

**Caregiving For Children  
Who Have Had A Traumatic Brain Injury:  
Structuring For Security**

**By**

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### **Attestation of Authorship**

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person nor material which to a substantial extent has been accepted for the qualification of any other degree or diploma of a university or other institution of higher learning, except where due acknowledgement is made in the acknowledgements.

Signed .....

Dated .....

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I wish to give my sincere thanks to all the people who have supported me throughout this study. In the first instance, I am indebted to all the participants, who shared with me their homes, their families, and their understandings. I have found their commitment and knowledge to be invaluable, and an inspiring example of what it is possible to achieve.

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Ethical Approval to proceed with this research was granted by the Auckland Ethics Committees on 08/02/02, application number AKX/02/01/011. Approval to proceed was granted also by the Auckland University of Technology Ethics Committee on 11/03/02.

## **Grammar, Spelling and Style**

There is no uniform guide to grammar, spelling and style in the English language. Protocols for grammar and spelling vary for different countries and also change with time. This has presented some difficulties in the preparation of this thesis. In the face of the lack of a clear path to follow, the thesis has been written to reflect its New Zealand context.

This has meant the application of English grammar as outlined in the Collins Pocket Dictionary of English Usage (Hardie, 1992); the use of New Zealand English spelling as programmed into Microsoft Word 2000, backed up by The New Zealand Oxford Paperback Dictionary (Deverson, 1998), and, in line with Auckland University of Technology guidelines for the presentation of theses, application of the styles required by the American Psychological Association (2001).

Nonetheless, the use of original spelling and grammar in quotations from other works has brought about some disparities. Additionally, quotations of the participants in the study are largely verbatim, and incorporate grammatical inconsistencies. Apologies are extended to those readers who find this usage differs from their own practices.

## **Abstract**

This New Zealand study used a grounded theory methodology to explore the day-to-day occupations of family caregiving for children who had sustained a traumatic brain injury. Semi-structured interviews and participant observations were employed to gather data from five families including children of pre-school and school age and their parents. Constant comparative analysis of the data revealed a central caregiving category, Structuring For Security, which encompassed two simultaneous and interdependent caregiving processes. A model is presented illustrating the processes.

Structuring For Security describes the way the parents' caregiving is directed towards building a framework that provides for the present and future safety and success of their children. Holding Things Together explains endeavours to contain the distressing events resulting from the accident, with a focus on protecting the children from physical and emotional dangers. Joining My Child With Others explains what is happening when parents set things up for their children to spend time in activity with other people. The two processes are mediated by support from others, and involve learning and use of practical knowledge about the child. Successful implementation of the processes results in parents' increasing awareness of their ability to cope, progress in the children, and children's successful participation with other people. Participation in the processes is ongoing, responding to change in the child and in the environment.

The study findings suggest a basis for the development of a framework that families and clinicians might use to guide caregiving for children after a traumatic brain injury. The findings also indicate the importance of supporting parents in developing effective caregiving structures that fit with their concerns for their children's safety and success with others. Consideration needs to be given to policies that take into account the safety issues involved for children and the support needs of parents following the accident.

## **Chapter One: Introduction and Context to Study**

Traumatic brain injury in children holds serious consequences, not only for the children, but also their families and wider society (Appleton, 1998; Taylor et al., 2001). As a result of such injury children require greater support to participate at home and at school, and are at risk of developmental delays. Family caregivers experience ongoing feelings of stress and burden as they adapt to changes involved in looking after them. Significant costs to the wider community are accrued through the ongoing need for professional assistance and support for children and their families (Conoley & Sheridan, 1996; Rivara, 1994).

This study explores the day-to-day occupations of family caregiving for children who have had a traumatic brain injury. Caregiving in this context is defined as looking after a child who has previously sustained damage to their brain as a result of an external force such as a traffic accident or severe fall. Occupations are the range of activities encompassed by the caregiving, including caregivers' actions, their interactions with the children and others, and the meaning these activities hold for caregivers.

The study employs a grounded theory methodology (Strauss & Corbin, 1998) which is concerned with discovering and explaining what happens as a result of the actions, interactions, and meanings inherent to real life situations such as caregiving (Charon, 2001). In order to learn more about these processes as they occur during caregiving, interviews and observations were conducted with five New Zealand family caregivers of children with traumatic brain injury.

The study endeavours to augment current knowledge about caregiving for children with traumatic brain injury. In the past, the field has been dominated by a medical perspective, which has emphasised clinical assessment and management of neuropsychological, physical, and behavioural difficulties in the children, and psychological phenomena in caregivers. Studies to date have largely employed a positivist paradigm, with the researchers using tools to quantify and establish causal relationships for discrete variables such

as memory, attention, and behaviour. There is now growing awareness of the influences family caregivers have on outcomes for children with traumatic brain injury (Taylor et al., 2001). However little is known about the ways families provide care on a day-to-day basis, and the occupational processes occurring during caregiving which may affect these outcomes.

My own research interest in this field comes about through a background as an occupational therapist employed in a New Zealand rehabilitation setting for children. A part of my role has involved assessment of the amount and type of caregiver assistance required by children with traumatic brain injury. My concern with the similarities and differences in the ways families provide care and adjust to the changes in their children and their caregiving role prompted me to undertake the project.

This chapter describes the context of the study. The incidence and costs of traumatic brain injury in New Zealand children are outlined for the reader, as well as the mechanisms, pathology, and sequelae of traumatic brain injury. Service provision for children with traumatic brain injury in New Zealand is described. The researcher's perspectives on occupation are examined, and their relevance to the study is explained. A definition is provided for the construct of caregiving. The chapter moves on to explain the researcher's area of interest in the field, and the significance of the study in terms of current knowledge. Chapter One concludes by stating the research question and aims, and overviewing the content of the thesis.

## ***Traumatic Brain Injury in Children***

### ***Incidence and Costs in New Zealand***

The shock of a child's traumatic brain injury impacts on the lives of many New Zealand families each year, with the adverse effects of such injuries extending well beyond the acute stage and initial recovery period for a great number of these families. Costs to the community are substantial. In the six months between July and December 2002 alone, 72 new cases of concussion/brain injury in New Zealand children aged 0-14 years were recorded in Accident Compensation Corporation (ACC) Injury Statistics (2002). The estimated total cost of these cases to ACC for this period was

\$290,000 (Accident Compensation Corporation, 2003b). These figures reflect the financial cost of rehabilitation and support over the initial six months, but do not reflect practical and emotional costs to families. Neither do they account for the cost of hospital inpatient treatment, which is bulk funded (Accident Compensation Corporation, 2003b; Simpson & Stephenson, 2002). Further to this, in the same time period, 157 ongoing cases of concussion/brain injury that occurred in childhood were recorded at a cost of \$3,324,000 (Accident Compensation Corporation, 2003b).

This data does not provide a detailed breakdown of the severity of injuries linked with costs. It is possible that a large number of these claims involved mild concussions not requiring hospital treatment, while a relatively small number of more severe injuries incurred most of the costs (Simpson & Stephenson, 2002). The data does, however, inform us about serious injuries. These are high input claims often requiring around the clock care, which include, although are not limited to, a high proportion of claims for serious traumatic brain injury. In the year 2001, 64 new serious injury claims for children were recorded, with a total rehabilitation and support cost, over and above hospital costs, of \$1,521,000. In the same period, there were 632 ongoing serious injury claims that occurred in childhood, costing the corporation \$33, 551,000 (Accident Compensation Corporation, 2003b).

### ***Mechanisms and Pathology***

Causes of traumatic brain injury in children include playground accidents, motor vehicle accidents, pedestrian accidents, cyclist accidents, and non-accidental injuries. Injuries can be described either as a) open (penetrating) brain injury, where an object depresses or penetrates the skull and dura (brain lining) or b) closed (non-penetrating) where the brain is shaken inside the skull. Primary damage occurs at the time of the accident, and can include skull fractures, scalp and facial lacerations, and bleeding and bruising of the brain. Movement of the brain within the skull results in shearing, twisting, and tearing of multiple neurons. Secondary damage can arise from factors such as swelling, and inadequate oxygen due to pressure change, or changes in respiratory or circulatory function (Appleton, 1998; Ylvisaker & Feeney, 1998a).

### ***Consequences of Injury***

Injuries may be classified as mild, moderate, or severe, dependent on depth and duration of coma and the duration of post-traumatic amnesia. In some instances, injuries can be diffuse, with global changes in function, while in other instances, specific areas of the brain may be affected, leading to functional deficits in certain areas only (e.g. movement, memory, sensory processing, or communication skills) (Appleton, 1998; Ylvisaker & Feeney, 1998a). Neurodiagnostic imaging (e.g. CT scan or MRI scan) is not always able to provide a full picture of damaged brain structures, making prediction of functional changes difficult (Ylvisaker & Feeney, 1998a).

Further complicating understanding of the types of changes that might occur after a traumatic brain injury, are the individual differences that are present in brain function, in people themselves (e.g. their previous experience, personality, and skills), and in their physical and social environments. Secondary changes in function may present as stress disorders resulting from the emotional trauma of the accident (Demellweek, O'Leary, & Baldwin, 1998; Ylvisaker & Feeney, 1998a). Behavioural changes that are not directly attributable to neurological causes may also take place due to feelings of frustration or incompetency associated with loss of skills (Ylvisaker & Feeney, 1998a; Ylvisaker, Feeney, & Mullins, 1995).

Traumatic brain injury has particularly serious consequences for children. Initially brain injury in children was thought to have few long-term effects on development, due to neuroplasticity factors, or the ability of other areas of the young brain to assume function for damaged areas. However, recent studies of developmental outcomes after traumatic brain injury indicate that the younger the age of injury, the greater the long-term developmental delays. As well, delays in the attainment of quite specific skills can occur if injury occurs at times that are critical for maturation of specific areas of the brain and for skill development (Chapman & McKinnon, 2000; Lowenthal, 1998; Verger et al., 2000; Ylvisaker & Feeney, 1998a).



### ***Service Provision Following Traumatic Brain Injury***

As this study was carried out with families living in New Zealand, this section describes the way in which services are provided for people who have sustained a traumatic brain injury in that country. While privately run accident insurance schemes operate in New Zealand, the majority of accidents to individuals are currently covered through the Accident Compensation Corporation (ACC). This crown entity administers the accident compensation scheme to provide accident insurance for New Zealand citizens, residents, and temporary visitors. Funding for the scheme is sourced through insurance premiums paid by employers, employees, direct government payment, and tariffs on petrol and vehicle registrations (Accident Compensation Corporation, 2003d).

The first accident compensation scheme came into force in 1974, and has had frequent revisions of its legislation by successive governments. The scheme is currently governed through the Injury Prevention, Rehabilitation and Compensation Act 2001 (Accident Compensation Corporation, 2003c). The present web-site description of ACC's undertaking, "to prevent injury, to provide the best treatment and care if injury occurs, and to quickly rehabilitate people back to work or independence..." (Accident Compensation Corporation, 2003a) has been a consistent central theme. Rehabilitation under this current Act includes social rehabilitation, vocational rehabilitation, treatment (such as hospital treatment, physical rehabilitation, and cognitive rehabilitation), and ancillary services such as transport and accommodation. ACC's rehabilitation goal emphasises quality of life for claimants, through identification of needs, provision of support and entitlements, restoration of function, and promotion of participation (Accident Compensation Corporation, 2003a). This reflects contemporary concerns regarding participation of people with traumatic brain injury in the community (World Health Organization, 2002; Ylvisaker & Feeney, 1998a).

The area of rehabilitation of particular concern to this study is that of social rehabilitation, described by the 2001 Act as being directed towards restoration of health, and independence in order to carry out life roles. Through social rehabilitation, claimants may be supported with entitlements such as

training for independence, provision of equipment, housing modifications, home help, child care, and attendant care (Accident Compensation Corporation, 2003a).

### ***Attendant Care***

The focus of this study is on caregiving, and therefore the concept of attendant care is of particular relevance. The giving of care is termed attendant care in the Injury Prevention, Rehabilitation and Compensation Act 2001, and includes assisting claimants to carry out personal cares, maintaining their safety, and supporting cognitive activities such as social interactions, and task performance. The emphasis is on helping the claimant to carry out the specified activities as independently as possible, although there is recognition of the need to balance the level of support to avoid situations where claimants may be unmotivated to attempt tasks themselves due to over-assistance, or where family caregivers may become overburdened due to inadequate assistance (Accident Compensation Corporation, 2002, 2003e). Care may be sourced through an agency that provides nursing and attendant carers, or may be provided by the family themselves; either parents, direct family members, or a person the family nominates.

Caregiving in the ACC framework is focused on precise types of injury related assistance required by the claimant to enable completion of specific tasks such as self-care activities or social interactions throughout the day. The number of hours of attendant care payable weekly is determined by an assessor who is contracted to ACC, (either an occupational therapist or a registered nurse), and the assessment is required to specify the different intensities and skill requirements in care provided over 24 hours. Level One Direct Cares are those specialized cares which require a high level of skill or training, such as management of nasogastric feeds or tracheostomy cares, while Level Two Direct Cares are basic hands-on cares such as bathing, dressing or turning in bed. Supervisory Care refers to indirect cares such as verbal cues given to a claimant to carry out tasks successfully, or to generally ensure safety. Sleepover Care refers to the requirement for a person to remain in the home overnight to attend to intermittent care requirements (Accident Compensation Corporation, 2002, 2003e).

### ***ACC Service Provision for Children with Traumatic Brain Injury***

This study explores caregiving for children with traumatic brain injury, and consideration is given here to ACC literature which is specifically concerned with meeting children's and families' needs. In 1998, ACC, in conjunction with the National Health Committee, published comprehensive guidelines for the rehabilitation of people with traumatic brain injury in New Zealand. Although social rehabilitation for children with traumatic brain injury remains governed by the same legislation as that for adult rehabilitation, these guidelines are one of the few areas of ACC literature to acknowledge the special needs of children with traumatic brain injury and their families. The guidelines aimed to increase understanding of the need for rehabilitation for people with traumatic brain injury. They highlight important features of rehabilitation services, provide a starting point for building improved services, and identify areas where further research is needed in the field (Accident Rehabilitation and Compensation Insurance Corporation & National Health Committee, 1998).

The guidelines are broad in their considerations and recommendations, but stress the importance of the family in bringing about positive outcomes for children, the effect of traumatic brain injury on children's developmental progress, the impact of different parenting styles and family circumstances, and the implications for siblings. Recommendations include provision of adequate and appropriate support for families, the need for rehabilitation services to view the child with traumatic brain injury in the "context of their family unit" (p. 27), and the family unit's interconnectedness with school, and the broader community (Accident Rehabilitation and Compensation Insurance Corporation & National Health Committee, 1998).

Current attendant care legislation also refers to special circumstances guiding the provision of care for children. Children are defined as being under the age of 14 years, and the legal parental responsibility to provide supervision to children below this age is stressed. Support with attendant care should be over and above that required by a typically developing child of a similar age, but should also reflect the influence of the injury on the achievement of normal developmental skills (Accident Compensation Corporation, 2003e).

### *Caregiving versus Parenting or Caring*

The term caregiving was used in the study rather than “parenting” or “caring” for a number of reasons. Firstly, ACC legislation allows for care to be provided by parents, extended family, family friends, or paid attendant carers contracted through an agency. New Zealand families may employ a variety of these options in caring for their children with traumatic brain injury; thus the term parenting was seen as too narrow in its application. Additionally, the term “parenting” implies the act of being a parent, which may or may not involve the occupation of providing care for a child (i.e. some parents do not directly provide care for their children due to separation etc.).

As it eventuated, all those who consented to take part in the study were the children’s parents. It could be argued that it is not possible to separate out the emotional aspects of being a parent from the actions of caregiving. However, the grounded theory methodology used within the study aims to discover and explain what is going on for the group being studied at a particular time and place, and therefore for this group, the caregivers’ roles also as parents were considered an integral part of the study. Additionally, the term caregiving was maintained as participants made frequent reference to other caregivers who assisted them with the role.

Caregiving implies caring. References to the concept of “caring” abound in nursing literature, and there is debate over its precise meaning (Husted & Husted, 1998; Orem, 2001). Orem (2001) defines caring as an essential, moral human quality involving love and concern for other people. Caring is defined by The New Zealand Oxford Paperback Dictionary (Deverson, 1998) as feeling “concern or interest”, or “affection or liking” (p. 111). The term caring therefore implies the use of emotional energy, but not necessarily the physical actions which must be used in caring for a child. Since actions as well as emotional and intellectual energy are important within this study, this term was considered inadequate. A caregiver is described in this New Zealand Dictionary as a person who routinely provides cares “for an elderly, sick, or disabled person,” indicating the doing nature of caregiving, and differentiating it from parenting (p. 111).

## *Defining Occupations*

Caregiving is about doing things, and is therefore about occupation. Human occupation is complex and multifaceted (Royeen, 2002; Wilcock, 1999). Rather than constraining openness to discovery by offering one concrete definition of occupation, this section describes for the reader those broad aspects of the term which I see as most relevant to caregiving. In this way I understand that the word occupation refers both to doing, and also to what is done.

Firstly, occupation is acting, or doing. Occupational scientists tell us that the need to do is an essential human need (Wilcock, 1993), and that human occupation may be directed at a purpose or may involve doing simply for the sake of enjoyment (Kielhofner, 2002; Wilcock, 1999). Thus, it is understood that caregivers are doing things within their caregiving role, and that these actions may be directed at a particular purpose (e.g. re-training skills with their child, or playing a ball game for fun).

Building from this, occupation can also be the name describing *what* it is that is being done (e.g. dressing a child, giving medications, and teaching a child how to use cutlery are all names of occupations). In occupational therapy literature, the names attached to different categories of things that are done also include tasks, or activities (Kielhofner, 2002). The things that constitute a certain occupation are shaped by physical and social circumstances (Kielhofner, 2002), and are understood by other members of that person's cultural group. For example, people who are not caregivers to a child with traumatic brain injury may not understand the caregiving occupation of naso-gastric feeding.

Within the bounds of the grounded theory methodology (Strauss & Corbin, 1998), this study is concerned not only with caregivers' *actions* or doing, (explaining when, where, how, why, and with whom they do things), but also with discovering and describing through an interpretive process *what* it is that caregivers see themselves as doing. The term occupation in the study is therefore used to describe the actions or doing, and is also used in the plural, occupations, as the interpreted names given to certain categories of caregivers' actions.

Occupational therapists see that occupations take place over time, and that they are dynamic. Things may change or be maintained as a result of the occupation. Therefore the term occupation when used in this study also connotes a process (Hocking, 2000; Kielhofner, 2002; Wilcock, 1999) and one way of understanding this process is described in the following section.

### ***The Model of Human Occupation***

Kielhofner (2002) has developed a model that helps to explain some of the processes that occur when humans engage in occupations. As an occupational therapist, this model guides my daily understandings of the occupations that I observe in my clinical practice. The model is briefly outlined here to draw the reader's awareness to my own assumptions about occupational processes prior to beginning the study. I refer back to the model again in the discussion chapter, Chapter 7, in order to consider the results of this study against what is currently known.

Using Kielhofner's model (2002), the human is depicted as an open, dynamic system. The system is seen as being shaped and organized through occupation, in response to the characteristics of the occupations and also the environment. Motivation, patterns of behaviour, movement skills, energy levels, self-concept and so on develop, are maintained, and change as a consequence of engagement in occupation. Change may also occur within the system due to internal changes (such as growth, illness, or injury) or external changes in the physical and social environment.

Within the model of human occupation, three interrelated phenomena are conceptualised by Kielhofner (2002) as contributing to the organisation of peoples' occupational behaviour. Volition explains the human drive to participate in occupations in response to an innate need for action and personal beliefs about ones' skills, values, and interests. Habituation describes the human tendency to order behaviour into patterns and routines. These patterns of behaviour are guided both internally (e.g. by body rhythms or internalised attitudes) and externally (e.g. environmental layouts, societal expectations for behaviour). Performance capacity refers to peoples' ability to carry out particular occupations, arising from their objective physical and mental

structures and functions (e.g. muscle strength, memory skills, attention control), and also from subjective experience of these abilities or limitations.

