on effects on other family members. Siblings and parents are clearly not immune to the stressful nature of the transitions endured with ABI. Change and loss are two of the many processes which families may undergo. Family members may experience a double pain, not only for the child with ABI but also for themselves. The experience of a child family member acquiring a brain injury during their lifecycle was an emotional and traumatic experience for families in this study.

Both research and practice appear to neglect the well-being of the sibling in the aftermath of ABI. The current study, however, highlights the short and long-term adverse effects of this stressful life event on a substantial minority of siblings. A number of siblings also gained increased responsibility following their brother's or sister's injury, which had an impact on their role within the family.

Parents frequently appeared to become consumed with the needs of their ill child and many parents adopted multiple new roles following their child's illness or injury. From the reports of parents and professionals, it appears that parents frequently became an advocate for their child, a caregiver of a child with special needs, a co-ordinator of services, and an educator of others following their child's injury. The present study reveals that the burden of care which typically lies on parents, severely restricts the time parents have for themselves and the time they have available for other family members. Parental reports revealed that following discharge from the NRH, there appeared to be a lack of follow-up support services for the family as a whole. Paradoxically, the period after discharge from the NRH may be the time when families need most support; as the burden of care lies heavily on families, the

extent of the child's limitations may become more apparent during this time, and normal family routine may experience much upheaval.

The current study highlights the insufficient availability of family support for families of children with ABI. It suggests the need for family-centred care within the community and the need to recognise the support and advice required by those on whom the burden of care currently lies. Options to facilitate this process could include the following:

- The availability of emotional or psychological support for family members on a rapid response basis at the time of injury/illness;
- The long-term availability of emotional support for children and their families for some time after the return to the home environment. Some families may devote much of the initial years fighting for services and actively seeking to do the best for their child, and may only be ready for counselling some years after the initial trauma. For those families who wish to avail of emotional support following their return home, it must be accessible and convenient. Therefore, consideration should be given to the availability of home visits from professionals, for those who may require them;
- The development of links, if desired, between parents (or other family members) and members of other families who have experienced similar situations, to facilitate the sharing of experiences and concerns;
- The provision of respite care for parents that would be appropriate to the needs of children with ABI. In order to facilitate parents' use of such a service, if it were available, it would be important to ensure that the facility would be appropriate to

their child's needs, and to reassure parents of the potential benefits gained from respite for all concerned (e.g. parental time with other siblings, time out for parents, social interaction for the child with ABI).

In addition, for the children themselves there should be enhanced efforts to combat the social isolation which many young people experience, and to assist children in coping with their newly acquired disabilities. The children's interviews revealed numerous changes which they experienced in their lives. These interviews also revealed that the children viewed ABI as a negative emotional experience.

Thus a primary recommendation of the current research is to develop measures to foster the well-being of young people with ABI and to support their social integration within family, neighbourhood, school and leisure activities. The following measures could help to improve the social difficulties which some children have experienced:

- The establishment of peer support groups in order to encourage affiliation and friendships among young people with ABI;
- The facilitation of electronic communication via interactive websites to encourage communication amongst children with similar experiences;
- The development of programmes within the mainstream school environment to foster acceptance and integration amongst peers and to de-emphasise the difference between children with disabilities versus non-disabilities;
- The availability of social skills training for children with ABI. This was particularly identified as an need during the interviews with teachers and NRH professionals. Children who display

inappropriate behaviours or have difficulty interacting with peers may benefit from this form of support. There also may be a need to develop programmes to underpin this work;

- The development of disability-friendly sports and activities for young people and the establishment of links between families, clubs and activities.

A further recommendation relating to the provision of on-going support to young people and their families pertains to the need to provide support and guidance prior to and during life transitions and developmental changes, for example, from primary to secondary school and from secondary school to young adulthood. The completion of secondary school may be a time when young people need particular support and guidance regarding training, further education or residential options.