Although surrounding literature informs us that family caregivers of children with traumatic brain injury adapt in some ways to the changes in their child (Lezac, 1978, 1988; Rivara, 1994), authors have not adopted a focus on occupations, and the applicability of Kielhofner's model (2002) to the processes of caregiving occupations was unclear prior to commencing the study. However the model provides a comprehensive, general understanding of human occupation, incorporating contemporary issues from disability literature (Kielhofner, 2002). Experts in the grounded theory methodology tell us that although existing literature and theory should not be allowed to constrain openness and discovery, they can provide a starting point for questions when beginning a project (Strauss & Corbin, 1998). Using Kielhofner's model (2002), it was possible to speculate that families caregiving for children would begin to change the way they provide care in response to a child's brain injury (external change to social environment). Parents could experience differences in their motivation, and routines may change. Their feelings about their ability to caregive for their child may be affected by the accident. My interest in the occupation of caregiving arose through my involvement with parents who are caregiving for children with disabilities.

### ***Researcher's Area of Interest***

My clinical role as an occupational therapist working in a post-acute rehabilitation service for children has been a motivating force to carry out this study. The occupational therapy role in this setting has a key focus of enabling children with traumatic brain injury to engage in occupations they want and/or need to do. Within the service, the families of these children are an integral part of the rehabilitation team, and the occupational therapist works side by side with them during the rehabilitation process. An important part of my practice involves supporting families, by assisting them to develop the skills they need to carry out their changed caregiving occupations, ready for their child to begin successful participation in their own home and school environments.

I have observed families adjusting as their children move through the rehabilitation programme into the community. I have also noticed links between families' actions and the children's own ability to carry out occupations. For example, some family caregivers may be able to provide safe levels of assistance when the child is relearning how to ride a bike, and encourage independence in their child where possible, while others are uncomfortable with allowing their child to participate in this type of occupation at all due to safety concerns. However these observations have not been rigorously examined, and there is little guidance in existing literature as to their relevance or veracity.

From the perspective of being a parent myself, I see these families at a time when their skills as caregivers, critical to the outcomes for the child, are being challenged to extend beyond the scope of a normal caregiving role. Families are learning to manage increased levels of dependence, to cope with changed responses and interactions with their children, and to adjust to new routines. Children are seldom able to cope with full time attendance at school, and spend large parts of their days at home as they gradually integrate back into the school environment. This process may take extended periods of time, depending on the severity of the injury. I observe the difficulty parents have, despite stress and fatigue, in accepting assistance from paid attendant carers. On occasion I have observed the negative impact on children and families of inadequately informed attendant carers.

In addition, some of the children with traumatic brain injury have received their injuries as a result of physical abuse (non-accidental injury), and are in the custody of Child Youth and Family Services (CYFS) until long-term placements are found. The paucity of literature regarding the skills caregivers need and practical actions they could use to effectively give care for children with traumatic brain injury complicates the process of selecting and training caregivers for both CYFS and rehabilitation personnel.

Another part of the occupational therapy clinical role involves assessing the children's attendant care requirements. This task involves discussions with parents and family caregivers to ascertain the cares they carry out with their child, as well as observations of the child during therapy, in daily activities, and at play to determine their functional abilities. Attention is paid to the type



and purpose of assistance given, the level of independence the child is capable of, and the level of care that would be developmentally appropriate for the child. To meet ACC requirements, the assessment relies heavily on developing a 24-hour diary with families, detailing the cares given in a typical day. A standardised assessment is also used to measure the levels of assistance given in basic daily living tasks, functional mobility, and social interactions for younger children (Haley, Coster, Ludlow, Haltiwanger, & Andrellow, 1992). Through these assessments, an awareness of the complexity of caregiving actions that caregivers use with their children also guided my decision to carry out this study. The occupations of caregiving do not seem to be adequately described using the diary and standardised assessment, and actions that are important to families are not always acknowledged.

### ***Current Knowledge and Significance of the Study***

Initially after a child sustains a brain injury in an accident, parents undergo a raft of emotions. They move from the trauma of the injury, through the uncertainty of the acute period in hospital, and onto adjusting to the changes in their child back in the community as the longer term rehabilitation process begins (Rivara, 1994). A number of different professionals may support the child's return to the community over the long term, including medical and nursing staff, psychologists, physiotherapists, occupational therapists, and speech language therapists. However parents are usually the primary caregivers, taking an active role in helping their children participate in their daily routines. It may be months before children can cope with full-time attendance at school, and they therefore spend extensive periods of time at home (Jaffe et al., 1993).

Numerous studies have been undertaken overseas which have investigated outcomes for children and their families following paediatric traumatic brain injury, but it remains unclear whether they have fully explored families' concerns. The majority of studies have employed standardised assessments to measure discrete components of children's neurobehavioural function such as memory, attention, visual perception and intelligence, or to measure children's ability to manage social behaviours, classroom tasks and

daily living tasks (Bigler, Clark, & Farmer, 1997). Studies which measure outcomes for those who are caregiving for children with traumatic brain injury have largely involved caregivers of adult children, but confirm the increased levels of stress and burden experienced by parents, with the presence of psychological symptoms such as anxiety and depression (Wade, Drotar, Taylor, & Stancin, 1995). Another body of literature has demonstrated the moderating effects that social support, education, and coping styles have on these types of caregiver outcomes (Stanton, 1999). Recently, a small number of published studies have identified important links between measures of caregiver and family function and outcomes for children with traumatic brain injury (Taylor et al., 2001).

There has, however, been little emphasis on families' perceptions of the changes in their children following the traumatic brain injury. When families' perceptions have been explored, standardised assessments and rating scales have been used. These direct the areas of questioning and quantify phenomena, but are not able to fully explore issues of concern, and risk overlooking previously unidentified issues which may be concerning families.

Further to this, assessments of how well children carry out social behaviours, classroom tasks or daily living tasks relative to their peers may not accurately reflect the complexity of issues families may face in caring for their children after a traumatic brain injury. It is possible that age appropriate performance of these activities is not of a high priority for some families, and children are spending most of their time at home. Additionally, it is unclear in which way the stated neuropsychological and behavioural difficulties are impacting on children's day-to-day actions and interactions within the home, or the ways in which caregivers endeavour to address these difficulties.

Despite acknowledgement of the effects that different sociological factors such as race (Yeates et al., 2002), education, and social support (Stanton, 1991) have on caregiver outcomes, only one study of caregiving for people with traumatic brain injury has been carried out by New Zealand researchers, and this involved families who were caregiving for adults (Knight, Devereux, & Godfrey, 1998). Although families are seen as central to rehabilitation after traumatic brain injury (Accident Rehabilitation and Compensation Insurance Corporation, & National Health Committee, 1998)

little is known about the ways in which the ACC system of rehabilitation is able to support New Zealand families providing care for younger children with traumatic brain injury. Moreover, in spite of increasing acknowledgement of the importance of occupation in peoples' lives, there have been no published studies that have directly investigated the caregiving occupations that are used by family members after a child sustains a traumatic brain injury.

This study asks the question “what is involved in the day-to-day occupations of caregiving for a child who has had a traumatic brain injury”? The study aims to contribute to the development of a theory which explains the processes involved in the day-to-day occupations of caregiving for the child with traumatic brain injury, and to identify things that assist and things that hinder families during these occupations.

### ***Structure of the Thesis***

Chapter One of this thesis has outlined the context of the study, beginning with background information about the mechanisms and pathology of paediatric traumatic brain injury. It has discussed the provision of services for people with traumatic brain injury in New Zealand, and has provided definitions of terminology. The significance of the study with regard to current literature and my own clinical practice has been described.

Chapter Two reviews and critiques literature relevant to caregiving for children with traumatic brain injury. In Chapter Three the application of the grounded theory methodology employed in this study is described and a rationale is provided for its use. The findings of the study are presented in Chapters Four, Five and Six. Chapters Four and Five describe the two caregiving processes that emerged from the data, while Chapter Six overviews the processes from the point of the central category. Chapter Seven provides a final discussion of the findings in relation to existing literature. Included in this chapter is an examination of the clinical implications of the study, and considerations regarding service delivery. The limitations of the study are discussed, and suggestions are made for further research.

## **Chapter Two: Literature Review**

Experts in the grounded theory methodology recognise that many researchers are appreciably familiar with the background literature in their area of specialty before they commence a study (Chenitz & Swanson, 1986; Strauss & Corbin, 1998). It is stressed that it is important to avoid this knowledge influencing the analysis of the data. However, Strauss and Corbin (1998) suggest that instead of claiming to be completely free from bias, it is more useful for researchers to acknowledge their existing perspectives and understandings. In this way, it is possible to utilise knowledge to stimulate sensitivity and questioning, and also to be aware of situations when familiarity with a subject is restricting thinking and discovery.

On beginning this study, the researcher was aware of the growing body of literature informing us about the effects of a traumatic brain injury for children and their families. This chapter outlines and critiques this literature to provide a background of the current knowledge understood as having relevance to caregiving occupations. The review includes discussion of the sequelae, interventions, and caregiver outcomes for this population. Qualitative understandings about caregiving are explained. Gaps and inconsistencies in the literature are identified and the position of this study in relation to these is stated.

The review centres on information about the occupations of caregiving for children with traumatic brain injury. It was not apparent prior to commencing the study whether other topics from the wider body of literature would be pertinent to any theory that emerged. As recommended by Strauss and Corbin (1998), in undertaking this study, the researcher wished to avoid being restricted by pre-existing knowledge. The discussion therefore does not include broader review of the psychological constructs of stress, coping, and social support, which are identified as variables in caregiving literature. Neither does it draw extensively on references to the wider literature around parenting non-disabled children and children with other disabilities. Instead, relevant

concepts that became apparent over the course of the study are explored in more depth in the discussion chapter, Chapter Seven.

### ***Sequelae for Children after a Traumatic Brain Injury***

Sequelae for children who have sustained a traumatic brain injury are reviewed here to summarise what is known of their behaviours, and to draw attention to issues that caregivers may be managing during their day-to-day interactions with the children. Children's progress following traumatic brain injury has been extensively assessed using an array of standardised tests, including formal psychometric testing, questionnaires, and also parent and teacher report during structured and semi-structured interviews.

Studies have quantified a variety of the children's objectively measurable capacities, including components of neurobehaviour such as intelligence, and the prevalence of emotional sequelae such as stress and mood disorders. Objective measurement has also been made of children's physical changes after traumatic brain injury, and of their participation in functional tasks in the classroom and at home. An important aspect of neurobehaviour is that of executive function. It is introduced here before a wider consideration of neurobehavioural sequelae as it is central to the regulation of cognitive and social aspects of behaviour, and plays an important role in children's development.

#### ***Executive Function***

Traumatic brain injury differs from other types of neurological insult in that it very frequently involves direct impact to the front of the head, and/or damage to the front of the brain with excessive and rapid backwards-forwards and twisting movement of the brain inside the skull. Important areas of the brain typically affected by these types of injuries are those known as the frontal lobes, the pre-frontal cortex, the limbic regions, and the temporal cortex (Ylvisaker & Feeney, 1998a). These areas together are responsible for executive function.

Executive function encompasses a variety of capacities. These include problem solving in novel situations, insight into one's own and others' behaviour, the ability to set realistic goals, to organise behaviour, to initiate and

cease activity, to control impulses, to regulate emotion, and to monitor outcomes and adjust behaviour accordingly (Mateer, 1997; Ylvisaker & Feeney, 1998a). Damage to executive control areas of the brain has serious effects on children's occupations. Particular difficulties are evident with novel, more complex tasks that cannot be carried out automatically. Organisational difficulties interfere with the ability to stay on task, and also with the ability to understand familiar patterns of action across occupations that enable development of routines; limits to organisational schemas and routines are then thought to then impact on children's ability to cope with unfamiliar situations and tasks (Baldwin, Seddon, Demmellweek, Hughes, & Fishwick, 1997; Ylvisaker, Szekeres, & Feeney, 1998).

The frontal lobes are slow to mature, and are thought to play a role in myelination due to their multiple connections with other areas of the brain. Therefore damage to the frontal areas is also thought to particularly impact children's development, and holds implications for their future ability to gain skills necessary as an adult for successful community living (Chapman & McKinnon, 2000; Ylvisaker & Feeney, 1998a). Ylvisaker and Feeney (1998a) use the example of a pre-school child who is self-centred, inflexible, poorly organized, impulsive, and who has tantrums when things don't go right. At 3 years old, this is relatively normal behaviour. However, at 8 years old, if the child has not matured along with his peers due to frontal lobe damage, these types of behaviour create considerable concerns for caregivers.

Apart from the impact of executive function impairment on task performance and developmental skills, considerable levels of disability may also be present in social interactions in the home. As discussed above, behaviours reported to be associated with frontal lobe injury can include impulsivity, inappropriate behaviour, difficulties picking up on and responding to social cues, disorganisation, rigid patterns of behaviour, apathy, irritability, and aggression (Ylvisaker & Feeney, 1998a; Ylvisaker & Gioia, 1998; Ylvisaker, Szekeres, & Feeney, 1998). Literature tells us that children's behaviour after traumatic brain injury is one of the changes that caregivers find the most challenging to manage (Connolly & Dowd, 2001; Dell Orto & Power, 2000; Kehle, Clark, & Jensen, 1997; Waaland, 1998). Although these changes are frequently reported by family caregivers, formal assessments have not been

easily able to identify and classify the cause of the difficulties (Ewing-Cobbs, Levin, & Fletcher, 1998; Ylvisaker & Gioia, 1998). Inappropriate social behaviour is often submitted as arising directly from executive function impairment, but also as being secondary to it (e.g. a response to repeated failure at tasks), and as a response to an external stimulus (e.g. teasing) (Ylvisaker & Gioia, 1998).

Additionally, children with executive function damage may obtain relatively good results on standardised assessments of neurobehavioural functions, such as intelligence, attention, memory, visuospatial tasks, or even tests that specifically require executive components of function for successful completion. However, components of such tests are commonly short and highly structured, and they are administered in a carefully controlled setting. It is thought that this type of task and setting may compensate to a good extent for deficiencies in frontal lobe function, supporting levels of achievement which are less evident in the child's school or home environments (Ylvisaker & Gioia, 1998). Studies that have examined different aspects of these neurobehavioural functions in children who have had a traumatic brain injury are reviewed next.

### *Neurobehavioural Sequelae*

For the purposes of this review, neurobehaviour is defined as including mental capacities such as executive function, intelligence, problem solving, visuo-spatial and visuo-motor skills, learning abilities, memory, attention control, and language skills (Ewing-Cobbs, Levin, et al., 1998). These capacities have been extensively assessed, and only recent key works are mentioned here.

The majority of studies show that following traumatic brain injury in children there are initial improvements early in recovery (Barry, Taylor, Klein, & Yeates, 1996; Chadwick, Rutter, Brown, Shaffer, & Traub, 1981; Dumas, Haley, Ludlow, & Rabin, 2002; Ewing-Cobbs, Fletcher, Levin, Iovino, & Miner, 1998; Jaffe et al., 1992; Jaffe et al., 1993; Ponsford et al., 2001). However there is also a body of evidence indicating that neurobehavioural function in children is adversely affected in the longer term, particularly for children who are younger at the time of the injury (Anderson, Catroppa, Morse,

Haritou, & Rosenfeld, 2000; Chadwick et al., 1981; Fay et al., 1994; Garth, Anderson, & Wrennall, 1997; Taylor et al., 2002). Furthermore, studies consistently find a relationship between the severity of injury and neurobehavioural outcomes (Anderson, Catroppa, Morse, et al., 2000; Chadwick et al., 1981; Donders & Ballard, 1996; Donders & Strom, 2000; Fay et al., 1994; Jaffe et al., 1993; Massagli et al., 1996; Taylor et al., 2002; Yeates et al., 2001).

A significant relationship between injury severity and measures of neurobehaviour was found by Fay and her colleagues (1994), in a comprehensive, 3-year cohort study involving 72 children with moderate and severe brain injury. Capacities assessed included intelligence (Wechsler, 1993), concept learning, speed of information processing, memory, adaptive problem solving, reading, spelling, mathematics, social skills, and behavioural status. At 3-year follow-up, few of the children had returned to pre-morbid levels of function. Further to this, function was significantly worse for the children on 40 out of 53 variables than for the controls, who were individually matched for age, gender, school grade, and pre-injury classroom ability.

The results of this study are relatively robust due the inclusion of multiple types of measurement across time, both pre-injury measurements and a matched control group, and the employment of both formal testing and parent and teacher report (Fay et al., 1994). However, several inconsistencies were apparent between clinician, teacher, and parent ratings of children's function. Parent ratings, but not those of clinicians or teachers, indicated a significant effect of injury severity on behaviour regulation, social skills, independent living skills, and gross and fine motor skills (Fay et al., 1994). The reason for these differences was not addressed in the study. However the possibility must be considered that children cope adequately with some types of neurobehavioural assessments and with classroom work, but that difficulties are more apparent at home where caregiving takes place.

A similar study of 30 children with severe traumatic brain injury using a battery of neuropsychological tests (Massagli et al., 1996) also found a significant relationship between injury severity and neurobehavioural function at initial and 1-year follow-up testing. Children experienced difficulties with speed and strength of movement, information processing, memory, and



academic performance. Particular difficulties were found with adaptive problem solving. This study underscored the importance of considering changes in children following traumatic brain injury relative to their own pre-injury performance, and also relative to peers from their own community. Massagli et al. (1996) compared results from the children with traumatic brain injury against test population norms and also to pre-morbidly matched controls. It was found that changes identified by test population norms were less marked than those found by comparing the results to the matched controls. It is possible families may notice changes in their children after a traumatic brain injury that are not readily identified by standardised assessments.

The findings of Fay and her colleagues (1994) and Massagli et al. (1996) are substantiated by other, more recent studies, indicating possibly greater challenges over time for caregivers in the case of children with more severe injuries, and children who are injured at a younger age. Verger et al. (2000) employed the same measure of intelligence (Wechsler, 1993), but different measures of memory and visuospatial function, and also included specific evaluation of executive function in a follow up of 29 children at least 6 years post-injury. In line with previous findings, children were found to have reduced performance on half of the test variables when compared to matched controls. When controlling for injury severity, those injured at a younger age demonstrated greatest intellectual impairments.

An extensive Australian study by Anderson, Catroppa, Morse, et al. (2000) involving 124 children with mild to severe traumatic brain injury provides even further robust support for an association between intellectual outcomes, injury severity and younger age at injury, as does a study by Garth et al. (1997). In addition, the study by Garth et al. indicates that parents could find children respond more slowly during their daily activities in the home. Results of testing highlighted a close association between impairments to executive function and speed of information processing in the children.

However a similar study by Anderson and her colleagues that specifically involved younger children with severe traumatic brain injury (Anderson, Catroppa, Haritou, & Morse, 2000) had less conclusive results than these other studies. While it was found that the 96 pre-school children in this study consistently performed more poorly on intelligence tests, which is in line

with others' findings, the children did not demonstrate any clear pattern of memory deficits, even by 18-month follow-up. As memory is an aspect of neurobehaviour that is still developing throughout childhood, it is possible that assessment at this early age was not readily able to identify future deficits (Ewing-Cobbs, Levin, et al., 1998).

Attentional aspects of neurobehaviour have been less extensively evaluated in children with traumatic brain injury than the functions discussed above. Clinicians commonly acknowledge that problems with attention control can impact significantly on other test results, and also on actions and interactions in the home and school environments (Mateer, Kerns, & Eso, 1997). Despite this, results of studies do not indicate a clear pattern of attentional difficulties, which flags the complex nature of attention control and differential patterns of recovery at different ages. Studies employing computer-based tests have found abnormal or borderline levels of attention control in children who have had traumatic brain injury (Dennis, Wilkinson, Koski, & Humphries, 1995; Kaufmann, Fletcher, Levin, & Miner, 1993). However concerns have been raised as to whether such tests are accurate indicators of children's ability to attend in a busy classroom setting or family home (Silver, 2000). In contrast to studies using computer-based assessments, improvements in aspects of attention control over time have been found by studies employing checklists (Bakker & Anderson, 1999), and real-life activities (Anderson, Fenwick, Manly, & Robertson, 1998). The diverse results of these studies make it difficult to surmise about any role children's attentional difficulties might play in caregiving occupations in the home.

Difficulty with communication is another aspect of neurobehaviour that could be expected have an effect on caregiving occupations. Studies have consistently found severity related impairments in receptive and expressive language skills in both pre-school and school-age children with traumatic brain injury. Areas of concern identified in children include intelligibility, object naming, verbal fluency, description of objects' function, and comprehension, with deficits occurring in communication that are still apparent at 1-year follow-up after injury (Cahill, Murdoch, & Theodoros, 2002; Ewing-Cobbs, Levin et al., 1998). Age related patterns of difficulty are apparent, with pre-school children at greater risk of language difficulties (Ewing-Cobbs & Barnes,

2002), and having greater difficulty with expressive than receptive language functions (Ewing-Cobbs, Miner, Fletcher, & Levin, 1989). Recently there has been increased attention paid to children's ability to use language-based skills functionally. Older children particularly have been found to have greater difficulty with higher-level use of language in a functional context, or discourse (Ewing-Cobbs & Barnes, 2002).

Studies of changes in children's discourse after traumatic brain injury have found fewer words used, less information conveyed, reduced ability to include essential information, and changes in narrative structure (Chapman et al., 2001; Ewing-Cobbs, Levin et al., 1998). On a more positive note, in another study of discourse, children with brain injury were found to have the same level of skills as uninjured peers for evaluating the appropriateness of behaviour and producing suitable responses (Lewis, Morris, Morris, Krawiecki, & Foster, 2000).

### ***Psychoreactive Sequelae***

Less attention has been paid in the literature to children's emotional reactions after experiencing a life threatening traumatic brain injury. However the stress and grief arising from such an event differentiates traumatic brain injury from neurological disorders that have been present from birth, and are thought to play a significant part in children's adjustment back into school and family life (Dell Orto & Power, 2000; Sherwin & O'Shanick, 1998; Ylvisaker et al., 2001).

Studies indicate that children are at risk of psychiatric disturbances following traumatic brain injury, and caregivers may need to manage a variety of symptoms in the children. During hospital admission and at follow-up 4 or more weeks later, Burleson Daviss et al. (2000) used parent and nurse questionnaires and child interviews to identify the presence of acute stress disorder symptoms in 54 children. Only 24 of these children had a traumatic brain injury, and symptomatology was not analysed against specific diagnoses. However, acute stress disorder symptoms on 4 out of 5 criteria were found in one third of the children.

Extending these time frames, a recent study by Luis and Mittenberg (2002) focussed more specifically on traumatic brain injury. Standardised tests

were used to compare 61 children 6 months after traumatic brain injury with an orthopedic control group. A relationship was found between new onset mood and/or anxiety disorders and traumatic brain injury in the children. Furthermore, stress levels and the severity of the injury were the strongest predictors of the onset of disorders.

A study which incorporated even later follow-up measures by Max, Arndt, and their associates (1998) found an increased presence of attention-deficit hyperactivity symptoms in children with traumatic brain injury at 3, 6, 12, and 24-month follow-up. Furthermore, these symptoms had a significant correlation with the presence of oppositional defiant symptoms.

### ***Physical Sequelae***

It is generally acknowledged that after traumatic brain injury, in most cases children's physical function improves more rapidly than other aspects of their neurobehavioural function (Dumas & Carey, 2002; Wilkening, 1997). Although intellectual and social-emotional impairments appear to play the greatest part in determining outcomes after traumatic brain injury and are the most difficult for family caregivers to cope with (Kehle et al., 1997), a variety of persistent physical disturbances may also impact on function. While these disturbances are identified by studies as being present, their implications for children's behaviour at home and their effects in terms of caregiving have not been widely explored.

Such disturbances can include but are not limited to visual impairments (Poggi et al, 2000), changes in auditory processing, loss of movement and sensation, spasticity, joint contractures, decreased coordination, and movement planning difficulties (Clark, 1997; Farmer, Clippard, Luehr-Wiemann, Wright, & Owings, 1997; Weston, Kinley, Hughes, & Fishwick, 1998). Other physical problems reported in the literature include fatigue, headaches, dizziness, seizure activity, appetite changes, and sleeping disturbances (Clark, 1997; Nash, Appleton, Rowland, Saltmarsh, & Sellars, 1998; Tomlin, Clarke, & Robinson, 2002).

Results of studies also indicate a residual effect of the injury on both fine and gross motor function, with children with moderate to severe traumatic brain injury achieving lower scores than controls for standardised measures.

Motor impairments, including reduced speed of movement, strength, balance, and dexterity have been noted at least 5 years after injury, and have been found to be more marked in children who sustained injury at a younger age than those who sustained injury when they were older. As with other neurobehavioural components, performance has been consistently related to injury severity, and also to time since injury (Dumas et al., 2002).

Whether children with mild traumatic brain injury also experience these difficulties is less clear. Wallen, Mackay, Duff, McCartney, and Oflaherty (2001) reported little difference between children with severe traumatic brain injury, children in a control group, or children with mild traumatic brain injury for standardised assessments of fine and gross motor function. However, observations of muscle tone, grasp, handwriting, and bilateral skills found increased difficulties for children with severe traumatic brain injury.

Studies that focussed more on mobility skills have found that as few as 64% of children with moderate to severe injury achieve independent ambulation (Fay et al., 1993; O'Flaherty et al., 2000), and reduced levels of motor fitness in children with traumatic brain injury have been reported by Rossi and Sullivan (1996). Reductions have also been found in children's walking speed, step and stride lengths (Kuhtz-Buschbeck, Stolze, Golge, & Ritz, 2003).

The extent to which these measurable residual impairments translate into functional difficulties is unclear however. A study by Coster, Hayley, and Baryza (1994) specifically measured functional motor skills such as the ability to climb in and out of the car or bath, walk indoors and outdoors, manage stairs, and transfer on and off furniture. Assessments at 1 month and 6 months after discharge found that children had no difficulties relative to their peers. The assessment tool used in this study (Haley et al., 1992) relied on parent report, and while children with traumatic brain injury achieved at the higher end of the normal range for their actual functional movement skills, scores for levels of caregiver assistance perceived to be required with these tasks were slightly below the mean. Although the children were capable of carrying out these movement skills themselves, their parents perceived a need for increased levels of assistance. The reason for this discrepancy is not addressed in the study.

Despite the numerous studies which have investigated the sequelae for children after traumatic brain injury, it is difficult to fully ascertain the ways in which these neurobehavioural, psychoreactive, and physical changes affect children's daily activities in the home environment with family caregivers (Silver, 2000). There is a dearth of empirical literature that clarifies this relationship. However, several studies of outcomes for children with traumatic brain injury have focussed more on functional activities which take place largely in the home environment, including daily living skills and psychosocial function. These studies shed a little more light on caregiving occupations, and are discussed in the next section.

### ***Functional Outcomes for Children***

Overall, studies of children's daily living skills and psychosocial function after traumatic brain injury have established the presence of significant long-term difficulties. As with neurobehavioural sequelae, difficulties become more apparent with increasing severity of injury. While there may be some initial improvement in the first 1-2 years after the injury, over the longer term children tend to fall increasingly behind their peers in their development in these areas (Arsanow, Satz, Light, Lewis, & Neumann, 1991; Donders & Ballard, 1996; Fay et al., 1994; Fletcher, Ewing-Cobbs, Miner, Levin, & Eisenberg, 1990; Massagli et al., 1996; Max, Koele et al., 1998; Taylor et al., 2002).

The studies employ multiple measures of children's function, including assessments of components of neurobehaviour and psychoreactive sequelae alongside standardised measurements of daily living skills. The measures of psychosocial function utilised by the studies screen for the overall presence of a number of psychoreactive sequelae, and the outcomes are generally described under the umbrella term of behaviour. Studies reflect a consistent trend for ongoing behavioural difficulties which are identified by parents as being particularly stressful (Coster et al., 1994; Taylor et al., 1999). Studies have also uncovered the presence of relationships between the child's function and family function (Coster et al., 1994; Max, Castillo et al., 1998; Max, Koele et al., 1998; Taylor et al., 1999; Taylor et al., 2002), pointing to the importance of

gaining a fuller understanding of the issues involved in family caregiving occupations.

Three studies (Arsanow et al., 1991; Fletcher et al., 1990; Max, Koele et al., 1998) which investigated functional changes in children following traumatic brain injury all used the same two measures of daily living skills and behavioural adjustment. The Vineland Adaptive Behaviour Scales (Sparrow, Balla, & Cicchetti, 1984) are based on parent report of children's communication, daily living, socialisation, and movement skills. The Child Behaviour Checklist (Achenbach, 1991) is an assessment that surveys the overall level of behaviour problems based on the presence of 113 aspects of children's psychosocial function, including constructs such as happiness, anxiety, depression, activity, withdrawal, socialisation, immaturity, attention, delinquency, self destruction, aggression, school performance, and appropriate behaviour.

Using these assessments all three studies found daily living skills and social behaviour were significantly lower in those children with moderate and severe traumatic brain injury (Arsanow et al., 1991; Fletcher et al., 1990; Max, Koele et al., 1998). Donders and Ballard (1996) who also used the Child Behaviour Checklist (Achenbach, 1991) similarly found that children's social behaviour was negatively affected, with significant deteriorations in their sample on these characteristics, despite pre-injury dysfunction which was no more common than for the general population.

Children's independence in daily living skills was also evaluated in the studies by Fay et al. (1994) and Massagli et al. (1996), but conflicting results were obtained. Both studies used the Woodcock-Johnson Scale of Independent Behaviour to measure skill levels (Bruininks, Woodcock, Weatherman, & Hill, 1985). This assessment relies on parent report of the child's function in the areas of eating, meal preparation, toileting, dressing, personal self-care, domestic skills, time and punctuality, money management, work skills, and home and community function. Although the 1994 study by Fay et al. found that injury severity was significantly related to eating, dressing, and work skills, this was not supported by Massagli et al.'s (1996) study. Features of the study designs may explain these differences. The study by Fay and her colleagues (1994) was a much larger study involving 72 children at multiple

levels of severity with a late follow-up at 3 years. In contrast, the study by Massagli et al. (1996) involved only 30 children at 1-year follow-up, all falling within the diagnosis of severe traumatic brain injury.

It is also possible that the differences in daily living skills outcomes resulted from external factors such as the family environment, which was not evaluated in either of these studies. Some initial support for this proposition is provided by the previously mentioned study by Max, Koele et al. (1998), who incorporated a measure of family function in addition to the measures of child function. Although the study involved only 24 children, it was found that family dysfunction was significantly associated with the variation in children's functional skills. Unfortunately pre-injury measures of function were not included in the study design, limiting the validity of the results.

More extensive support for the impact of the family environment on children's functional progress was gained by Taylor et al.'s (1999) examination of 94 children in the first year after moderate and severe traumatic brain injury, a study which also took family function into account. In line with other studies, assessments (Achenbach, 1991; Sparrow et al., 1984) found children with traumatic brain injury had significantly worse composite scores than their matched controls and that the severity of injury was positively associated with the severity of deficits. Importantly however, when environmental factors were taken into account alongside injury severity, it was found that pre-injury factors and family function were also both predictive of children's outcomes in terms of fine motor skills, behaviour problems, social competence and daily living skills. Increased levels of parent distress and family burden were associated with greater deficits in the children. Furthermore, follow-up at a mean of 4 years after injury indicated the presence of ongoing challenges for family caregivers (Taylor et al., 2002). Even at this late point, it was found that the children's ongoing difficulties with behaviour and daily living skills were mediated by the family environment.

When considered together, the studies by Max et al. (1998) and Taylor et al. (1999, 2002), indicate the importance of acknowledging the role of the family in any consideration of the events following a child's traumatic brain injury. While these studies take into account parent report of functional skills, they rely however on standardised tests with pre-determined questions, and are



not fully able to inform us as to how families endeavoured to address the difficulties. Additionally, the findings are limited by failure to take into account the levels or types of intervention the children were receiving between assessment points. It is conceivable that intervention could have had a significant impact on children's abilities at testing. The next section of the review provides an overview of the intervention approaches that are commonly used with children after traumatic brain injury.

### ***Intervention for Children***

In literature relating to children with traumatic brain injury, there are few studies which empirically investigate outcomes of different interventions (Michaud, 1995; Ward, 1995; Warschausky, Kewman, & Kay, 1999). The interventions that are discussed vary in their approaches, in the range of issues being addressed and in claims of effectiveness. Treatment programmes may include but are not limited to pharmacological interventions (O'Shanick, 1998), restorative and compensatory approaches to cognitive rehabilitation (Ben-Yishay & Diller, 1993; Blunden & Smits, 2000; Mateer, 1997; Toglia, 1991; Ylvisaker & Szekeres, 1998), behaviour management (Kehle et al., 1997; Mateer, 1997), assistive technologies (Chester, Henry, & Tarquinio, 1998), educational intervention (Ylvisaker et al., 1995; Ylvisaker et al., 2001), social skills training (Demellweek et al., 1998), and retraining of motor skills (Weston et al., 1998).

Studies into the outcomes of interventions and rehabilitation programmes are hampered by the difficulties associated with controlling for the diversity of ages, injury sites, presentations, developmental histories, and sociocultural factors (Michaud, 1995). Further to this, provision of rehabilitation services varies widely between countries and geographic areas (Cronin, 2001; Hawley, Ward, Magnay, & Long, 2002; Oregon Health Sciences University, 1999; Tomlin et al., 2002). It is reasonable to speculate that such programmes could have a significant impact on children's abilities, with further implications for family caregivers; programmes might contribute to possible improvements in a child's function, or alternatively, to increased responsibilities for parents with carrying out home based therapy activities. Little is known however about families' participation in interventions or

rehabilitation programmes for children with traumatic brain injury, and still less known about programmes involving New Zealand families.

More recent intervention approaches stress the importance of collaborating with families and significant others in any programmes, and adopt a focus on strategies involving the child's successful participation in day-to-day routines and activities in their home and school environments (Willer & Corrigan, 1994; Ylvisaker & Feeney, 1998a, 1998b). Studies have demonstrated some success with this type of approach (Feeney & Ylvisaker, 2003; Gardner, Bird, Maguire, Carreiro, & Abenaim, 2003), but the emphasis has been on outcomes for the children, with minimal comment on the ways in which such interventions affect the occupations of caregivers.

A recent New Zealand study by Piggot, Paterson, and Hocking (2002) highlighted some of the processes affecting parents who were involved in home therapy programmes for their children with cerebral palsy. It was found that parents felt compelled to do all they could for their children, involving persistent efforts to optimise their children's achievements. Initially parents needed to come to terms with their children's diagnosis, before moving on to make efforts to maximise their children's abilities. Motivation to participate in therapy programmes moved in a cycle: observation of their child's gains drove further motivation to participate more in the programme, while failure of their child to progress led to reductions in motivation and less involvement in the therapy programme.

While this study informs us about the ways parents participate in such programmes when a child has cerebral palsy (Piggot et al., 2002), no such studies have been carried out with children with traumatic brain injury. Cerebral palsy and traumatic brain injury can differ in neurological and functional presentations. Moreover, traumatic brain injury occurs as a catastrophic event in the life of a child rather than becoming apparent shortly after birth, as is the case with cerebral palsy. Parents could be expected to experience different responses, and the children's care requirements may also be quite different. A number of recent studies have focussed on families' responses to caregiving after a child's traumatic brain injury, and these are discussed next.

### ***Caregiving After a Child's Traumatic Brain Injury***

Literature around traumatic brain injury has traditionally been encompassed by a medical perspective, involving a dominant focus on pathophysiology and neurobehavioural assessment. However works by Lezak (1978, 1986, 1988) and Polinko, Barin, Leger, and Bachman (1985) broke new ground. Based on clinical experience, these authors formally acknowledged that the effects of a traumatic brain injury extend beyond the person injured to the wider family. They also identified stages of post-injury reactions for families.

Initially after a person sustains a brain injury in an accident, the family experiences feelings of shock and fear. As the person recovers consciousness, emotions may shift to relief and optimism. However, these feelings frequently give way to a sense of loss, anger, and grief as families gradually come to terms with caring for a member who has changed in many ways (Conoley & Sheridan, 1996; Dell Orto & Power, 2000; Lezac, 1978, 1986; Polinko et al., 1985; Rivara, 1994; Waaland, 1998). Waaland (1998) goes on to emphasise the broad variation in families' responses to a person's brain injury. She acknowledges the ways in which medical experiences, cultural understandings, knowledge, support systems, and crisis reactions all influence families' perceptions of an injury event and adjustment.

Much of the literature which has emerged around outcomes for family caregivers has involved adults with traumatic brain injury, and has adopted a focus on psychological aspects of caregiving. Within this literature, studies find that caregivers have increased levels of stress, anger, perceived burden, depression, and anxiety (Connolly & Dowd, 2001; Kausar & Powell, 1996; Kosciulek, 1999; Kreutzer, Marwitz, & Kepler, 1992; Livingston, Brooks, & Bond, 1985a, 1985b; Mitchley, Gray, & Pentland, 1996; Perlesz, Kinsella, & Crowe, 1999; Perlesz & O'Loughlan, 1998; Smith & Schwirian, 1998). Caregivers may also experience decreased self-esteem, and feelings of incompetence (Connolly & Dowd, 2001). With increased time spent in the caregiving role, there is less time spent on social participation and leisure occupations (Connolly & Dowd, 2001; Livingston et al., 1985b). In general these responses are associated more closely with changes to the patient's

personality and behaviour than with their physical disabilities (Connolly & Dowd, 2001; Kausar & Powell, 1996; Livingston et al., 1985b).

It is unclear how valid it may be to apply this literature to parents caregiving for pre-school and school-age children. Many of these studies also involve spouses caring for a partner (Connolly & Dowd, 2001; Kausar & Powell, 1996; Kosciulek, 1999; Livingston et al., 1985a, 1985b; Mitchley et al., 1996; Perlesz & O'Loughlan, 1998; Smith & Schwirian, 1998), which involves very significant role changes. Additionally, caregiving for an adult does not necessitate involvement in developmental activities such as play and learning, or the promotion of developmental progress. It could be argued that parents would be caring for young children in any instance, and that when a child is brain injured, stress may be more related to grief over the changes in the child than with additional burden.

A modest but increasing number of studies are now focussing on the caregiving for young children and adolescents with traumatic brain injury (Kreutzer et al., 1992). As with the adult literature, these studies focus on outcomes for caregivers in terms of stress, burden, and psychiatric sequelae (Perlesz et al., 1999), and are concerned with investigating measurable variables and establishing causality. An additional focus is on the more social construct of family function, with little discussion of the caregiving occupations which family members may be engaging in. Studies consistently find relationships between outcomes for children, the pre-injury function of the child and of the family, and outcomes for the family. Information has generally been gained through the use of caregiver rated scales and assessments, thus basing the study results to some extent on family opinion of their own and their child's function (Degeneffe, 2001). While it is possible to make some inferences about caregiving occupations that might be impacting on outcomes, the studies do not fully explain what the caregivers are doing with their children on a day-to-day basis.

A study that aimed to determine which family strengths contributed to positive outcomes (Rivara et al., 1996) involved a large sample of 81 children with traumatic brain injury. Although 43 of these children sustained only mild traumatic brain injury as measured by depth of coma, data analysis was used to control for this feature. Outcome measures for the children included parent and

teacher rated versions of the Child Behaviour Checklist (Achenbach, 1991). Eight measures of family function were employed, evaluating areas such as global family function, relationships, stress, strain, mood, behaviour control, anxiety, communication, and roles.