HEALTH AND SOCIAL SERVICE DELIVERY

Parents' experiences of the care received within the NRH and the care received within the community following their return home often revealed a contrasting experience. Contact with multiple professionals within the NRH who understood and were experienced in the area of ABI and the availability of multiple services dedicated to ABI were frequently not matched in community service provision. In addition, many NRH professionals and parents identified the heavy burden that lay on parents to fight for services and seek the optimum care possible for their child. The current research indicates a lack of co-ordination amongst services and service providers. Often, it appears that the responsibility of organising and co-ordinating a child's care falls on the parents.

However, this is not to take away from the commitment and capacity of those working

within the community. From speaking to both parents and professionals, there is much to be commended in terms of the nature of their work and the efforts they exert. The will and desire of those on the ground was often present, but reports from numerous respondents suggest many problems exist in the organisation and resourcing of community health and social services. The community health professionals in some settings worked in isolation with limited resources such as: staffing, heavy caseloads, minimal availability of multidisciplinary teams and little expertise in ABI. For some community professionals, the absence of a team approach or the ability to call on other professionals for support and advice restricted the provision of a comprehensive service that was tailored to the needs of individuals. It was deemed important by many of those interviewed that the health system was capable of meeting the short term and long-term needs of children with ABI. Flexibility of approach is therefore likely to be an important component of service delivery to children and young people with ABI.

The interviews with young people revealed the value they placed on therapeutic interventions in their recovery from ABI. However, the experiences of community and NRH professionals and families themselves revealed that at the most basic level there was an urgent need for more community resources to facilitate on-going rehabilitation and family support at a regional and local level. As part of this process there is a need to enhance the range of services that are available within local areas. NRH professionals reported that at times they experienced difficulty in locating services that were suitable for their clients, with families frequently facing long delays in obtaining much needed support or services. The adoption of a multi-disciplinary approach to the care needs of children with ABI and the deployment of a range of services that are customised to the changing needs of individual families has emerged as an

important need from the current research. The range of services required may include the following: medical and nursing care; physiotherapy; occupational therapy; speech and language therapy; dietetics; home support; psychological services and social work services. Consideration also needs to be given to the availability of community respite and residential facilities that are appropriate to the needs of young people with ABI.

The availability of sufficient community resources is essential in facilitating the transfer of care from the NRH to the local community. The absence of such resources can result in a failure to capitalise on the many gains that were achieved during the initial rehabilitation process and the expenditure invested. It is important to bear in mind the accessibility of services for families, as this emerged as an important concern during interviews with parents. The provision of services without adequate transport may negate the potential benefits of services offered. Overall, reports

from parents, NRH professionals and community health professionals suggest there is a need for a co-ordinated system of care that is responsive to the needs of children and their families with adequate resources to provide a prompt service as required. It is important that all domains in a child's life are incorporated into the planning and care process, therefore, school liaison remains an important part of this process.

The development of responsive, flexible and accessible community services ultimately depends on the adequacy of communication and the provision of information to all relevant parties in the child's care network. Reciprocal communication and an adequate flow of information amongst the key players within a child's care network were regarded as the key components of intersectoral collaboration from the perspective of those in the community. Many community health professionals sought information and feedback from other services which their



Figure 11.1 Model of communication between professionals in relation to the care of children with ABI

clients attended and identified the potential benefits of such a collaborative approach. A key recommendation to arise from this study relating to health, social and educational service delivery pertains to the need to improve links between existing services and to allow for the consistent passage of information through the system thus incorporating the acute hospitals, the NRH and the community health, social and educational services. This passage of information should be a two-way process (see figure 11.1).