At 3 years after injury, two-thirds to half of the families reported relatively low levels of strain. Deterioration in family function was associated with increased severity of the injury. A key finding was that pre-injury family function (including variables such as family relationships, psychological function, effectiveness of communication, coping skills, problem solving, and social support) was the best predictor of post-injury family function. Other variables that mediated family outcomes, albeit less significantly, were levels of family activity, and clarity of roles; lower levels of activity were associated with increased stress, and less clear family roles were associated with increased depression for parents (Rivara et al., 1996).

For children with severe brain injury, more positive behavioural outcomes occurred in families with lower levels of control and higher levels of expressiveness present pre-injury. These constructs are not well defined, but are loosely interpreted as the level of rigidity and openness of communication adopted by families. Other family skills that were associated with positive child outcomes were flexibility of roles, good problem solving, and effective use of resources (Rivara et al., 1996). While the difference between flexibility of roles and poor clarity of roles was not discussed, it appears both are important in mediating outcomes.

In line with Rivara et al's (1996) study, an extensive prospective research project by Wade, Taylor, Drotar, Stancin and Yeates (1998) also found an association between the severity of a child's injury and levels of family stress, burden, and psychological symptoms. This study involved 189 children. Assessments were made shortly after injury, at 6-month, and at 12-month follow-up, and an orthopaedic injury group was used to control for pre-injury family status and the effects of an acute hospitalization. A caregiver rated scale was employed to identify levels of injury related stress with respect to the child's progress, and reactions of spouse, family, and friends. Other scales employed in the study used parent report of the level to which the injury

impacted on the family, of their psychological function, and of overall family function.

Significantly higher levels of injury related stress and family burden were experienced by parents of children with traumatic brain injury, than were experienced by parents of children with orthopaedic trauma. Additionally, 41% of the parents of children with traumatic brain injury experienced significant psychological symptoms at 12-month follow-up (Wade et al., 1998). While the study provides important knowledge about the psychological impact of traumatic brain injury on the family, the assessments do not focus on the occupations the parents carry out when giving care for their children.

It is of interest that an earlier write-up of the same study discussing preliminary findings does provide some limited insights into the ways parents carried out caregiving (Taylor et al., 1995). Data analysis found that parents of children with traumatic brain injury spent greater amounts of time listening to their children and reasoning with them than did parents of children with orthopaedic injuries. Additionally, parents of children with traumatic brain injury felt emotionally closer to their children, had more family arguments, and had greater sharing of responsibility for household chores between family members. Differences were also found between the two groups in terms of particular issues contributing to burden, with parents of children with traumatic brain injury having greater difficulty managing the behaviour of the child and their siblings, difficulty paying for care of siblings during the child's hospitalisation, disagreements over how best to care for the child, and more concerns over others' opinions of discipline strategies used.

As discussed earlier in this paper, the later write-ups of this same study by Taylor and his colleagues (1999, 2002) with 6-month, 12-month, and 4-year follow-ups highlighted an association between the well-being of parent caregivers and the children's functional outcomes. These findings are supported by results of a recent Australian study by Anderson et al. (2001), which suggested the presence of a two-way relationship. The short-term (6-month) outcomes of this study found correlations between family function and child behaviour, which were best predicted by the child's psychosocial and pre-injury function. The level of burden for families was significantly related to injury severity, functional limitations of the child, and child behaviour.

Coster et al.'s (1994) study in the occupational therapy literature also found evidence for reciprocal relationships between family function and children's behaviour and functional skills following traumatic brain injury. This study used the Child Behavior Checklist (Achenbach, 1991), but also employed the Pediatric Evaluation of Disability Inventory (PEDI) (Haley et al., 1992) and the Impact on Family scale (IFS) (Stein & Riessman, 1980). The PEDI evaluates a child's ability to perform self-care, mobility, and social function activities, and measures their abilities against normative data. Children's scores at 1 and 6 months after hospital discharge were compared to a group of children who had sustained non-central nervous system injuries. The evidence provided by the study is weakened by uncertainty as to the children's previous functional skills and the short time frames of the assessment period (Coster et al., 1994). It is also possible that the findings underestimate the problem due to a failure to provide a pre-injury status matched control group (Massagli et al., 1996). Additionally, children were identified as having mild to moderate brain injuries only (Coster et al., 1994), levels of severity that have given conflicting outcomes across other studies (Fay et al., 1993; Ponsford et al., 2001).

Nevertheless, it was found that for children with traumatic brain injury, an increased degree of caregiver assistance was required at follow-up in the areas of self-care and social function relative to controls (Coster et al., 1994). Significant correlations were found between the amount of caregiver assistance required and parents' perceptions of the impact of the children's injuries on the family. Significant correlations were also found between the children's behaviour problems and the impact on the family.

These associations between child functioning and levels of family burden and distress were unraveled further by Taylor and his associates in a more recent study (Taylor et al., 2001). The study employed a sophisticated data analysis technique, and the report is complex to follow. However, it was found that the severity of the traumatic brain injury was predictive of child behaviour problems, family burden, and family distress when controlling for the child's pre-injury behaviour function. Data also showed that the bulk of effects of the severity of the traumatic brain injury were occurring indirectly. That is, more severe traumatic brain injury resulted in more severe behaviour

problems, and therefore greater deterioration in family function. Additionally, it was found that child behaviour and family function influenced each other reciprocally over the 12-month period of the study.

Taylor et al. (2001) suggest their results are indicative of a negative spiral where difficult child behaviours impact on the family's ability to adjust and manage these behaviours, which in turn has further detrimental effects on the child's behaviour. Although this is plausible, the emphasis remains on family stress and burden, and little attention is paid to parent-child interactions or what the parents are actually doing on a day-to-day basis in dealing with the behaviour. The references to the value of positive parent-child interactions and the value of assisting families to manage children's behaviour are extrapolations only, and are not indicated by this study which did not measure interactions or ask parents whether they would find these things valuable.

Another recent study that involved parent ratings of their own adjustment and their children's neurobehavioural function after traumatic brain injury was carried out by Yeates et al. (2001). The study does not focus on caregiving occupations, but is notable in that it provides some information about parents' concerns for their children's physical symptoms such as headaches and fatigue. Parents identified the presence of cognitive/somatic (physical) symptoms and emotional/behavioural symptoms in their child, and indicated whether the symptoms had worsened since the injury. Cognitive abilities in the children were measured by clinicians. The results of these assessments were compared to parent rated measures of family function, presence of parental psychiatric symptoms, perception of burden, types of stressors, and levels of social support.

Injury severity, and also the severity of the child's pre-morbid behaviour and cognitive difficulties were significantly predictive of post-injury levels of cognitive/somatic symptoms. Injury severity, post-injury cognitive function and family function significantly predicted emotional/behavioural symptoms. Both cognitive/somatic symptoms and emotional/behavioural symptoms were significantly predictive of parent's perceptions of burden (Yeates et al., 2001).

It is important to note that this study looked for the presence of significant *numbers* of a certain type of symptoms, and a significant



relationship between a collective symptom type of and perceptions of burden (Yeates et al., 2001). Individual symptom frequency and severity in children were not measured, and it is therefore uncertain in what ways and to what degree specific symptoms were contributing to burden. It is also possible that some symptoms may have been mildly and occasionally present in significant numbers of children, were relatively unimportant to the family in terms of providing care, but collectively created feelings of burden due to others' reactions in the community. Alternatively, due to the symptoms' collective impact on the child's ability to join in family life, they could have contributed indirectly along with other factors to feelings of burden.

The authors put forward several hypotheses as to processes that might have been occurring, (e.g. increasing intolerance of symptoms over time, reductions in social support over time, or increased demands on children with recovery in terms of school and resumption of daily activities) (Yeates et al., 2001). However this study did not ask these questions of parents and could not explore these processes. Questions about processes that might be involved when parents are caregiving for their children remain unanswered.

A small study by Sokol et al. (1996) involving 25 children also found levels of parental stress were significantly related to perceived difficult child behaviour, including areas of thought, attention, delinquency, and aggressive behaviour. An additional behaviour checklist developed for this study contains several items that relate more directly to the children's day-to-day function, including questions regarding functional mobility, daily living skills, academic function, chores, social function, physical status, mental status, and emotional function. Using this checklist however, only the domain of emotional function was found to be significantly related to levels of parental stress. The results of this study contrasted to those of Taylor et al. (2001) in that the severity of injury was unrelated to the degree of perceived behavioural problems, a result that was not well explained.

On a more practical focus, Waaland, Burns, and Cockrell (1993) explored caregivers' perceptions of their needs, and the effect of their economic status on their prioritised needs. This study involved 49 families with children aged between 3 and 16 who had sustained mild to severe traumatic brain injury. Caregivers in both low and high-income families valued frankness

from health professionals, explanations they could understand, information provision, assured quality of care, and understanding. Personal needs, family support, and future patient-related concerns were not valued as highly.

Also along this line, Warzac, Allan, Ford, and Stefans (1995) investigated parents' and psychologist's perceptions of common problems in children's daily functioning after traumatic brain injury, ranking the frequency and severity of the problems. Forty-seven parent caregivers of children aged 2 to 19 years, and 49 psychologists were involved in this study. Caregivers identified obstacles to daily function in areas such as activities of daily living, safety, communication, cognition, emotional adjustment, perseverative behaviour, social function, academic function, and leisure activities. Obstacles most frequently identified by parent caregivers included the areas of emotional adjustment, safety, and social skills, with anger control rated as the most difficult problem. Modest but significant discrepancies were found between caregiver and professional evaluation of obstacles, highlighting the need to carefully explore the broader perceptions of caregivers.

The influence that parent coping has on outcomes for caregivers and children following paediatric traumatic brain injury has also been addressed in several studies (Rivara et al., 1992; Rivara et al., 1996; Wade et al., 2001). Rivara (1996) found that at 3-year follow-up, increased severity of injury in the children was associated with reductions in parents' coping resources, alongside increased family stress and an increase in parents' psychiatric disturbances. A more extensive study carried out by Wade and associates (2001) added to these findings. Wade et al's study involved 102 children with traumatic brain injury, and 71 children with orthopaedic injury matched for pre-injury characteristics and hospitalisation stays. Although results of the study were not conclusive, for both groups, associations were found between acceptance and lower levels of perceived burden, and between denial and greater levels of distress. Following traumatic brain injury, active coping was associated with higher distress, and the use of humour with lower levels of distress. Individual coping strategies however were not predictive of change in caregiver burden, stress, or family functioning. Rather, coping entered the arena of family and child outcomes as a moderating variable. While this is useful information insofar as assisting families to use appropriate coping

strategies during the process of adjustment to a child's traumatic brain injury, coping is a psychological construct, and does not necessarily involve occupation. The extent to which these findings might inform this study is limited.

Another variable that appears to moderate family outcomes is that of social support. A comprehensive study by Ergh, Rapport, Coleman, and Hanks (2002) found that parent perceptions of social support were strongly predictive of family functioning and that these perceptions had a robust mediating effect on levels of caregiver distress. The literature around adult traumatic brain injury includes studies that have investigated the mediating effects of social support on perceived levels of stress and burden for family caregivers (Degeneffe, 2001). Types of social support investigated include social work telephone liaison (Albert, Im, Brenner, Smith, & Waxman, 2002), education programmes (Smith & Testani-Dulfour, 2002), mentoring programmes (Hibbard et al., 2002), information provision (Kolakowsky-Hayner, Miner, & Kreutzer, 2001), instrumental support (Kolakowsky-Hayner et al., 2001), professional support (Kolakowsky-Hayner et al., 2001), and behaviour management programmes (Carnevale, Anselmi, Busichio, & Millis, 2002). The benefits of some of these programmes are variable however, and although effects have been found in terms of reduced levels of caregiver distress, these effects do not always approach significance (Albert et al., 2002; Hibbard et al., 2002). Ergh et al. (2002) emphasise that it is parents' perceptions of the support rather than the amount of support provided that is associated with improvements in family functioning, and it is possible this factor affected the outcomes of these studies. As with the employment of coping strategies to assist parents, it is unclear from these studies whether social support plays any role in caregiving occupations after a child has a traumatic brain injury.

Although the studies discussed here which investigate caregiving for children with traumatic brain injury have involved parent report of the family's and the child's function, all but one of them (Warzac et al., 1995) employed assessment tools such as standardised measures, questionnaires, and rating scales. While the results of the studies reflect parents' opinions, these are constrained by the questions incorporated in the tools. None of these tools investigated caregiving occupations. Additionally, the ability of the studies to

explain any of the processes that may be involved in caregiving is limited to the variables assessed. A small number of studies using qualitative methodologies have explored the experience of caregiving for children with traumatic brain injury from the parents' perspectives. These studies contribute further information about the issues involved for these parents, and give some understanding of the processes that take place.

### ***Qualitative Understandings of the Caregiving***

Three studies that sought to gain knowledge of the experience of caregiving for a child with traumatic brain injury adopted qualitative methodologies. While these studies do not focus on caregiving occupations, the studies sought to interpret and describe the meanings and understandings parents attached to their experiences. Although not providing a full picture, these studies provide some additional insights into the occupations and processes that might be taking place for primary caregivers, and complement the quantitative literature.

In particular, a study by Carson (1993) reveals some understandings of the different occupations that parents carry out when an adult child has a traumatic brain injury, and the way that these occupations contribute to adaptation by the child and parent. This was a grounded theory study which involved parents and their adult children in the USA, and it focussed on the experience of caregiving. Carson (1993) termed the theory "Investing in the Comeback" (p. 167), and described three phases parents moved through.

During the first phase of Centering On, parents initially stepped in and focussed on caregiving activities for the adult child (Carson, 1993, p. 167). Direct activities involved actually performing ADL tasks for the child, while indirect activities involved accessing and coordinating services and modifying the environment. During the second phase Fostering Independence (p. 170) possible options to enable the child to carry out personal care tasks and household tasks independently again were explored by parents. Participation in social activities was promoted. In the final phase of the process, Seeking Stability (p. 172), parents strived for long-term balance by maintaining the child's progress while leveling this against other family demands.

This study provides some understanding of the shifts in focus as experienced by parents when they adapt to the event of their adult child's traumatic brain injury and engage in caregiving. It is, however, uncertain how well this theory applies to the situation of younger children with traumatic brain injury or to a New Zealand situation. The children in this study were aged 17-34 years, and presumably required little parental support in carrying out their occupations before their injury, while younger children may not have achieved this stage of their development. Furthermore, the occupations of young children vary considerably to those of adults. Play is an important occupation for young children, and it is unlikely the parents in Carson's (1993) study needed to facilitate play activities. Additionally, the processes identified by Carson in this USA study might vary in a New Zealand setting where rehabilitation and funding may reflect the different avenues for service provision (Accident Compensation Corporation, 2003 a; Cronin, 2001).

Guerriere and McKeever (1997) also carried out a qualitative study of parents who were caregivers to children with traumatic brain injury, but in this case, the participants were mothers caring for children aged 3-13 years with severe disabilities. The aim of the study was to describe the subjective experience of caregiving and the relationship between the caregiver and child.

The study demonstrated that the mothers' self-identities and perceptions of the post-injury mother-child relationship had evolved through reflective thinking, and interaction with their children (Guerriere & McKeever, 1997). Mothers initially identified being shocked by their children's accidents, basing their understanding of the severity of the injuries on others' reactions. The mothers blamed themselves for the accident and felt they had no internal control over their lives. Life was viewed as a card-game, with these mothers experiencing the misfortune to be dealt a bad hand. The feelings of relief that came when their children regained consciousness were overtaken by grief with the realisation of profound changes. Although new understandings were formulated through "observing and interacting" with the children (p. 109), reflections on the lost child remained common.

The study provides a brief discussion of the skills that the mothers had developed such as caring for equipment, administering medications, and provision of physical therapy activities (Guerriere & McKeever, 1997).

However the study did not aim to explore of the occupations involved in the new caregiving role for these mothers, or the ways that their experiences impacted on what they did.

A third qualitative study of parents of children with traumatic brain injury shares similar themes. Smucker's (1996) unpublished study like that of Carson (1993) used a grounded theory methodology, but involved parents of young children. It was found that a process of empowerment occurred when parents approached unfamiliar challenges within the caregiving role. This process involved a circular sequence of learning, action, and reflection. The parents in this study described an initial learning stage when, in line with Carson's (1993) study, they discovered the changes in the child, and what the child's new needs were. In the acting stage, parents described the different types of work they had to do within the caregiving role, and the effect of the work on them. As in Carson's study (1993), tasks included tracking the child's needs, and accessing and coordinating resources and care for the child. During this phase, the parents took one day at a time, and feelings of burden were associated with inadequate time to balance household tasks with the care their child required. For some, isolation resulted from low levels of support from friends and professionals. In the reflecting stage, parents reviewed the outcomes of the work and what they had learned. Pleasure was experienced in the child's achievements and gains, and parents grew to understand and accept their own limits. Although parents' action formed an important part of this study, there is limited focus on the day-to-day components of this action or the way the action changed over time.

### ***Summary***

This chapter has reviewed the current literature relating to caregiving for children who have had a traumatic brain injury. The review has encompassed the sequelae that are involved for children, and both quantitative and qualitative aspects of caregiving. The literature tells us that traumatic brain injury in children results in ongoing neurobehavioural, psychoreactive, and physical sequelae. Delays occur in children's development of daily living skills, and behavioural changes impact on their psychosocial function.

Increased severity of injury, a younger age at injury, and pre-existing difficulties with behaviour result in increased levels of disability for the children.

The literature also provides evidence that parents who are caregiving for their children experience feelings of stress and burden, and are at risk of psychiatric sequelae. Family function deteriorates. Furthermore, the behaviour of the child, family function, and the parents' well-being are interdependent, and continue to influence each other over time. Particular features of family function that bear on outcomes for the child and family include activity levels of the parents, effectiveness of communication, flexibility of roles, the ability to problem-solve, the use of resources, coping styles, and the perception of social support. Parents spend increased time listening to and reasoning with their children, and feel emotionally closer to them. Although there is disagreement over how to best manage the child's behaviour, parents feel closer to their child. They may move through stages of carrying out daily living tasks for them, facilitating their independence, and balancing these activities with other household demands. The caregiving appears to involve an ongoing learning process for parents, and their actions and interactions result in a gradual adjustment to the changes in their child.

The collective information provided by these studies provides a partial picture of what might be occurring when parents are caregiving for children with traumatic brain injury. However the body of literature investigating caregiving for young children with traumatic brain injury is limited, and that which has been published has a focus on measuring psychological and social constructs relating to parents and children. Qualitative information to come out of studies particularly highlights the role played by parent-child interactions and occupations in mediating longer-term outcomes, making a case to gain a fuller understanding about what parents are doing to manage the problems they encounter with their children.

Despite this, there is little attention paid in the literature to caregiver occupations. Questions about what caregivers are actually doing on a day-to-day basis, how they are doing things, why they are doing these things, and what happens when they do them remain, for the most part, unanswered. The next chapter discusses the qualitative research perspective, the philosophical

understandings, and the grounded theory methodology used by this study in its endeavour to provide answers.



### **Chapter Three: Research Methodology**

This chapter begins by summarising the key features of the qualitative research perspective and the relevance of these features to this study's research question and aims. The fit of the qualitative perspective with the field of occupational therapy is discussed. Following on from this, the philosophical understandings behind the grounded theory methodology used in this study are explained in greater detail, with reference to the study's area of focus and to the researcher's own understandings.

The latter half of the chapter outlines the procedures involved in carrying out a grounded theory research project, based around an in-depth description, examples, and justification of those specifically used in the design of this study. Included are the particular methods used to access the field, gather and analyse data, ethical issues encountered, and the ways in which rigour was established.

#### ***Methodological Choice for this Study***

Studies of caregiving for children with traumatic brain injury have, as previously discussed, relied largely on quantitative methodologies, incorporating standardised measures to evaluate outcomes for children and their families. Variables are already identified within the measures selected or developed for the study, and the focus is on quantification of variables and proof of hypothesised relationships. Despite the gradual expansion of quantifiable knowledge used as a basis for therapies and supports, caregivers continue to experience stress and burden, and these factors impact on outcomes for the children (Taylor et al., 2001). Furthermore, such quantitative studies provide little information about what is involved in the occupations of caregiving for children with traumatic brain injury, or of the interactions caregivers use with these children on a day-to-day basis. Schutz (1994) advocates for greater use of qualitative research methods to increase our depth of knowledge. This study responds to that advice. My choice of the qualitative methodology of Grounded Theory has been directed by the nature of the

research question, but has also been influenced by my world-view as an occupational therapist.

### ***Research Question and Qualitative Research***

This study asks the question “what is involved in the day-to-day occupations of caregiving for a child who has had a traumatic brain injury”? The study aims to contribute to the development of a theory which explains the processes involved in the day-to-day occupations of caregiving for the child with traumatic brain injury, and to identify things that assist and things that hinder families during these occupations. The emphasis of the study is therefore on understanding caregiving occupations carried out in the context of daily life, on processes associated with these occupations, and on what caregivers see as meaningful in the performance of these occupations. The study endeavours to explain a phenomenon about which little is currently known.

Grounded theory falls within a complex group of research perspectives collectively described as qualitative. Qualitative research is implicitly associated with a need to understand processes and meanings. Within the qualitative perspective, studies explore the way reality is constructed through social interaction. Interaction between the researcher and the participants is directly acknowledged, and is utilised to increase understanding, whilst the impact of environmental factors on participants is actively explored (Denzin & Lincoln, 1998). This is in contrast to the quantitative perspective where researchers endeavour to avoid influence of the subject by the researcher and the environment.

The features of qualitative research correspond directly with many of the understandings occupational therapists hold about occupations (Cook, 2001). Occupational therapists recognise that occupations not only involve processes that are immediately observable and quantifiable, but also include invisible processes that can only be accurately understood through establishment of direct communication between the person seeking knowledge and those involved in the occupations (Cook, 2001). Occupations are seen as complex, dynamic processes, in which people formulate and reformulate

understandings, and maintain or change their capacities through interaction with particular physical and social environments (Kielhofner, 2002). Occupational therapists value the unique knowledge and meanings that people associate with their daily occupations, and see them as essential to understanding and collaboration (Cook, 2001).

Grounded theory is a well-established qualitative research methodology which employs an approach that is both inductive and deductive, rather than relying on deductions from pre-existing theories and assumptions. In this way, grounded theory is able to generate comprehensive explanations about little understood social phenomena, which are based on, and built directly from the data (Polit-O'Hara & Hungler, 1997). Hutchinson (1993) asserts that the aim of grounded theory is “to shed dogmatic beliefs in order to perceive reality more clearly” (p. 180). Hutchinson posits two types of grounded theory. Formal theory is associated with an abstract phenomenon which has already been conceptualised, while substantive theory is concerned with a more concrete domain of inquiry, and can be used to build formal theory. This study is directed at contributing to the generation of substantive theory. In line with the aims of this research, according to Strauss and Corbin (1990, 1998) this methodology enables formulation of theory grounded in real life situations and, by explaining reality, it is able to provide a strong framework for the development of action strategies.

### ***Philosophical Understandings***

Grounded theory methodology rests on the philosophical understandings of symbolic interactionism, which has its roots in the field of social psychology (Charon, 2001). Mead (1934), a leader in the development of this theoretical approach, was a philosopher who held that individuals formulate a sense of self through social interaction within roles. He was concerned with the way that individuals create meaning from events and reality, and with the way that individual and shared beliefs guide actions. Mead believed that through social interaction, the symbolic meanings of objects, gestures and language become shared and understood by groups. Blumer (1969), another key figure in the development of this approach, advanced three

key assumptions of symbolic interactionism: (a) people's actions are based on the meanings that things hold for them, (b) this meaning evolves from interaction within a particular social context, and (c) meanings are interpreted and changed as individuals deal with the things and events they encounter.

Through these understandings, symbolic interactionism is able to provide a basis for thinking about the way caregivers of a child with traumatic brain injury might be influenced by the meaning of their occupations and interactions, and the way changes may come about during the caregiving process. Guided by Mead's thinking (1934), my perception as a researcher is that my interaction with the caregivers is essential in order for me to understand their occupations. This thinking also suggest that the caregivers will make new meanings of their occupations through the interactive processes involved in contact with the researcher.

In line with the aims of this study in gaining understanding of the processes involved in the day-to-day occupations of caregiving, symbolic interactionism is built on an interpretivist philosophical approach. Interpretivism bases knowledge on interpreted understandings of the real world and its meanings (Crotty, 1998). Thus, the researcher is required to work cooperatively with caregivers, to examine and accurately interpret the symbolic meanings behind their occupations, interactions, and words into language and theory that can be understood and shared by others. Existing research around paediatric traumatic brain injury has largely involved an explanatory positivist stance, claiming freedom from interpreted meanings. This position may not be yielding the social understandings necessary for a theoretical basis on which to design interventions to best equip caregivers to carry out the occupations within their changed role.

Symbolic interactionism is also informed by a constructionist epistemology. Taking this view, the assumption is that meaning and knowledge are constructed by humans as they interact with and interpret their world (Crotty, 1998). In this way, human experience and objects within the world should not be described in isolation from each other, as they are interdependent in building meaning. It is conceived that caregivers' understandings are constructed during their interactions with people and the physical environment in the context of caregiving occupations. As such they should be seen together

within this context for others' fullest understanding to come about. Within these understandings too, it reasons that that the researcher is able to construct theory out of the interpreted meanings of participants.

The pragmatist philosophy behind symbolic interactionism (Charon, 2001; Crotty, 1998) reinforces this view, and promotes the study of values and meanings relative to real-life practices and practical outcomes in social groups. This philosophy fits with my own perspective as an occupational therapist, and my interest in meanings, values, and changes as they affect people's occupational performance in their own environments (Kielhofner, 2002).

### ***Grounded Theory Methodology and Design for this Study***

Originally developed by Glaser and Strauss (1967), the grounded theory approach proposed a specific set of procedures for generating theory, including addressing preconceptions and existing knowledge, selection and collection of data, and analysis of data (Dey, 1999). The later publication of "Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory" by Strauss in collaboration with Corbin (Strauss & Corbin, 1990) resulted in ongoing debate between the authors and their various proponents (Dey, 1999). This study adopts the grounded theory approach put forward by Strauss and Corbin in 1998. The approach provides detailed guidelines for the analysis of data, and a paradigm is outlined to aid understanding of the conditions affecting phenomena. Through the use of Strauss and Corbins' structured approach it is hoped to assist rigour of data and results.

### ***Sampling Strategy***

Sampling within Grounded Theory methodology is purposive, and employs theoretical sampling. Within these parameters, the need to gain data relevant to the emerging theory directs the search for further information, and sampling occurs reciprocally with data analysis. Because the focus is on phenomena related to people's actions and interactions, sampling is generally guided by the need to gather information about particular incidents rather than demographic characteristics. Sampling ideally ceases when no new data appears relating to the categories, and both categories and their relationships are adequately developed (theoretical saturation). However it is acknowledged

that there are inherent difficulties in categorically defining a point at which no new information is emerging, and consideration is given to the impact of time and money constraints on data collection processes (Strauss & Corbin, 1998).

### *Access to the Field*

The setting for this study was that of the greater Auckland area in New Zealand. This area has a large urban population, and is where relatively high numbers of children with traumatic brain injury are based. It was hoped these numbers would give greater scope in terms of the purposive sampling technique (Strauss & Corbin, 1998). It was expected that this would be particularly important as the study progressed in the event that additional participants needed to be sought to provide further exploration of emerging concepts.

In New Zealand, children with traumatic brain injury who no longer require inpatient services are referred by ACC for any further rehabilitation needs to private therapy providers in the community. As the paediatric rehabilitation service in which I am employed is based in the Auckland area, I was familiar with several of these therapy providers, and anticipated that this relationship could facilitate the recruitment process. Initially one group of providers was approached for assistance with access to the field, then, as more participants were needed, another group was also contacted.

Access was gained to the field in accordance with the ethical principals required by the Auckland Ethics Committee, minimising risks of coercion and ensuring informed consent was obtained. The managers of the provider groups were contacted by telephone, the study was introduced, and support was gained for the researcher to approach the therapy teams regarding their assistance with accessing participants. For the first group, arrangements were made to attend the next team meeting, where therapists were provided with written summaries of the study, and packages to give to families who met the inclusion criteria. Each package contained an information sheet, consent forms for the parents and children with traumatic brain injury, a caregiver details questionnaire, and a stamped addressed envelope (Refer to Appendices A, B, & C). For the second group, a meeting was held with the senior occupational therapist who undertook to inform clients about the study herself.

Therapists were requested to provide a brief verbal introduction of the study to families who met the inclusion criteria, and to give them each a package. Therapists were encouraged to stress to families that participation in the study was voluntary, and would not impact on their therapy in any way. Parents who were interested in taking part in the study then completed the consent forms and questionnaire at their leisure, and returned them to the researcher in the stamped addressed envelope. The questionnaire was used to gain brief demographic data, contact details, and families' understandings of their children's skills to assist the theoretical sampling process.

Although the study sought to include both parents and family caregivers, it was planned that the parents would be approached initially in terms of gaining informed consent. This was to acknowledge the parents' role as the legal guardians of their children (Greig & Taylor, 1999). As it eventuated, all those parents who returned informed consent were also the main caregivers, and no other family caregivers were involved in the study.

On receipt of returned consent forms and questionnaires, the researcher contacted the families by telephone, thanked them for their support, and made tentative times for initial interviews. Due to the need to analyse data as it is gathered when using a grounded theory methodology (Strauss & Corbin, 1998), time delays between initial contact and interview time were expected to occur. Therefore this method of accessing participants did risk families dropping out of the study before the time fell due for their interview. To minimise this risk, when families were initially contacted, the possibility of time delays was explained, with all those who returned consent forms remaining in the study.

### ***Participant Selection***

Parents and family caregivers of a child who had sustained a severe traumatic brain injury met the criteria to be included in the study provided the child was aged 3-17 years, the injury had occurred at least three months previously, and the family was living in the greater Auckland area. It was felt that a time period of at least 3 months from the time of injury would allow for the child to have been discharged from inpatient settings. This time period also enabled recruitment of participants who had adequately experienced the

phenomena of interest, assisting the richness of the data gathered. A wide range of ages was allowed for in order to explore caregiving activities across a broad spectrum. Another requirement was that families could express issues and ideas in conversational English. This was in order that understandings conveyed in the dialogue could be optimally interpreted by the researcher. No families who had a child receiving therapy through the researcher were accepted onto the study to avoid coercion, biases, or a conflict of interests.

As limited numbers initially responded to the invitation to be on the study, all the families who gave informed consent to take part were accepted. It was anticipated up to 10 families would be needed to participate in the study. Eight of the families approached by therapy providers returned consent forms and questionnaires. One family who was accepted onto the study was referred shortly afterwards to the researcher's own employment setting, and this family was notified that participation in the study was no longer possible. Interviews were completed with five families and observations were carried out with four families before adequate saturation of the categories was reached. The total time spent in interviews and observations was 19 hours. At this point when a theory emerged and variations could be explained, no further data was gathered from the families. Two families who had been accepted onto the study but who were not included were contacted and thanked for their support, and were invited to attend a presentation of the findings.

### ***About the Participants***

Both male and female parent and child participants were involved. Two families were single parent families. For two families, both parents were present at interviews and observations. Participants included two Maori families, one Pacific Island family, and two New Zealand European families, one of Jewish religion. The children ranged in age from 4 through to 11 years. There were no adolescent participants. All the children were independently mobile, and none were reliant on technology for feeding or communication. The following table provides basic background details of the participants. Details are limited and some more minor details have been altered to avoid possible identification of participants.





### ***Data Collection***

Grounded theory studies may employ a variety of modalities to collect data, including different types of interviews, observations, and incorporation of existing theory. The methods used to collect data must be relevant to the research question and aims, and must also be feasible to implement with the group being studied (Gerson & Horowitz, 2002; Strauss & Corbin, 1998). Gerson and Horowitz (2002) put forward the benefits of incorporating a combination of interviews and observations, which they identify as supporting each other and therefore lending strength to the study.

This study initially employed both semi-structured interviews, and participant observations. Interviews and participant observations fit with the study's aim of gaining understanding of a phenomenon about which little is currently known, while capturing dynamic processes across time, exploring meanings, and learning about actions and interactions in the participants' day-to-day environments. Interviews particularly provide a means to explore people's understandings and the meanings things hold for them, as well as a way of exploring changes over longer periods of time, while observations are a modality which can provide insights into actions and interactions in the participants' real life world (Gerson & Horowitz, 2002).

Interviews were semi-structured, and the initial four interviews followed the schedule in Appendix D, with the intention of establishing rapport, and of gaining a broad and open understanding of the occupations caregivers themselves identified as important, the children's responses, and changes that might have occurred (Mason, 2002; Strauss & Corbin, 1998). The interviews were audio-taped and were approximately 1 hour in duration. Ethical approval had been sought to carry out up to two interviews and up to two periods of observation with each family. However, after discussion with supervisors, it was decided not to proceed with a second period of observation due to density of data already gathered and constraints associated with a master's level thesis.

Caregivers were given a choice of venue for the interviews, and four of five caregivers elected to carry out interviews in the home. This created some challenges in terms of interruptions and noise from the children, but provided valuable insights for the researcher in terms of the demands inherent in the

caregiving role. Caregivers showed sensitivity in their conversation about problems in front of the children, either engaging in open discussion of any difficulties with the children, or waiting until the children were out of hearing distance. The presence of the children did not appear to place limits on the issues caregivers were able to share.

The interview opened with a brief introduction to the study, reminding participants of their rights, and checking that they were comfortable to proceed with the interview. The schedule of questions was used as a guide only, and flexibility was used in exploring caregiving occupations directed by the perspectives of the caregiver. Efforts were made by the researcher not to “lead” or pre-empt the caregivers’ responses, whilst still maintaining the dialogue around caregiving issues. Brief notes were taken during the interviews of key points and issues that required further questioning. Themes which emerged and points which required further clarification were reflected back and followed up in an unstructured way. Prompts along the lines of those on the interview guide (Appendix D) were employed to elicit further depth of information or to clarify points.

Initial interviews were followed by participant observations with four families in the home environment. Field notes were taken during observations. Observations lasted between 1 and 3 hours, dependent on caregiving routines and the energy levels of the child with traumatic brain injury. During observations, the researcher interacted with the child and caregiver as necessary and as seemed natural. Observations of the caregiver/child actions, interactions, and environments were written up in narrative form afterwards. These formed a background to information obtained during interview and also provided a way of confirming information and interpretations.

Strauss and Corbin (1998) explain that theoretical sampling is directed at seeking information around events, incidents, and happenings, and need not necessarily involve seeking particular persons. As initial data was analysed and compared with data from other participants and observations, follow-up interviews with three of the participants and an initial interview with the fifth participant incorporated theoretical sampling techniques, where particular information was sought around specific categories, their relationships, and their dimensions (see sample interview guide, Appendix E).

Illustrating this process, during the second interview with Simon's mother, the following question was posed by the researcher to gain further density of data around the subcategory of "understanding". *"A lot of families have talked about support people, being understanding. What do you see as understanding? What is it they understand about?"* Theoretical sampling also required questions to follow up characteristics that could have been contributing to different dimensions within subcategories. For example, during an interview with Bailey's mother, the researcher asked *"Do you think the challenges for you of keeping that routine and monitoring the fatigue but still letting her join in and do some things, do you find that's getting harder as she gets older? Why do you think that is?"*

As data analysis progressed and a central category became apparent, descriptive themes that were present in the literature were then introduced as a secondary source of information. These themes contributed to the density of data around the central category. In line with theoretical sampling techniques, relevant data from existing literature can be incorporated into a grounded theory study to contribute further perspectives and information about emerging concepts (Strauss & Corbin, 1998). Sampling ceased when all new information was explained by the theory that had been developed, and no further concepts were emerging.

### ***Ethical Considerations***

Ethical consent to proceed with the study was gained from the Auckland Ethics Committees and from the Auckland University of Technology Ethics Committee. An analysis was made of possible risks to families and also the possible benefits to families of taking part.

The likelihood of harm occurring to caregivers or children was considered to be extremely low. However, caregiving for children has been linked with stress, and the emotional impact of a child's traumatic brain injury is also considerable. Consideration was given to the possible tensions involved around discussion of these issues. Additionally, although interviews were of a similar length to a routine therapy session (1 hour duration), observations were proposed for 3-hour blocks, with the possibility of families feeling uncomfortable with having an unfamiliar person in their home.

Before beginning data collection, parents and family caregivers were reminded of their right to terminate the discussion or observations, delete material from tapes and transcripts, and of their right not to answer any questions they felt uncomfortable with. Families were able to nominate to have a support person present if they desired, and were made aware of the option of referral to a medical practitioner or ACC in the event they required support with any issues that emerged.

Although no children were directly involved in the interview process, both the child with the traumatic brain injury and siblings were present during 10 of the interviews and observations. Greig and Taylor (1999) emphasise the ethical requirement to facilitate children's understanding of their involvement in any research project and to gain their informed consent through appropriate means. Informed consent to participate was sought from the children with traumatic brain injury who were given a verbal explanation by therapists, and who then either signed a simplified consent form (Appendix B) or indicated their consent verbally. Consent was not sought from siblings, as they were not the focus of the study.

Possible benefits to participants included the opportunity to have thoughts and concerns heard, and access to reports. During interviews and observations families expressed that they felt that the study was based around important issues, and were positive about their participation in terms of a contribution to improved understanding around children's traumatic brain injury.

Because the study involved the researcher's entering people's homes, cultural respect was an important aspect of the study, and sensitivity was shown for individual cultural issues during interviews and observations. Two Maori families participated in the research, but preferred not to involve any specific cultural supports.

All audio-taped and written data were treated confidentially and were only available to the researcher, her supervisors, and a confidential transcribing typist. Pseudonyms were used in all written materials, and a code known only to the researcher was used to relate names to pseudonyms. In writing the thesis, the use of quoted materials which might enable identification of the participants was avoided. On completion of the study, audio-tapes were erased.

Typed transcripts and electronic data will be stored securely in a locked cabinet at the researcher's place of work for up to 10 years, before being destroyed. Families were given copies of their own transcripts and observation notes, and were given the opportunity to have edited any statements they may have had a concern with. None of the families expressed concerns with the transcripts or notes.

### ***Data Analysis***

Interviews were transcribed then checked and corrected by the researcher. Copies of the transcripts and of the narratives were given to participants who were encouraged to check them, and contact the researcher if there were any parts they felt were inaccurate or wished to be changed.

Grounded theory methodology entails the simultaneous analysis of data with the interview and observation processes. This process is called constant comparative analysis, whereby data analysis from initial interviews guides and is constantly compared with the data given during subsequent interviews. Three overlapping stages of data analysis are proposed, including open coding, axial coding, and selective coding (Strauss & Corbin, 1998). The following discussion utilises an example of the progression followed for one code from the study to illustrate the data analysis process.

In the first stage of data analysis called open coding, transcripts were analysed and coded line by line, taking apart sentences and phrases to consider the meaning of phenomena, and labelling each abstract concept or idea with a name capturing its meaning. Characteristics of concepts during this stage were compared with other concepts that emerged. Names given to the concepts arose from the researcher's own thoughts, from existing literature, or were words or phrase in the data which delineated the essential meaning of the concept (an "in-vivo" code) (Strauss & Corbin, 1998, p. 115).

The following phrase from the data was originally labelled and coded under "safety", as the phrase was concerned with the safety risks to the child following their head injury.

I suppose for safety you are conscious of safety. You are conscious of further head injuries. That's probably the main thing. [Theresa, I1]

Concepts of “risk of further head injury”, “knowledge of implications”, “need for vigilance,” “explaining to others,” “physical risks,” and “behavioural risks” were also grouped under the code “safety” as a key category, as they all appeared to be primarily concerned with the safety needs of the child.

During this open coding phase of data analysis in grounded theory, the process of developing categories in terms of their properties and dimensions was begun. Information was accumulated about each category to understand its special features and how these features ranged along a continuum. “Physical risk” was identified as a property of safety, and was found to involve the child’s clumsiness and fatigue, ranging in terms of frequency and severity.