Measures that could be considered to facilitate improved links between relevant parties could include the following:

- The facilitation of multi-disciplinary meetings between the NRH staff, local therapists and teachers prior to the child's discharge back into the community. The child and their family should be included in these meetings insofar as they can participate;
- The identification of a central liaison person or link person for each child. This individual could function as a case manager and as such could be the central link between all team players, the child and the family. Within this capacity, they could function as the first point of call in the event of a parent requiring information or advice. Additionally, this person could be responsible for the following:
 - Setting up initial meetings with NRH professionals to identify a child's needs;
 - Liaising with school personnel prior to the child's return and providing appropriate preparation and advice;
 - If desired by families, speaking to peers in the child's class to prepare them for the child's return and enhance their understanding;

- Liaising with professionals in the community and the NRH both initially and on an ongoing basis;
- Collaborating with parents on regular occasions following discharge to monitor the child's progress, prioritise child's needs and seek appropriate services and support;
- Having adequate knowledge regarding service availability and the entitlements of families and informing them accordingly.

It seems advisable that the NRH would have a continued role in planning, advising or supporting a child's care provision at a local level. Community professionals commonly acknowledged the expertise which the NRH had to offer. The annual review process which is carried out within the NRH may have beneficial effects for the child, family and the associated professionals in the community who provide on-going care. This has the dual function of assessing the child's progress and changing needs as they move through the life cycle, while also providing service providers with up-to-date assessments of service and support needs.

An additional component of enhancing inter-sectoral collaboration amongst the NRH and community services could be to strengthen the discharge planning process within the NRH. While discharge planning is currently practised to some extent in the NRH, interviews with families, teachers and health professionals indicate the need for greater preparation in terms of information-giving and planning for appropriate resources and support. However, such a comprehensive approach to the discharge planning process places considerable demands on the resources and staff within the NRH, and therefore is likely to have significant resource implications. Nonetheless, advance preparation prior to a child's discharge is an important contributor to the early identification of a child's needs within the community. This process could involve:

- Making contact with relevant service providers to make necessary arrangements for the prompt availability of resources when the child or family requires them. This would entail advanced preparation for the following: remedial or resource teaching requirements; home tuition; carers allowance and various other financial supports that families may be eligible for.

The availability of written information on a child's condition or on ABI in general would be important in enhancing the knowledge of all concerned. Such information would be important not only at the time of discharge but also in accordance with the child's changing needs. It would also be beneficial to have written information available on services, resources and entitlements that may be applicable to those with ABI.

EDUCATIONAL SERVICES

Children, parents and teachers identified numerous academic difficulties which children experienced following their ABI. The primary challenge faced by teachers, particularly in the mainstream sector, was the lack of familiarity with the nature of acquired brain injury and the sequelae of ABI that children may manifest. Teachers who taught large mainstream classes were faced with a multitude of needs from a large body of students and attending to the individual needs of a given child was increasingly difficult. Parents and teachers identified the potential of secondary school to place particular demands on a student with ABI given the complexity of the environment and the enhanced challenges children may face not only academically but also socially.

The previous recommendations regarding the training of community professionals are particularly pertinent in the educational sector given that school represents one of the primary domains of a child's life. Two further key recommendations can be made in the area of education. Firstly, there is a clear need to develop a strategy for preparing teachers for

the education of students with ABI. This not only arises in the initial return to school, but as the child moves through the educational system. Secondly, there is a need to track and monitor a child's progress as they move through the educational system. This may facilitate identification of the child's changing needs. Options to consider in enhancing the educational experiences and capacity of children include the following:

- The establishment of on-going liaison between the NRH and the child's local school would help to prepare the child's teacher both in the initial days for the child's return and thereafter in terms of meeting the child's on-going needs. The availability of a liaison teacher may be useful element in this process.
- The need to give careful consideration to the placement of the child within an appropriate educational environment. Teachers' and children's reports revealed that the return of the child with ABI to a class where they already had friends can facilitate the child's re-adjustment back into the school environment. However, this is clearly dependent on the child's academic needs and abilities. For those parents, considering a special school for their child, they will need advice and support during the decision-making process.
- The involvement of teachers in the child's care network, thus recognising the role of educational personnel in the planning and provision of a child's care.

FUTURE RESEARCH

This study had a broad remit and explored a diversity of issues amongst a variety of participants. The research approach incorporated the views of a variety of stakeholders, with an emphasis on involving children in the research process, where possible. Giving children a voice on matters which affect their lives and giving their views

due consideration in accordance with their age and maturity are key principles of both the *UN Convention of the Rights of the Child* (1990) and the *National Children's Strategy* (2000). To date, there has been little attempt to understand the impact of ABI from the child's perspective within an empirical study, either in Ireland or internationally. The present study provides an insight into the child's view of their world following ABI.

There is much scope for developing further insight into children's perspective of this stressful life event. As is frequently the case, the researchers in the present study had no prior contact with the child before the interview and as such represented a stranger to the child being interviewed. Given the special needs of many of those interviewed, the authors recommend that future research on children's life experiences following ABI would involve a series of short interviews with the young person. This would allow the development of greater rapport between the participant and the researcher and would enhance the child's comfort in expressing their concerns, fears and opinions. It may also allow the child time to reflect on the changes they have experienced. Furthermore, the initial contact between the researcher and the child would allow the researcher to tailor all future interviews according to the child's abilities and needs.

A potential avenue of exploration for future research is the combined use of interviews and observational techniques to further illuminate the social experiences of children with ABI. The social experiences of children and the antecedents and consequences of social difficulties experienced, demand further attention. The use of observational techniques would illuminate children's interaction with peers and also identify the status of children with ABI within the school or other social environments.

Human nature is characterised by growth and lifelong change. This change can involve both progression and regression. Children and adolescents are in the midst of an even more rapid pattern of change. Therefore, in order to

identify the outcomes attributable to ABI for the developing child, there is a need to conduct longitudinal studies with regular assessments across time. There are two such approaches which the authors would regard as providing a significant contribution to our understanding of ABI during the period of youth.

One such approach involves the use of community-based epidemiological type studies that would follow-up large community-based samples over a long duration and subsequently identify from this sample those who acquire a brain injury over time. The benefit of such a study is the availability of pre- and post-injury data, thus allowing one to control for pre-morbid risk factors and identify the unique sequelae of ABI. An additional type of longitudinal study that is required involves the assessment of a broad sample of head injury cases from the point of Accident & Emergency units onwards. A sample of children within such a unit could be assessed regularly to observe the social, psychological, physical and other outcomes relating to ABI. The significance of such a study would be the inclusion of cases across the head injury continuum thus allowing investigators to compare the various outcomes of participants in relation to initial injury indicators.

Much has been learned from the findings of the present study, yet much remains to be discovered. While a number of problematic areas were highlighted in this study, it is important to bear in mind that all efforts to intervene and remedy the problems that are present must be open to investigation. Therefore, attempts to enhance the quality of services and the lives of individuals must involve an evaluation of the outcomes achieved following changes in service provision, so as to ensure they have the desired effects.

CONCLUSION

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Serving the needs of children and their families following a severe acquired brain injury is a challenge to service providers, policy-makers and administrators. Yet there remains much hope for the future. The determination and goodwill encountered by the researchers amongst families and professionals provide an excellent basis for the enhancement of existing services and structures and improving the health and well-being of children with ABI.

This empirical study provides an in-depth illustration of children and adolescents who are faced with the reality of living with an acquired brain injury. The inclusion of the views of children, their family members and those who work with the family in the aftermath of ABI can be viewed as individual pieces of a jigsaw that fit together to reveal the overall picture. The evidence emerging in this study reveals the multitude of factors that impinge on children and their families in their efforts to cope with the stressful nature of ABI. Table 11.2 highlights key recommendations that

emerge from this comprehensive study. Quality of life issues relating to both the children and their families must lie at the forefront of the agenda in the enhancement of future service provision. Supporting children to fulfil their potential is best served by a holistic approach in terms of care provision, and demands a concerted effort from all.

This document can be seen as contributing towards a blueprint for the future. The hope is that it will instigate a move towards building on existing positive structures and services. There is a need to capitalize on the current work that is underway within the NRH and extend this on a more comprehensive basis into the community. While some community and regional services have made great inroads in this area, others suffer from a lack of resources, knowledge and personnel. It is hoped that this research will highlight the needs and experiences of children who acquired a brain injury and provide the impetus for the future development of services.