She just whoops. She’s always got greasies on her shoes. [Rona, I1]

She was very, clumsy. I was always scared she was going to trip. [Rona, I1]

It seems to be that she gets more clumsy, falls over and stumbles and trips...it becomes more noticeable with her when she’s tired. [Rona, I1]

The second stage of data analysis, axial coding, involved the linking of categories to subcategories along their properties and dimensions (Strauss & Corbin, 1998). Subcategories are those categories which provide information about a key category, such as “when, where, why, who, how, and with what consequences” thus helping to explain the category (p. 125). At this stage, a further category associated with “safety”, “fear”, was becoming apparent (see Rona’s quote above). It was identified that more frequent and more severe physical safety risks and increased knowledge of consequences were both associated with increased levels of fear in the caregivers. Theresa, whose son had more marked physical risks, and more severe repeat injuries than Rona’s daughter describes her concerns as follows.

You know you can’t have another one, and he’s had a couple of minor ones since then, but he had quite a bad one at kindy last year where he definitely lost consciousness... [Theresa, I1]

Because you’ve seen your child lying unconscious in the Starship and thought “is he dead or not”. You don’t really, can’t face going through that, and also you are told from day one at the hospital he cannot afford to have another one. He cannot afford to have another one. You know this is going to have really more serious effects than the

first one. You think, “I can’t even cope with this one. How can I cope with another one?” [Theresa, I2]

Organisation of the data during axial coding was assisted by the use of the conditional paradigm (Strauss & Corbin, 1998). The paradigm provides a scheme for ordering the connections between categories and subcategories, and identifying the differences between causal, intervening, and contextual conditions, actions/interactions, and consequences involved with a category. Categories were tested for their fit within the paradigm and with new data as it became available, and were recoded in line with their ability to support answers to the researcher’s questions about the emerging theory.

Using the paradigm, later in the axial coding process, when considering the question “what does safety involve?” it became evident that the category of “Safety” was in fact a subcategory, and was involved both as a contextual condition (i.e. the context in which actions/interactions occur) and as an action/interaction (i.e. things that people do or say in response to situations) (Strauss & Corbin, 1998). When children were perceived as having a high safety risk, people who were fearful responded with strategies to maintain the safety and lower or prevent the risk. Rona reported responding to her daughter’s clumsiness in the following way:

Just Katie, I’m standing beside the playground...Right beside her. She has a free rein, but I’m right there. I would want to be there just in case”. [Rona, I1].

This response was also observed during participant observations. Taking into account the links that had been previously identified between “Safety” and “Knowledge of Consequences”, the category of safety was then re-coded into two separate categories, as a contextual condition “Learning the Dangers”, and as an action/interaction “Protecting”.

During the third stage of data analysis, selective coding, the emerging theory was integrated and clarified. Relationships between categories were confirmed, and a core category which was central to all other categories and which depicts the main theme of the research was formulated (Strauss & Corbin, 1998). As data analysis had progressed, it appeared that two key interdependent processes were involved with the caregiving. Initially



caregivers were endeavouring to “Hold Things Together” (ie. contain factors contributing to physical and emotional dangers for their child), and later also made efforts to “Join Their Child With Others” (i.e. social interactions with others). These categories are explained more fully in Chapters Four and Five.

Earlier in the phase of axial coding, it seemed that the core category was about caregivers achieving a balance between “Holding Things Together” and “Joining My Child With Others”, and a central category of “Balancing” was explored for its fit with the data. However, this category was not adequately supported, and ongoing data collection specific to the two key categories identified that caregivers in fact maintained some degree of focus on “Holding Things Together” throughout the process of “Joining My Child With Others”. Additionally, the overarching concerns for the future and towards which the two key processes were directed, were for their children to be able to keep themselves safe in the future and to be able to succeed in their endeavours within the community. The two processes were both involved in putting in place a structure for these things to occur, and the central category “Structuring for Security” was arrived at.

During these coding processes, memos were written as questions, ideas, reasoning, hypotheses, and strategies for following up issues of concern with theoretical sampling arose (Appendix F). Memos serve to support conceptualisation and abstraction of concepts from raw data, and assist in recording analytical processes (Strauss & Corbin, 1998). During this study, memos questioning concepts that required further exploration frequently resulted from open and axial coding sessions. Earlier memos were focussed on naming and comparing categories, while later memos tended to consider the way different categories related to key processes and the possible central category. Ongoing diagramming was incorporated into memos as a way of picturing processes that might be occurring, and to assist in testing and understanding relationships between categories .

### ***Framework and Methods Promoting Rigour***

Glaser and Strauss (1967) propose that rigour in grounded theory studies is founded on the detailed strategies used to gather and analyse the data.

This view is supported by Brink (1991) and Denzin (1994). Brink states “the Glaser and Strauss methods follow a rigid protocol for data collection and analysis that essentially eliminates the problems of reliability” (1991, p. 180). The grounded theory approach adopted for this study (Strauss & Corbin, 1998) provides comprehensive and systematic procedures and tools to support grounding of the theory in the data. Included are in-depth discussions of the procedures used for the different coding stages supported by examples, and careful explanation of tools used in analysis, including microscopic examination of data, questioning, comparing, and the use of memos and diagrams. The synchronicity of data collection, data analysis and sampling assists in ensuring that the evolving theory grows out of the data itself and that data which does not fit is explored and explained in terms of its variability.

Strauss and Corbin (1998) devote a chapter to evaluation of the research process and the adequate grounding of study findings, and suggest a number of criteria to this end. The importance of explicating the criteria employed is acknowledged. However, the chapter does not contain an overall framework from which to consider the wider range of rigour issues that may require consideration. Strauss and Corbin (1998) allude to several of these issues such as the need to evaluate the research process, the grounding of the theory in the data, and adequate development of the theory, but refer the reader to a variety of other texts. The tenor of their advice is that the canons for evaluation of quantitative studies may require change before application in qualitative inquiries.

In line with Janesick (1998) and Strauss and Corbin (1998) I believe that the more traditional positivist understandings of validity and reliability require refashioning to fit with the interpretive aspects of qualitative research, and that different strategies are also required. Maxwell (2002) presents and justifies a model that outlines five different canons on which the legitimacy of qualitative research can be established. Maxwell’s notion of validity sees it as related to the different levels of understanding implicit to qualitative research projects. Using a realist rather than an instrumental approach, he argues that validity is not necessarily reliant on the existence of an exact truth or reality which may or may not be adequately proved by a recipe of strategies, but that it

is relative to the view taken by the investigator and the phenomena being investigated.

Maxwell's (2002) approach is cohesive and embodies the issues discussed in Strauss and Corbin's chapter on criteria for evaluation (1998). I have adopted this framework as the basis from which to consider features of this study which facilitate rigour. The five different levels of validity and the ways in these aspects of this study have been promoted are outlined below with reference to the particular issues raised by Strauss and Corbin (1998).

1. "Descriptive Validity" refers to the accuracy of the actual materials used in the study, such as recordings, transcriptions, and field-notes (Maxwell, 2002, p. 45). All interviews in this study were recorded using two audio-tape machines, so that in the event of a lack of clarity on one machine, transcribing could still be accurately guided by the other machine. As it happened, children were often present during interviews, and noise from their play distorted recordings on occasion. Any uncertainty over words actually used at these times was represented in transcriptions by a question mark, and the unclear words were omitted. Audio-tapes were initially transcribed by the researcher herself, and after transcribing were re-checked for accuracy. Later, a typist transcribed taped interviews, and these were checked by the researcher.

Field notes taken during observations focussed on what was directly observed and notations were made of discussions between the children and their parents. The aim was to increase descriptive validity through a focus on things actually seen or heard during the gathering of data rather than inclusion of interpretive comments at this stage. Inconsistencies or uncertainties were then checked with participants at a later interview. Observations in the home environment were written up within one week of the visit to assist accurate recall of what was seen and heard.

Participating caregivers were provided with copies of their transcribed interviews and narratives, and were invited to read them at their leisure and to contact the researcher if they felt there were inaccuracies or if they wanted material deleted or changed. A direct request that they check the transcripts was avoided, as this would have placed significant demands on participants. While it is possible that participants may not have read the transcripts, none of

the participants re-contacted the researcher requiring material to be altered, increasing confidence in the descriptive validity of the study.

2. “Interpretive Validity” is the term Maxwell (2002) applies to the study’s accurate interpretation of the participants’ understandings about phenomena, actions, and interactions (p. 48). Prior to beginning this study, the researcher was interviewed by a peer to assist awareness of pre-conceptions and biases that could affect interpretation of data. The interview was recorded and analysed by the researcher and the supervisors. Based on clinical experience and literature, my preconceptions included that parents would have increased feelings of closeness to their child, that they would spend time protecting their child against cumulative head trauma. There was an expectation that parents would probably spend time re-structuring their physical environment for the child, and I anticipated that there would be an early focus on the physical skills of the child, although the child’s behaviours would be of concern. I was aware that parents would be moving through a process of adjustment and grief, and that they would experience the transition from inpatient rehabilitation to the community as frightening with the increase in responsibility.

As data analysis progressed, some of these preconceptions were partially borne out, such as parents’ closeness to the child, their efforts to protect their child physically, their concern with behaviour, and reconstruction of the environment. What had not been anticipated was that they were also actively involved in protecting the child against their behavioural outbursts, and that fear arose more from worries about their child’s safety than from responsibility. My assumption regarding parents’ focus on physical skills was correct insofar as they contributed to enabling the child to be safe, to progress, and to do things with others, and other skills in this context were also considered important. An unexpected finding was that structuring extended well beyond the environment to included structuring of the whole day and of the activities that took place during the day.

During the data gathering and data analysis stages of the study, the researcher’s thoughts and responses to interviews and observations were noted in a journal and reflected on, to gain awareness of and avoid any distortion of the meanings being interpreted from the data. An initial practice interview was

also carried out with a person who was not part of the study, and this interview was reviewed jointly by the researcher and her supervisors to help the use of interview techniques which were guided by participants' understandings rather than the researcher's own thoughts and perspectives.

At this level, validity was assisted by the grounded theory methodology. As suggested by Strauss and Corbin (1998), where possible, concepts and categories were described by "in-vivo codes" using the participants' own words (p. 115). As concepts were generated, the meanings of these concepts were checked back with participants, initially using probes and checking meanings (see Appendix D). Interpretation was also supported through observations, when greater insight and depth of understanding of the issues described by participants was obtained. As data analysis progressed, further checking of emerging categories was carried out at second interview (see Appendix E) and across participants, aiding accurate interpretation of meaning and understanding of variation.

The correct interpretation of data was also facilitated through the supervision process, when codes and their meanings were reviewed with senior lecturers at the School of Occupational Therapy. Their understandings of the codes as described after analysis were checked against the researcher's own understandings of the meanings, with disparate understandings guiding further analysis, data collection and sampling.

3. "Theoretical Validity" is the ability of an account to function as a legitimate abstract description and explanation of the phenomena, their relationships and the processes, pertinent to the situation being studied (Maxwell, 2002, p. 52). These latter two types of validity described by Maxwell (2002) encompass the criteria for evaluation described by Strauss and Corbin (1998), which examine the research process and the empirical grounding of the study. Checklists provided by Strauss and Corbin (1998) focus on ascertaining that logical data collection and analysis was used by the researcher to reach decisions about categories and explanations, and that these categories and explanations are grounded firmly in the data.

In response to these concerns, this chapter has endeavoured to incorporate dense description of the research process and an example of the coding process to illustrate the ways in which the theory was developed.

Chapters Four, Five, and Six which describe the theory use dense description of categories based on the data to facilitate understanding of the logic used.

Memos were made throughout the data analysis process, and were reviewed by the supervisor along with regular discussions about the emerging theory to check that the theory made sense and was cohesive, that theoretical formulations steered data collection, that hypotheses relating to relationships among categories were based on logical deductions, and that justification for analytical decisions were based in the data. A group to support students carrying out grounded theory studies was also attended, and the emerging theory has been presented and critiqued by peers and by lecturers experienced in grounded theory studies.

Glaser (2002) warns against over-emphasis being placed on the use of participants to evaluate the theory as a test of validity. He advises that participants may not fully understand the abstract theory which may explain a much bigger picture of patterns of behavior, of which their own is only a part. In contrast, Strauss and Corbin (1998) suggest checking the theory with participants, stating that they should be able to recognise their own part in the bigger story. As this study has been guided by Strauss and Corbin's model (1998), the emerging categories and theory were checked with several participants, to see that they accurately applied to their situation. These participants were satisfied with the theory as an explanation of what was occurring, and identified strongly with a number of the concepts.

Theoretical validity can also be ascertained through consideration of its situation to current literature and Strauss and Corbin, (1998) propose that the literature can be used to corroborate findings. The final chapter in this thesis compares the logical fit of the theory with existing knowledge and understandings. In this chapter, many areas of compatibility are identified, and reasons for variations are explored.

4. "Generalizability" is the degree to which the account is valid for other people, periods, or environments (Maxwell, 2002, p. 54). Emphasis is given by Maxwell to the particular need to establish the level of internal generalizability of the theory relative to other time frames and environments for the group involved. This chapter has provided demographic details relating to the gender, age and functional level of the children involved, details about

the caregivers, and the time frames since the accident, in order to identify the population on which the theoretical sample was based, and against which other applications can be compared. The two interviews completed with four of the participants were made several months apart, assisting the degree to which the categories held true to wider time frames. Additionally, the interviews explored caregivers' concerns relating to caregiving outside the home environment, this eventually forming a central theme in the study.

Although the sample included children of a variety of ages and cultures, for the purposes of this Master's level study, the sample is relatively small, limiting the wider application of the theory beyond the features of the sample. Further studies would be needed establish the applicability of the theory to other populations, such as adolescents, or children with more severe physical disability.

5. "Evaluative validity" is the term used by Maxwell (2002, p. 57) to describe the application of the researcher's or other's value systems to the account. Maxwell sees this category of validity as less central to qualitative research, as qualitative researchers do not routinely make claims to critique the phenomena forming their theory on the basis of particular perspectives and values (eg. from a feminist perspective, or a critical theory perspective). Crotty (1998) points out disparities between the worlds of the symbolic interactionist and the critical theorist. While I have deliberately endeavoured to identify my personal understandings and biases as the research has progressed, and to identify when they have impacted on my interpretation of incidents, the final chapter of this thesis does evaluate the theory against my understandings as an occupational therapist.

This chapter has introduced the grounded theory methodology employed in this study, and justified its choice in relation to the research question and aims. The philosophical understandings underpinning grounded theory methodology have been explained, and their fit with the researcher's own understandings has been described. The methods used to gather and analyse data have been explained and the ways in which rigour has been established have been outlined.

## **Chapter Four: Holding Things Together**

### ***Introduction***

The three chapters that follow present the findings of the study. The findings are drawn primarily from data obtained during interviews held with caregivers, and are supported by observations of caregivers' interactions with the children. Themes from surrounding literature are used to contribute further understanding of the concepts that emerged around the central category.

Two distinct but interdependent caregiving processes emerged from the data. These processes are named Holding Things Together, and Joining My Child With Others. The two processes were ongoing, and while commonalities were shared between participants, individual variations were apparent with regard to the degree of their involvement and the effectiveness of their actions within the processes at different points in time. Holding Things Together and Joining My Child With Others were found to be embodied within one central category, Structuring For Security. This category provided a comprehensive explanation of that which was occurring for caregivers and children during both the processes. In this chapter, the first process, Holding Things Together is examined. The second process, Joining My Child With Others is examined in Chapter Five, and the central category, Structuring For Security is addressed in Chapter Six.

Holding Things Together refers to the phenomena involved when caregiving actions are directed towards managing distressing events resulting from the child's injury. The dynamic relationships between the categories and subcategories comprising Holding Things Together are represented for the reader using Strauss and Corbin's conditional paradigm (1998). The paradigm is a framework that provides a systematic way of understanding the ways categories relate to each other and the part they play in a process: Causal conditions involve the things or events that play a part in triggering a person's response; contextual conditions are the circumstances within which people are responding; intervening conditions are the factors which might alter or affect



people's responses; actions and interactions are people's responses, or what they do and say; and consequences are the outcomes of the actions and interactions.

Excerpts from interviews and observations illustrating the different categories, subcategories, variations, and processes are presented throughout the findings. The source of each excerpt is identified in brackets using the parent's or child's pseudonym followed by I1 or I2 to indicate first or second interview, or Obs to indicate observations (for example, [Rona, I2], [John, Obs]). Within the text, the categories and subcategories are written as names, using upper and lower case font, (for example, Recognising Signs) to assist in distinguishing them from interview or observation excerpts.

### ***Holding Things Together***

Holding Things Together grew from the data as one of the two caregiving processes that the parents were involved with on a daily basis. The following table lays out the different categories and sub-categories that comprise the process of Holding Things Together (Strauss & Corbin, 1998).

**Table 2**

#### **Holding Things Together**

<b>Paradigm Component</b>	<b>Categories</b>	<b>Sub-categories</b>
Causal Conditions	Black Days	The Accident A-Z Change Losing It
Contextual Conditions	Learning the Dangers	Becoming Aware Alert to Threats Recognising Signs Fearing Further Knocks
Intervening Conditions	Close Support	Going Through it Together Working Together
Actions/Interactions	Protecting	Doing With, Doing For Guarding Safe Routines
Consequences	Getting Through	Knowledge Seeing Progress Handling It

The notion of Holding Things Together incorporates the understanding that things are in turmoil for the families following the accident, and that it is necessary for parents to work actively to prevent their own and the children's lives flying apart further, and draw things safely back in again. Words used by parents depicted this sense of things falling apart, and their efforts to contain them.

Black Days are the way parents see the changes in their own and their child's lives following the accident and these are the conditions that cause them to begin the caregiving process. While in a context of Learning about the Dangers facing the child, parents begin actively Protecting them from further harm. This process is mediated by the amount of Close Support that surrounds them. As a result of their actions, parents identify a sense of Getting Through for both themselves and the child.

The chapter now moves on to consider each of these categories and subcategories in detail, providing each category with a definition, outlining the relevant properties and dimensions and discussing the connections with other categories and with the process of Holding Things Together.

### ***The Cause: Black Days***

A child's accident and brain injury create situations that leave parents with little choice but to endeavour to Hold Things Together for their own and the child's safety and wellbeing. Parents perceive the situation after the accident as a time of disorder, and darkness, with feelings similar to that of being unable to escape the grip of a bad dream. Almost all parents referred to this time as a "*nightmare*". "*Black Days*" was a term used by John's mother [11], and has been used here as it implies sudden and complete change: day turns to night, everything is dark, and it is not possible to see where you are going. Black Days are associated with storms, where the elements become frightening and destructive. Black is also a colour in our culture associated with death and loss.

Terrible ...I call them my "black days" because when I came home and the doctor said right, you will need to spend most of the 6 weeks at home with him .... and after 2 weeks he hadn't slept for 2 weeks and he was wearing no clothes because I couldn't

get him dressed. He would only drink milk. No food. I had gone. He was really aggressive and irritable and crying .... You know he lost the walking, his talking stopped. He just went, yeah .... You know I didn't probably know what I was doing. [Theresa, I1]

...I didn't want to go on. I wanted to leave. I wanted J to be taken away. I used to tell M (the case manager) to come and take John away. "I can't do it"... I just felt like it was such hard work. It was such hard work to keep him together, to keep everything on .... the whole thing is a fight. You know, smashing things, throwing things. Just his anger, his irritability and that "oh my God is he going to get better or is it going to be like this all the time". [Theresa, I2]

Black Days are worst immediately after the accident, but are not a time limited stage. All of the families in the study experienced episodes when things became dark, frightening, and chaotic again, such as when there were changes to the family's routines, or when the child became overtired or overstimulated. However, the severity of the days does decrease over time as the child moves through natural recovery, and is helped by the actions involved in Holding Things Together.

Although the circumstances and severity of the children's injuries vary, parents vividly recall the details of The Accident, The A-Z Changes that were wrought for their children and the family, and feelings of Losing It. This combination of factors drives the parents efforts, compelling them to begin to Hold Things Together.