Table 11.2 – Key recommendations**Policy issues**

- To develop strategies to promote family-centred care and to foster family unity and support during the period of rehabilitation within the NRH.
- To consider the care needs and service requirements of young people with ABI and develop a strategy for the management and treatment of all ABI cases.
- To consider the place of ABI in future disability policy.

Information and training

- To provide information and training to professionals in the community to support and enhance their work with children with ABI.
- To promote public awareness and understanding of acquired brain injury and its impact on children and their families.

Provision of services

- To develop family-centred care within the community and to recognise the support and advice required by the primary caregivers of children with ABI.
- To develop measures to foster the well-being of young people with ABI and to support their social integration within family, neighbourhood, school and leisure activities.
- To provide support and guidance to young people with ABI prior to and during life transitions and developmental changes (for example, from primary school to secondary school, and secondary school to young adulthood).
- To promote a co-ordinated system of care that is responsive to the needs of children and their families with adequate resources to provide a prompt service, as required.
- To improve communication between existing services and to allow for the consistent passage of information through the system thus incorporating the acute hospitals, the NRH and the community health, social and educational services.
- To develop a plan for preparing teachers in the community for the education of children with ABI.
- To develop a system for tracking and monitoring a child's progress and changing needs as they move through the educational system.

Future Research

- To encourage the development of longitudinal studies from a) the point of A&E onwards or b) community-wide epidemiological studies in order to account for pre-morbid factors.
- To initiate further research on the social experiences of different illness groups (e.g. stroke, traumatic brain injury etc) and to utilise observational methodologies to explore peer relationships and social adjustment.

References

- Bruce, D.A. (1995). Pathophysiological responses of the child's brain injury following trauma. In S. H. Broman & M. E. Michel (Eds.), *Traumatic head injury in children* (pp. 40-51). New York: Oxford University Press.
- Chapman, S.B. & McKinnon, L. (2000). Discussion of developmental plasticity: Factors affecting cognitive outcome after pediatric traumatic brain injury. *Journal of Communication Disorders*, 33, 333-344.
- Christensen, J.R. (1997). Pediatric traumatic brain injury rehabilitation: Challenges in care delivery. *NeuroRehabilitation*, 9, 105-112.
- Commission on the Status of People with Disabilities (1996). *A strategy for equality. Report of the commission on the status of people with disabilities*. Dublin: The Stationery Office.
- Dennis, M. (2000). Developmental plasticity in children: The role of biological risk, development, time, and reserve. *Journal of Communication Disorders*, 33, 321-332.
- Department of Health & Children (2001). *Quality and fairness. A health system for you*. Dublin: The Stationery Office.
- Department of Human Services (2001). *Acquired Brain Injury Strategic Plan*. Melbourne, Australia: Development and Planning Division, Victorian Government Department of Human Services.
- Dunn, K.A., Thurman, D.J. & Alverson, C.J. (1999). The epidemiology of traumatic brain injury among children and adolescents. In *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.
- Eames, P., Turnbull, J., & Goodman-Smith, A. (1989). Service delivery and assessment. In M.D. Lezak (Ed.) *Assessment of the behavioural consequences of head trauma*. (pp. 195-214). New York: Alan R. Liss Inc.
- Emanuelson, I. & Wendt, L. (1998). Medical management in south-west Sweden of children and adolescents with serious traumatic brain injury. *Injury*, 3, 193-198.
- Engel, G.L. (1977). The need for a new medical model: A challenge for biomedicine. *Science*, 196, 129-136.
- Engel, G.L. (1980). The clinical application of the biopsychosocial model. *The American Journal of Psychiatry*, 137, 535-544.
- Federal Register (October, 1990). Individual with Disabilities Education Act (IDEA-PL 101-476).
- Fletcher, J.M., Ewing-Cobbs, L., Francis, D.J., & Levin, H.S. (1995). In S. H. Broman & M. E. Michel (Eds.), *Traumatic head injury in children* (pp. 3-21). New York: Oxford University Press.
- Furlonger, R. & Johnson, D.A. (1989). Return to school. In D.A. Johnson, D. Utterley & M. Wyke (Eds.), *Children's head injury: Who cares?* (pp. 147-162). London: Taylor & Francis.
- Government of Ireland. (2000). *The National Children's Strategy: Our children – their lives*. Dublin: The Stationery Office.
- Hartup, W.W. (1992). Friendships and their developmental significance. In H. McGurk (Ed.), *Childhood social development: Contemporary perspectives*. Hove, UK: Erlbaum.
- Hawley, C.A., Ward, A.B., Long, J., Owen, D.W. & Magnay, A.R. (2003). Prevalence of traumatic brain injury amongst children admitted to hospital in one health district: A population-based study. *Injury*, 34, 256-260.
- Hawley, C.A., Ward, A.B., Magnay, A.R. & Long, J. (2002). Children's brain injury: A postal follow-up of 525 children from one health region in the UK. *Brain Injury*, 16, 969-985.

- Janus, P.L., Mishkin, L.W., & Pearson, S. (1997). Beyond school re-entry: Addressing the long-term needs of students with brain injuries. *NeuroRehabilitation*, 9, 133-148.
- Kinsella, G., Ong, B., Murtagh, D., Prior, M. & Sawyer, M. (1999). The role of the family for behavioural outcome in children and adolescents following traumatic brain injury. *Journal of Consulting and Clinical Psychology*, 67, 116-123.
- Kraus, J.F. (1995). Epidemiological features of brain injury in children: Occurrence, children at risk, causes and manner of injury, severity and outcomes. In S. H. Broman & M. E. Michel (Eds.), *Traumatic head injury in children* (pp. 22-39). New York: Oxford University Press.
- Lambert, S.A. (1984). Variables that affect the school-age child's reaction to hospitalisation and surgery: A review of the literature. *Maternal Child Nursing Journal*, 13, 1-18.
- Lash, M. & Scarpino, C. (1993). School re-integration for children with traumatic brain injuries: Conflicts between medical and educational systems. *NeuroRehabilitation*, 3, 13-25.
- Lezak, M. (1987). Brain damage is a family affair. *Journal of Clinical and Experimental Neuropsychology*, 10, 111-123.
- Max, J.E. (1998). Predictors of family functioning after traumatic brain injury in children and adolescents. *Journal of the American Academy of Child and Adolescent Psychiatry*, 37, 83-90.
- Michaud, L.J. (1995). Evaluating efficacy of rehabilitation after pediatric traumatic brain injury. In S. H. Broman & M. E. Michel (Eds.), *Traumatic head injury in children* (pp. 247-257). New York: Oxford University Press.
- Middleton, J.A. (2001). Practitioner review: Psychological sequelae of head injury in children and adolescents. *Journal of Child Psychology and Psychiatry*, 42, 165-180.
- National Disability Authority (2002) National Disability Authority Submission to the Department of Education & Science Education for Persons with Disabilities Bill 2002. [Online]. Available: www.nda.ie/cntmgmt.nsf/education.rtf
- O'Brien, D.P. & Phillips, J.P. (1996) Head injuries in the Republic of Ireland: A neurosurgical audit. *Irish Medical Journal*, 89, 216-218.
- Oddy, M. (1993). Head injury during childhood. *Neuropsychological Rehabilitation*, 3, 301-320.
- Osberg, J.S., Kahn, P., Rowe, K. & Brooke, M.M. (1996). Pediatric trauma: Impact on work and family finances. *Pediatrics*, 98, 890-897.
- Osberg, J.S., Brooke, M.M., Baryza, M.J., Rowe, K., Lash, M. & Kahn, P. (1997). Impact of childhood brain injury on work and family finances. *Brain Injury*, 11, 11-24.
- Rivara, J.M., Jaffe, K.M., Polissar, N.L., Fay, G.C., Liao, S. & Martin, K.M. (1996). Predictors of family functioning and change 3 years after traumatic brain injury in children. *Archives of Physical Medicine and Rehabilitation*, 77, 754-764.
- Santrock, J. (2002). *Life-span development*. Boston: McGraw Hill.
- Sarafino, E.P. (2002). *Health Psychology: Biopsychosocial interactions*. New York: Wiley.
- Savage, R.C., Pearson, S., McDonald, H., Potoczny-Gray, A. & Marchese, N. (2001). After hospital: Working with schools and families to support the long term needs of children with brain injuries. *NeuroRehabilitation*, 16, 49-58.