So you've got no choice. You've got no choice but to learn how to alter everything. [Donna, I2]

### ***Black Days: The Accident***

The circumstances and severity of children's accidents vary widely across families. However, The Accident is seen as a marking point for frightening changes in the child, and is sharply etched into the foreground of parents' memories as a time of trauma, not only in terms of the child's brain injury, but for the whole family. John's mother described the accident as an "*awful, awful, dreadful experience*" [I1]. Parents described the horror they experienced and could recall tiny details from the time of the accident. Theresa graphically related to me the circumstances of her son's accident, remembering

the smallest of details vividly; shapes, her body position, the sensation of her son's feet, and the noise he made. Seemingly as though time had stopped in her life from this point, almost three years later she found her watch still there.

...it was at my parent's place...there is a round spa pool here and it's probably that high off the ground and it's tiled, like those tiny tiles like that [points] and ... we had friends around and a couple of my girlfriends, three girlfriends ... and we had our little kids there, all having swims and stuff like that and I was sitting on a low, one of those recliner things like that ... and he was doing the bounce, bounce on my- you know how the kids do it... and he just jiggled...so he was quite a big baby and I was a little bit lower... and basically all he did was sort of shot that way, so he fell back that way ... I don't know how I must have been ... I must have caught him as he was going, but he fell and hit the back of his head across the spa pool. So it was kind of a weird accident... I mean I've only just found my watch. At the time my watch must have fallen through the deck of the pool... I must have ripped it off when I picked him up or something like that. And so when he fell back, he was still conscious then. He sort of looked up at me and I grabbed him quickly, but he made this murmuring noise, like this weird "arrrrrrr". You know. Not a cry, not a anything, and he was quite a bright little boy. He was counting to 20 and stuff like that then. He was walking you know really, running... And after that, well you know, it just turned to custard basically. That was the worst nightmare of all... [Theresa, I2]

Memories of the accident recur to parents in response to reminders in the practical context of their daily lives.

...not a day goes by when we don't think about what happened. Probably every day. Probably every day. Like you think you haven't, and then, but I think every day, something makes you think about it. [Rona, I1]

These memories of The Accident continue to replay over and over in parents' minds, sensitising them to the particular set of circumstances in which it occurred, and acting as a motivator to prevent re-enactment of a similar event. Katie's family modified their home, eventually moving house to eliminate the risk of ever having a second driveway accident the same as the first (Katie, Obs), while Simon's parents enforced strict rules around him ever opening the gate and running out onto the road on his own again (Simon, Obs). Katie's accident replayed to her parents every time they backed the car out.

Like you go and get in the car...and start to back...and you have to get out and have a look, even though you know .... Like sometimes the kids are all in the car strapped in, and I just can't back out ...You just never know ... Who's coming up, walking up your drive that you didn't know was there ... and, like we, I generally have the gate closed. Especially when Marcus [sibling] is awake. The gate's closed so no one can actually come in the drive. [Rona, I1]

Mum backs very cautiously up the drive, and stops, and stops again as she approaches the top of the drive, double-checking for anybody on the footpath or walking down while she is backing. Once on the road she drives confidently and smoothly...[Katie, Obs]

There is variation between parents as to the ease with which they are able to control the circumstances of the accident, and this intersects with the age of the child; for example, it is easier to prevent a young child running onto the road by building a fence than it is to prevent an older child opening gates and running off down the road. In general, parents are driven to contain their child most closely in situations where there is a high likelihood of a similar accident.

I'm really up tight about street things .... When you unload three children out of a car and the street there and I say Dylan, Katie, you go and stand up by that shop window and don't move .... and I really notice other parents not being like that. Like, the kids get out and run around the side of the car and I'm like, uuuhh, beside myself because I possibly wouldn't have been quite that paranoid before, and now I'm really extra extra with all the children, not just Katie. [Rona, I1]

...the family makes its way up to the school gate, children close around Mum, Dylan even holding onto his mother's jeans. Marcus is being carried, and Katie is following close in behind. Once out of the gate, it is harder. Katie finds a stick, and is more focused on this than staying close by Mum. Mum turns around frequently, checking that she is staying close and on the pavement. Other children are all around, stopping and getting into cars. "Stay on the path! Dylan, stay on the path!" For one heart-stopping moment, Katie and her stick are on the grass, then moving across to the road and parked cars before Mum calls her back. We reach the car. There are lots of directives from Mum while she unlocks it and starts to get the children in. "You just wait there. Go to the boot. Stay on the path. Stay on the path. Dylan, stay on the path. Watch your head. Wait on the path!"...Mum expresses her concern over the way other children are moving all around. She stresses that she always walks down to get Dylan,

and keeps the children with her. The children are never left to wait in the car alone.  
[Katie, Obs]

Although the parents did not focus on feelings of guilt or grief in discussions, the Accident remained as a vivid reminder of the random nature of life events, and of human vulnerability. It is the luck of the draw. Chance events bring about tragedy, and can strike any person again at any point in time. These perceptions are a stimulus to parents to endeavour to Hold Things Together in order to get them through the Black Days and achieve some control over seemingly unpredictable tragedy.

.....you know you just get caught out, just in that split second. And it can happen to anybody. No matter who you are or...And so it has made us extremely wary. Especially of her personal health or safety. [Rona, I1]

The parents had all faced the fear and terror of seeing their children near death as a result of The Accident, of thinking they had lost them forever: *“You’ve seen your child lying unconscious in the Starship [hospital] and thought is he dead or not?”* [Theresa, I2]. Despite acknowledging the bad luck or chance involved in their child having The Accident, *“a freak accident”* as Theresa described it, families also emphasise how lucky they are that their child, (albeit a changed child) has not been lost, and is still there with them. This relief creates a sense of how special this child is, reinforcing the need to attempt to work to Hold Things Together for them. Over the process of Holding Things Together, this special value placed on the child is reinforced further. *“...we just dote on him. You know we just love him to bits because we have probably put so much effort into what he does...”* [Theresa, I1]. This special valuing of the child was apparent with all participants.

It makes you appreciate .... Because, ... we know that she’s a real character.... And I mean I know all kids do that but, she just is special because she’s here and she nearly wasn’t. And I think anyone that has dived with death like that is a bit special .... It just makes you appreciate your family and that you’re lucky. [Rona, I2]

The Accident varied in terms of the medical assessment of severity of the injury incurred in the children. Some children such as Katie and Simon required immediate and extensive hospitalisation, while others such as Bailey

and Lucy were not diagnosed with a brain injury until some weeks after the event. However, this immediate medical measure of severity does not necessarily relate to the degree to which parents perceive Black Days. Rather the experience is directed by the extremity of the child's behaviour, which often seems to be independent of the immediate injury severity. At first interview when I asked Bailey's mother how severe she thought her daughter's injury was, she described The Accident, for which Bailey was not hospitalised. Later, she described the way she was overwhelmed by her daughter's extreme behaviour that followed this fall.

...she just fell from a high stool onto a granite bench and then flipped back onto a tiled floor. But what I hadn't realised that, I mean everybody probably doesn't realise, that everything's cumulative. And before then she'd fallen a lot because her head was quite big. And she'd knocked her head an awful lot before then, and the doctor explained to me ...that just put her over the threshold .... that was the threshold, and, she knocked herself out. [Pam, I1]

Her wild behaviour and her intolerance to situations, and just going into shopping malls and running away and all those things, because it was such a change from her normal behaviour because she was really very placid and very compliant .... Yeah, I mean nothing worked. All the normal discipline things that you put into place for the other children didn't work with her. [Pam, I2]

This contrasted with Katie, who sustained a serious head injury requiring immediate hospitalisation, yet fewer behaviour problems.

... she does a lot of that. That, resting ... she just gets a little bit unreasonable, and a little bit scratchy. [Rona, I1]

Although Rona found Katie's behaviour challenging at times, and still needed to Hold Things Together, her behaviour was less dramatic than that perceived by Bailey's mother, and Rona's experience of Black Days was not as intense.

### ***Black Days: A-Z Change***

The participants noted the way their lives underwent change as a result of The Accident, with different families coming to the realisation at different times that the change was permanent. "A-Z" was the way Simon's mother

described the change, conveying a total and sudden shift: one's life is at A, then suddenly shoots through to Z, losing all the letters in between. Along with this realisation of change emerges a sense of acceptance of the need to move on rather than look back; *"Cause your life goes from like A changes to Z and there's nothing that you can do to get it back to how it was"* [Donna, I2].

Change happens in families' attitudes to what is important, to the pattern of their lives, and to how they need to do things. This change seems to reflect a shift in values, again with acceptance that this is how life needs to be now.

Things that you thought really mattered before you don't give a hoot.... Things like being able to do things, to go out. Okay so if we're not on time, too bad. We got there.... You have no choice. Cause if he doesn't want to get there in a hurry, you don't get there in a hurry. [Donna, I1]

So, it's changed our attitude, but, ... it's just how careful we are with her.... The whole impact did, like, has changed our lives but not necessarily for the worse. I mean, obviously we would have liked our child to have a clean slate with no brain injury but, we can't change that now. But, it, out of it came a lot of good things as well, like, just, what people did for us and all that sort of thing. And it just made us more aware... [Rona, I1]

Different combinations of physical and behavioural changes are involved for children, with both being of concern to the parents in driving the need to Hold Things Together: *"...this wasn't the child that I knew"* [Theresa, I1]. *"... it took me about a year to realise that the old Bailey wasn't going to come back. We've got a new girl now, and we all have to protect her"* [Pam, I1]. Katie and Simon were both left with more obvious physical difficulties, having frequent falls, while for John, Bailey, and Lucy, the most obvious changes were to their behaviour. A particular concern for parents is that there might be change to the essential person that is the child. The shell of the child is still there, but is now different, maybe forever. Change for children is not just the immediate present, it is also about changing the future. Katie's mother describes her shocked response to knowledge of sudden and irretrievable change in her little girl.



I said “well, will she still be the same as, what’s going to happen?” and he [said] “oh she won’t be the same person that you used to know”...it was like someone had got a big club and hit me across the stomach with it, and we were just blown away .... that was one of my big concerns was that we had changed the course of time, and that she wasn’t going to be the person that she started this world intentionally, that mother nature or whatever intended her to be she wasn’t going to be any more. [Rona, I2]

Change is often at its most obvious shortly after the Accident, not only shifting the course of the child’s life, but also the life of the family. However the realisation of change occurs temporally along a continuum for different caregivers, affecting the degree of urgency to Hold Things Together. Early on, some parents such as John’s mother and Bailey’s mother noted behavioural changes in their children, requiring prompt action. “*Her personality changed almost overnight.... A dramatic change.*” [Bailey, I1]. In contrast, Lucy’s father became aware of change more gradually.

...watching her through then,...and she was 5 and still in the very junior classes at primary then. She’s just couldn’t pick up her school-work sort of thing. Just so hard for her to read or write. [Grant, I1]

Lucy’s changes had become apparent in a developmental context at school, and it was over time that they broadened in terms of their impact on the family.

### ***Black Days: Losing It***

During Black Days both parents and children are losing control. This provides impetus to do something to remedy the situation and Hold Things Together. Parents experience the feeling that they are Losing It in terms of their ability to care for their children. Their conversation during interviews revealed a view of things falling apart in their role during Black Days, with confusion and being unable to “*understand*” what was happening to their child or what to do about it. Descriptions of their experience at this time are evocative of only being half awake or in a trance, total exhaustion, unable to move to escape the grip of the bad dream, snatching at information which seems meaningless at the time, and life whirling around them out of control.

At the start...you don't know what's going on half the time. Things just fly by you really. You pick up half probably what you're told. Not through just not bothering, it's just too much stress eh. [Colin, I1]

I didn't probably know what I was doing. I didn't really have anything, I didn't know really much about how to manage someone with a head injury... they got me to sit quietly in a corner or something, just talked to me really quietly. It was pretty bad I suppose for the first I don't know, even two years I would say. In some ways it was a nightmare... The more therapists we went to, the more things that were wrong with him really. And I found like having too many and lots of therapists. I was having sometimes like two or three therapists a week, and it is quite overwhelming sometimes you know, that people visiting and appointments and all that sort of thing... I can remember when the occupational therapist used to come... I would just lie on the couch as it was my only rest from him... and I think it's the tiredness. You are just tired, you're really tired because you are having to think about things all the time. [Theresa, I1]

As well as the feelings of Losing It as a parent, participants also pointed out the ways that the children themselves Lost It. This involved the child Losing control of their behaviour and of their physical function, and appeared to be unrelated to their age or the severity of the injury. Parents all had different names for their child losing control of their behaviour, including “*out of control*”, “*spinning out*”, “*going psycho*”, and “*go berserk*”. The names and words all relay a sense of fury, and of behaviour flying apart. Different names were used to identify different degrees of Losing It.

I call it getting shitty because there's a difference. Shitty is not as bad as when he totally loses it. [Donna, I2]

Increased severity and instances of Losing It are a strong instigation for parents to act to Hold Things Together for their child, as there is a risk of damage to the environment and threats to their own and others' safety. The depth of the children's emotions when they build to this point can be violent and frightening. Parent's descriptions are strongly physical, and often included words that convey catching, grasping or gripping actions that indicate the urgency of the situation.

I just grab him by the arms and take him away, otherwise he will physically hurt the other kids.... He punches, pushes them and then yells at them and starts swearing at them. [Donna, I1]

Bailey's mother, Pam, describes the way her daughter would work up to Losing It, moving from a haze of tiredness through to an unleashing of a storm of physical aggression towards her siblings.

And she gets into the fog of a fatigue. She just goes "it's really foggy. My head feels foggy. Clogged...it's like buzzing and fuzzy." .. and if you can't catch her before that point, then, she just goes psycho. [Bailey, I1]

During my visit, John began working up to Losing It. He seemed to suddenly become tired during a colouring activity, and was completely unable to control his emotions. Theresa responded quickly to prevent an escalation.

John starts drawing, murmuring about the different colours, searching for them in the box... "That's gorgeous" says Mum...She returns to the kitchen where she is getting dinner ready early. John suddenly gets sad and dissolves into tears. "I don't like it" he sobs. Mum is beside him quickly, patting him gently as he lies on the floor sobbing... She picks him up and cuddles him, then sits with him on the couch. [John, Obs]

Katie's mother also described mild symptoms of Katie Losing It that were associated with reduced physical function, putting her at risk.

We have the lip and the stomp and the just you know, like four year old type like tantrum thing.....And she's tired, you know she lies on the floor and she just is unreasonable. Just um, then she pushes M. over and also the other thing which it seems to be that she gets more clumsy falls over and stumbles and trips.... I don't know for sure, but I'm presuming that she's losing it, and she needs to pull back and do something that doesn't require effort. [Rona, I1]

In contrast to Katie's mother who was able to direct her daughter into a quiet occupation, John's mother really struggled initially to know how to manage her 4-year old son's rampaging behaviour. Her description is similar to a cyclone ripping through the home.

I can remember numerous times, I think "God, he's out of control" I just can't get him to do anything...you know the amount of damage he used to do. He would, you know, tip over the TV, you know all my bowls would be smashed on the floor. [Theresa, I2]

Although these feelings were discussed as being particularly bad closest to the time of the accident, caregivers also spoke of the frustration when they felt they were managing to Hold Things Together and circumstances knocked them back down to a point where they could feel things slipping out of their grasp again. This might occur at any later point, re-triggering emphasis on Holding Things Together. Simon's mother Donna described how it was for her about a year after the accident when the children both got sick and Neil was working up North.

I've been up all week with him, I've, he's been ..., He's been sick. I can't handle it. I was crying, the kid, Simon was sick, Neil was at work, and I just couldn't.... [Rona, I1]

John's mother also described how it was when things had improved, then started slipping back again.

You know I can feel it going round in my head, getting me uptight.... I get anxious because he's tired the next day at school....You know it then starts that kind of spiralling down....sometimes when it's all starting to turn to custard, it's really hard for me to keep...I start getting angry with him and his you know behaviour.... because I know that it's all going to turn to custard and then you know I get so disappointed that it's not working out right... [Theresa, I2]

Again, her words capture a sense of the elements swirling around, efforts to control an approaching storm, but Losing It.

### ***The Context: Learning the Dangers***

Holding Things Together happens in a context of Learning about Danger. Although the parents are in a state of confusion and disorder during Black Days, as time passes, they begin to Become Aware of the reasons for the differences in their child. They are becoming more Alert to further Threats to their child's safety, and are beginning to Recognise Signs and patterns of responses in their child that can foretell of risks. Parents Fear Further Knocks happening, but find that these are a reality, understanding that life is fraught with dangers. Driven by Black Days to do something, and being in a context where they are Learning about the Dangers for their child provides the

foundations on which parents are gaining understanding and the capability to Hold Things Together.

### ***Learning the Dangers: Becoming Aware***

During the interviews, families indicated that they experienced an emerging awareness of the reasons for changes in the children. This awareness is not a static state, and involves a growing practical understanding of the links between the child's injury, behaviour changes, and different triggers.

There is variation in the ways that families Became Aware. Families described Becoming Aware after being informed by others, such as doctors, psychologists, or therapists. They also described gradually Becoming Aware through interacting, repeated "*observing*" and "*working out*" what was happening for themselves.

...a case manager that came in and then they explained it, and N. [Psychologist] ...explained the process. I mean this is over a certain amount of time. I suppose it took me a good year to really come to grips with what a head injury can do to a person. [Rona, I2]

Because we've like E and K [Therapists] are so awesome...if something's not happened or if something's wrong, we can talk and say well why is this, and they go through it with us.... I reckon a lot of it you work out yourself. I mean, people can tell you things, but everybody's different. You know, really, you just gotta watch him, and you see how he reacts to different things... [Neil, I1]

There is also variation in the speed at which families become aware. For all families, there is ongoing growth over time in their awareness as to the implications of the injury. However, for those families faced with a severe injury or extremes of behaviour in their child, the awareness emerges more rapidly. This differed for Katie's parents. Because she was very young when the accident happened, the awareness was still emerging several years after the accident. Her parents had ongoing doubts as to whether her behaviour was related to The Accident, whether it was in the normal realms of 2-year old behaviour, or whether it was just part of her normal personality. This drawn out nature of Becoming Aware meant living with uncertainty, questioning, and wondering for the future. Rona's words convey her watchfulness and analysing.

In the first year or so, if she threw a tantrum, I'd think, now is that brain injury or is that just because she's two? You know, who would know.....and sometimes I'd get worried because she'd be doing these ... personality clash type things and ...I'm just wondering if, you know, is she a little bit unhinged, because of the accident...[Rona, I2]

Likewise, Lucy's father had not realised until some years after The Accidents (which had involved repeated concussions) that Lucy's behavioural difficulties were probably linked with them. His words emphasise this gradual passage of time, with the use of *“getting to the stage”, “remember”, and “slowly”*. Grant, like Rona, also indicated this time of questioning and analysis as he was working through his doubt and Becoming Aware. Also present for Grant was a sense of looking at things more closely.

I was ...getting to the stage, what's wrong with Lucy, but, ... it's like no-one's telling me to remember Lucy did have a head injury..... then counsellors start talking to me and it reminds me that I have to be aware that Lucy does have a head injury..... I am slowly with it then. To me it's, Jesus Christ. You know, and slowly then I start focus and watching my daughter and sure enough...[Grant, I1]

Families Become Aware of the fact that it is the head injury rather than the child themselves or ineffective parenting that is responsible for the changes in their child's behaviour. Becoming Aware is not only watching and wondering what is going on, but is also a sifting and sorting process, dividing out what is involved and what is not; *“Then I understood it was from the head injury, not her or me” [Pam, I2]*. In parents' minds, the head injury and difficult behaviour, the good sides of the children, and the parents' own actions, are all split apart as they begin to understand what is happening. The behaviour almost seems to operate independently of the rest of the child, to be a separate entity.