- Scallan, E., Staines, A., Fitzpatrick, P., Laffoy, M. & Kelly, A. (2001). *Injury in Ireland*. Dublin: Department of Public Health & Epidemiology, UCD.
- Schaffer, D.R. (1999) *Developmental psychology: Childhood and adolescence*. 5th Ed. Pacific Grove: Brooks / Cole Publishing.
- Schwartz, G.E. (1982). Testing the biopsychosocial model: The ultimate challenge facing behavioural medicine? *Journal of Consulting & Clinical Psychology*, 50, 1040-1053.
- Taylor, H.G., Drotar, D., Wade, S., Yeates, K., Stancin, T., & Klein, S. (1995). Recovery from traumatic brain injury in children: The importance of the family. In S. H. Broman & M. E. Michel (Eds.), *Traumatic head injury in children* (pp. 188-217). New York: Oxford University Press.
- Taylor, H.G., Yeates, K.O., Wade, S.L., Drotar, D., Klein, S.K. & Stancin, T. (1999). Influences on first-year recovery from traumatic brain injury in children. *Neuropsychology*, 13, 76-89.
- Teasdale, G. & Jennett, B. (1974). Assessment of coma and impaired consciousness: A practical scale. *Lancet*, ii, 81-84.
- United Nations (1990). *Human rights: The rights of the child*. Fact Sheet No. 10. Geneva: United Nations.
- Waaland, P.K. & Kreutzer, J.S. (1988). Family response to childhood traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 3, 51-63.
- Wade, S.L., Taylor, G., Drotar, D., Stancin, T. & Yeates, K.O. (1998). Family burden and adaptation during the initial year after traumatic brain injury in children. *Pediatrics*, 102, 110-116.
- Warzak, W.J. & Anderson, C.M. (2001). Parenting children with brain injury. In M.J. Fine & S.W. Lee (Eds.), *Handbook of diversity in parent education* (pp.253-336). London: Academic Press.
- Ylvisaker, M. (1998). Traumatic brain injury in children and adolescents: Introduction; In M. Ylvisaker (Ed.). *Traumatic brain injury rehabilitation: Children and adolescents*. Boston: Butterworth-Heinemann.
- Zinner, E.S., Ball, J.D., Stutts, M.L. & Philput, C. (1997). Grief reactions of mothers of adolescents and young adults with traumatic brain injury. *Archives of Clinical Neuropsychology*, 12, 435-447.

Appendix A

Glossary of Terms

ABI	Acquired Brain Injury
GCS	Glasgow Coma Scale
HB	Health Board
NRH	National Rehabilitation Hospital



Joseph Murnane



JJ Ward



John Joyce

A Tiger's View

K. Bohan

"A zoo. It's prison, if you ask my opinion.
I hate it here, ya know, really really hate it.
Well, actually I DESPISE it.
I just hope and wish those who come after me
won't have to live like this.
It is desperate. Every night I dream I'm free.
Then I wake up and discover I'm still in here.
It's VERY depressing.
Would you like to be stared at all day?
Have no privacy?
I don't think you'd like it one bit.
So work towards a better world, for us and for others.
Set us free. YES, SET US FREE."



children's research centre
CENTRE FOR CHILDREN



Eastern Regional
Health Authority