So sometimes I wonder is it, is the injury, or is just her behaviour? And there are two parts to it....So a part of her injury that people start to look and see the bad side of Lucy and the funny side and the good side. She's got a few, all those better bit and pieces sides of her. [Grant, I1]

Becoming Aware is also about understanding the triggers for the child's behaviour. Parents are Becoming Aware of what happens when their child is

overloaded by too much noise or activity, is overtired, or is frustrated. These scenarios tend to result in the child Losing It, and parents subsequently learn that prevention is better than cure. Different things trigger different children into Losing It, and over time parents Become Aware of the triggers for their child. Tiredness, or “*fatigue*” is a common trigger factor in Losing It; “*So I think that’s a big thing is tiredness...*” [Neil, I1]. For Lucy, her father had learned that it was also heat intolerance that upset her.

...she gets very bad headaches...and it sometimes just knocks her out...She just grabs a chair or something, just throws it at them...angry, yeah, she’s got that type of little bit of that anger in her, and, because she’s just couldn’t stand the heat, or in winter they have the heaters on...[Grant, I1]

John’s mother describes the way she Became Aware over time that noise could trigger John’s distress.

I remember February last year...a friend and I went into a café in [shopping centre]and he turned around and said to me “mummy I can’t do this coffee noise mum. Please can we go”.... And that was one of his first times. You know I can remember early signs after the head injury going to a café with my family, and everybody was looking at him and he just went “no, no”. As a little two year old, “no”. He just couldn’t cope with the noise.... And he would get irritable at the nights it was the swim school. And we can go to the shopping centre now. I mean, it’s taken 3 ½ years to go to the shopping centre. [Theresa, I1]

Theresa gradually Became Aware as she noticed her son’s responses in different settings and began to understand the reasons for his behaviour.

### ***Learning the Dangers: Alert to Threats***

In the context of Learning the Dangers, families are in a heightened state of arousal, realising they need to watch out for further threats to their child’s safety. This involves remaining vigilant to threats in the environment, threats arising from decreases in the child’s physical abilities, and threats from the child’s own behaviour. As discussed in Black Days, the parents are already conscious of the way fate can intervene at any time with serious consequences. The parents in the study had all been made very aware by clinicians of the risks posed by a second head injury for the child, heightening their alertness.

You are told from day one at the hospital he cannot afford to have another one.  
[Theresa, I2]

Physical environmental threats include cars and roads, things that tempt the children to climb, places where they are at risk of slipping over, and busy or noisy places. As discussed above, these types of threats are often linked through to the circumstances of The Accident in parents' minds.

...a woman rang me today saying "I would really like to have John over to play on Friday" and I'm going "Oh, I don't want him to go and play", because I don't know what that place is like and is he going to be safe enough, and what happens if he's naughty....John hasn't got a trampoline. I never let two children jump on the trampoline together. Have they got pads on the trampoline.... [Theresa, I2]

Running back out on the road is a major big thing. [Donna, I1]

Social environmental threats involve people who do not understand the reasons for the child's behaviour, creating risks to the child's physical and emotional safety. For Bailey, Lucy, and Simon particularly, who were all of school age with greater involvement in activities outside the home, there was this added threat of the child putting themselves in danger as a result of their interactions with others. Emotionally traumatic interactions intersected with the child's reduced control over behavioural outbursts or Losing It, then placing them at physical risk.

She might get hurt. Just her getting hurt.... if she sees there's a smoke in the car, she will try to break into it. I am worried about if the people who own these things, like she might come across a violent person one day and this person might hurt my daughter. That's my main worry with my girl. [Grant, I1]

Learning about threats arising from limitations to the child's physical function is an important issue for parents, despite the relatively rapid recovery of movement skills that most children experience. Threats include things such as poor balance, a tendency to trip and fall, and slowed saving reactions. Threats are exacerbated if the child is tired or is not concentrating.

...she fell off her chair twice. .... and that's just what Katie does. And obviously it was the end of the day, she's tired, and she has to think, like she can't draw pictures and



then sit up to the table at the same time ... like she couldn't concentrate on her balance. Well, that's just what I think. [Rona, 1]

Threats that present from the children's behaviour also places parents on alert. All parents had concerns around the child running off, and almost all caregivers described the fear they felt when the children ran off. This fear arises from the possibility of losing the child, and also from the risk of them coming to harm, such as running out in front of a car. Losing It places the child at even greater risk. Parent's language holds images of rapid, fleeting movement, the children flitting past, vanishing from sight. Parents are catching at them but are unable to grasp, experiencing near panic, visualising the possibilities, or searching but being unable to find them.

When she's in an impulsive mood she can just take off out the front door, get on her bike and go. Or she can go and climb up and get the garage opener and get her bike out of the garage and disappears. [Pam, I1]

... bad moods, ... he will just not do what you want him to do. He will run away. "Ah run out the gate" [Simon's comment]. Yes. Climb the tree is our latest thing.... He knows that I get really upset when he climbs the tree... "Mum thought that I gonna fall down" [Simon]. [Donna, I2]

More often than not, the perception of danger arises from a combination of threats. Parents are on the edge, anticipating danger in every move.

It's like he's really impulsive when he gets fatigued. He will dart out on the road. I think "Oh my God, he's going to run out and do something". He's going to slip over because he falls over so much more. He is so clumsy when he is tired, ... and this is going to happen. [Theresa, I2]

When I visited Katie and her family, even though I work with children with head injuries, I myself was fearful for her safety numerous times during my observations, both in the home and on a visit to the school playground; she just seemed to be more at risk than the other children in the family. I observed her intentions and movements as rapid, with little thought to her own physical abilities or to possible danger, her safety tenuous.

Katie at four years finds a bottle of Mum's favourite fizzy drink in the fridge and climbs up onto the kitchen counter stool to try and pour it herself; Katie is perched

precariouly on the edge of a stool, seeming to be unaware of her balance limits, and I am tempted twice to rush to her to prevent a fall.... Katie climbs up, and then down, and then up and down and up again, balancing on the edge of the stool.... Katie wobbles around on the edge of the stool: Mum notices and says, "Katie, don't sit there like that, you'll fall!" [Katie, Obs]

The degree of alertness is more marked in unfamiliar environments, where parents are less familiar with what to watch out for, and have limited ability to set things up safely. At these times, parents describe being on edge, constantly appraising the environment, and assessing for the possibility of an accident. For Bailey's mother who had recently moved houses, her concern for her daughter's physical safety was noticeably heightened, despite her efforts to rent a house on a quiet street with fences.

In our [first] home we had an electric gate that she couldn't get out of, so she was reasonably safe. But since then we've had two rental properties. So it's actually very hard. We moved to C Rd...And it's reasonably quiet street,...in between two very busy streets.....I just have to keep my ears open all the time. Sometime's she's just taken off...and it doesn't matter how much you sit her down, and try and reason with her, she just doesn't seem to.... since her head injury she wanders...she doesn't sleep very well at all.... and we've got a very dangerous staircase to the rooms. So I thought it's easier for her to be upstairs because if she's going to wander to me.... [Pam, I1]

Pam was Alert to Threats from her daughter's tendency to run off, her wandering in her sleep, and her poor physical coordination on stairs.

### ***Learning the Dangers: Recognising Signs***

As parents interact with their children after The Accident, they begin to Recognise the patterns of behaviour in their children that can forewarn of Losing It. These signs are often physical, and are also associated with a variation from the child's normal rhythms. To the inexperienced person, many of these signs would not be noticeable.

When Bailey overloads, her head gets sore. But then if you don't get her out of that thing, she gets a full-blown headache. And you can see it in her eyes.... I can see in her eyes, they get droopy or less, they don't get as focussed. She gets quite, she looks like she's quite distant. [Pam, I1]

Theresa likened reading John's signs to a storm warning. These feelings are embodied within Theresa's earlier metaphor for this whole time, Black Days. During storms, daylight turns to dark, and the elements rage. The metaphor continues with flowing tears, which are like the rain, moving into an emotional flood for her child.

The tired. The rubbing the eyes, the stumbling and falling over....It's gonna get worse. Because he's tired too early. Like suppose he's rubbing his eyes at 7 o'clock. Great, fabulous. Night, night. But if he's rubbing his eyes at 10 o'clock in the morning, Evan and I look at each other and go "uh oh". It's like "uh oh, trouble- trouble's brewing up – a storm brewing down there" ready to happen like thunder and lightening.... it's crying, heaps of crying. The tears just flow and flow and flow, and ... emotions.  
[Theresa, I 2]

This ability in parents to notice indicators was not present early after the accident, but occurred over time. Theresa and Neil described the process after they returned from hospital to begin caregiving.

I think the early days, I just couldn't take anything in no matter what people told me really. I suppose I wasn't ready. [Theresa, I1]

Because when you get home, ..and you start, you know, you can see what different things that happen when they're tired. That's when their defects show up more. [Neil, I1]

Recognising Signs evolves during parent's interactions with their children, and is a process that involves observing, then putting two and two together.

### ***Learning the Dangers: Fearing Further Knocks***

Families often described being scared or frightened of caring for their child, realising the child's frailty and what could happen; *"It was so scary having her in our care, not the hospital's care"* [Rona, I1]. Apprehension is high, and the responsibility of looking after this child who has almost been lost is daunting in the knowledge of danger that can strike at any time. The child's hold on life is perceived as tenuous, surrounded by hazards are threatening over and over to blow things apart. Interviews are scattered with words such as *"paranoid"*, *"wary"*, *"up-tight"*, *"scared"* and *"worried"*.

All of the children on the study had experienced repeat injuries to their heads since their first serious injury. Families are aware of the risk of repeated head trauma (*he cannot afford to have another one* [Theresa, I1]) and fear the likely consequences (*I just get scared it will put him back* [Donna, I2]). As time passes however, families are seemingly learning an acceptance that further accidents will happen, regardless of their efforts; “*we don’t want her to have any further knocks to the head, although that does happen, without us being able to prevent it*” [Rona, I1].

This ambiguous and fatalistic attitude is in line with the parent’s beliefs that bad luck was to blame for the original accident, that it was a chance thing. To them, Further Knocks are to be Feared, but are also a reality; these children “*stumbled*” and “*tumbled*” over frequently and some of these falls involved Further Knocks to the head. Bailey had had “*several concussions and two times where she got knocked out since then*” [I1]. Katie’s mother described her as always having “*greasies on her shoes*” [I1]. Life for these children is about danger, and there is an expectation of the high likelihood of another accident, reinforced by what is happening. Bailey’s mother described regularly finding evidence of yet another accident.

So you’d be washing her hair or combing her hair, and you pull back her forehead, and she’d have bangs on it. [Pam, I1]

Participant observations found the children often moved rapidly, and were also clumsy. They got tired easily, and seemed to have little awareness of danger themselves. During my observations with Bailey, she was at twice at risk of injury in the first ten minutes of my visit, and her mother was checking for signs of further knocks.

Pam offers me a cup of tea, which I accept. She makes two cups. Bailey knocks one over which she cleans up then she joins me at the table. Bailey sits on the couch beside her brothers watching TV momentarily, but is not really focussed. “Have you done your homework?” Pam asks. Then, as Bailey gets up, “Keep away from the hot oil in the kitchen”. Moments later, “what is that scratch on you now Bailey?” Bailey explains in some detail hows she got it from some poison ivy on her walk, and a brief argument ensues when Mum asks further to determine the real cause of the scratch. I realise now that she is probably concerned at any further knocks and bumps Bailey sustains during the day, particularly if she isn’t there. [Bailey, Obs]

The parents are therefore apprehensive of the risks and at the same time are being made aware of the actuality.

You get lax. I've done that a couple of times, a few times. You think, oh yeah, he knows, he knows, he knows, and then something will happen... [Donna, I2]

You are conscious of further head injuries.... you know you just can't have another one and he's had a couple of minor ones since then, but he had quite a bad one at kindy last year where he definitely lost consciousness for a second or two.... and he had another one before that where he hit a edge of a concrete garden thing. [Theresa, I1]

These ongoing practical reminders are jolts, warning parents again and again to take heed, to never drop their guard. Further Knocks are Feared, but seem inevitable.

### ***Intervening Condition: Close Support***

Support from family, friends and professionals impacts on parent's ability to Hold Things Together. As an intervening condition, the important features of support in these circumstances were described in words indicating connectedness to the parent and the child, such as "*together*" and "*trust*" with an emphasis also on the person's presence through "*being there*" and "*with*" them. The support tempers the difficulties encountered during Black Days when parents are feeling discouraged or overwhelmed. Parents respond to having someone to help them through with increased motivation to Hold Things Together.

The amount of support perceived is based on the parent's impressions of the quality of the support. This quality ranges from people who are "*very good*" or "*amazing*" with the child, to others who are perceived as not very helpful or "*frustrating*." Some parents on the study had not had this level of Close Support (e.g. relationship breakdown, less contact with therapists), and these families struggled to Hold Things Together. Other parents perceived very high levels of Close Support from their family and friends; one parent described this support as being a "*buffer zone*" between the child and the rest of the world.

...so all of a sudden this big, in a spiritual sense it felt like this big circle of , like a big buffer zone from between me, and Colin, and the children, and the rest of the world.

And it was this buffer zone of amazing people.... So I felt like I was cocooned in this little zone where everyone else did everything else. Even feed me and clothe me and oh, cause I couldn't do anything but, you know, breathe. Basically. [Rona, I1]

The support appears to work for parents during the process of Holding it Together firstly by providing a form of emotional reinforcement or buttressing, and secondly by practical support in sharing the load. Parents emphasised the importance of someone Going Through the same learning process as themselves, creating empathy and understanding of what it is like for the child and the caregiver and what to do. They also spoke of how it helps to have someone who is always available and who knows what to do, to Work Together or closely in synch with them.

...having Evan there is a wonderful support. He never ever questioned the way, that we always used to discuss how we were going to do things, how we were going to manage things. We always worked together really closely. Always did the same thing.... doing it together supporting each other. [Theresa, I2]

### ***Close Support: Going Through it Together***

Going Through it is a phrase used by parents that describes someone who has “*gone through*” the same experiences and learning processes as themselves. This might be somebody who was there when the accident happened and who has been there for the family right through this time. It could be a person who has practical experience of being with someone with brain injuries. It might also be somebody who has been around more recently but who has close contact with the family and child, who has learned what is going on and who knows what to do through practical experience and frequent contact with other skilled people. Together is an important concept linked with Going Through it, indicating a conjoint learning process, hand in hand with the family, a connected presence, and therefore familiarity with this particular child and their situation.

...it's not so much at the accident, it's like going through everything afterwards that we've had to go through. Like all the physios and knowing that if it's got to be done, you've gotta drop everything and do it then.... And knowing that the looks of how he's looking at the time that can lead to make him shitty...[Donna, I2]

Going Through it Together results in Close Support that is described as “*understanding*”. Understanding involves implicitly knowing the total commitment and responsibility involved with the caregiving, that it is a demanding role that is all encompassing. Parents on the study felt supported emotionally to Hold Things Together when somebody else understood enough to share the experience with them and “*understood where you’re coming from*”. Understanding also involves knowing the same things that the parent has come to know about the child... the signs, the threats, and what to do. Different parents used different words to describe this understanding, including “*realising*”, “*thinking*”, “*training*” and “*knowing*”- all active and dynamic learning processes, achieved through ongoing interaction with the parent and child.

...someone that truly understood what was actually happening. That you could see that was, understood where you’re coming from. Although you know they don’t understand 100 percent unless they’ve worked with head injured people before. [Pam, I1]

Through the support person’s degree of understanding evolves “trust”, and this provides opportunities for that person to lend emotional and practical support by “sharing” the responsibility of caregiving. If a person has good levels of understanding, the parents trust that the child can safely spend time with them during the day or overnight, comfortable in the knowledge that Holding it Together will still take place. Parents describe people as “Really Understanding” or “Truly Understanding” when there is a very deep level of trust.

It’s learning to have more trust in other people, because like at school, I’ve got to trust Jan [teacher aide] to know when he’s tired, because if he gets too tired, then the next day, that’s wiped out, and he can’t do anything the next day, and it’s having that trust in others when they’ve got him. [Donna, I2]

One parent with low levels of close support described a situation involving her partner, who had actively rejected any opportunities to “Go Through it Together”. This avoidance had resulted in a view of the partner as having a lack of insight, “not understanding” what was going on for the child and parent, and a lack of trust. The parent was uncomfortable for the child to

spend time with the partner who she felt was not up with the play, even though firm offers had been made and a break from the burden of the care would have been welcome.

...I thought again, you've got no understanding where she's at in this point in time, where her head's at.... Well he was around when she had the head injury, he was offered, he, I mean obviously the specialists and everybody asked him to come and talk as well, because you know he just didn't and he's not up with the play. [Pam, I1]

In this same way, parents who went out to work found it difficult to cope with changes of paid attendant carers who did not fit easily into the family or who did not seem to be taking on board the knowledge they needed to work together with the child. These difficulties signalled paid attendant carers who had not “Gone Through it”, who had inadequate understanding, and who were not trusted.

### ***Close Support: Working Together***

Interactions between parents and people they perceive as being a Close Support have special “on the job” qualities which were described by parents and which were also evident during observations. These qualities are necessary to work together effectively and include the availability of the support person, spoken and unspoken communication, and the way in which the workload is shared.

People who are seen as being a Close Support are always readily available and have frequent contact with the parents as part of the “Going Through it Together” process. Therapists who visited on a weekly basis were seen by parents on this study as close support, as was a psychologist who was “always there” if you needed her, and also Case Managers who were reliably contactable by phone; “*she's great, you can ring any time*”. These people provide support not only through provision of information and problem-solving together, but also through giving reinforcement, encouragement, and enthusiasm over time. In some families, spouses particularly provided Close Support. Theresa described her husband as being available on the phone, and the way he would come home promptly when she needed urgent help to Hold Things Together with John.



I mean the number of times that I rang Evan at work saying “get home now!” I mean, you know, he would just stop work and come straight home because I can’t manage him any more. [Theresa, I2]

In contrast to Theresa’s situation, Lucy’s father Grant did not have anyone available as Close Support. He names people who are there, but they are compartmentalised, in separate boxes to him and his daughter. All of the day-to-day responsibilities at home are on Grant alone. Days are pressured with early starts, juggling work, family, and Lucy’s life. His own life seems back and forth, full on, so busy, but never getting there, always somewhere else to go, something else to sort out. People are in his life but he is isolated, and always with his daughter at home, needful of him.

At the moment there I don’t have anyone. There’s just the counsellor at school, that does school stuff, the social worker just do social worker stuff.... And her mother. Two years that was never anything to do with me and my girl. ....two years off she just leave it to me....Very Hard.... Lucy this. Lucy that. Lucy come here. Lucy all right, and, just like a little mate that I come home to sometimes just to check on her. She’s always there waiting for me. [Grant, I1]

Communication between parents and their Close Support is both spoken and unspoken. Frequent and effective communication creates increased support by contributing to a sense of joint learning and problem solving through experience. It also provides for flexibility to respond quickly to unpredicted change. At times, parents talked about and demonstrated extremely sensitive, almost instinctive unspoken communication between themselves and a Close Support person, where just a look at each other or a single word would alert them both to what was going on with the child and what needed to be done about it, a shared, tacit understanding.

We used to talk at work probably at least one a day or twice a day sometimes, and we always talk.... David will always ring me and say, how did the morning go? Okay, what do I need to do tonight? .... Mm, we don’t even need to talk, it .... And I just look and he just looks, and goes, right we will just do this, and we quietly do it without any, yeah.... He’ll just walk straight in the door, and he’ll look straight at me and I will go, you know yeah, “cool” and “great”. And that’s all we need to say. [Theresa, I1]

At the other end of the scale, support is ineffective and frustrating when communication isn't working, for example when partners are at odds with each other or when a parent has to repeatedly explain things to a paid attendant carer who is not gaining the understanding necessary to help Hold Things Together.

Our communication sometimes, it's really bad. [Grant, I1]

I can't do this much longer. I really can't. You know, having to keep on explaining to caregivers. Like you've got to follow this programme. You know that frustration. [Theresa, I1]

Because Close Support emerges during an interactive learning process, the way the parent and the support person share their work with the child is particularly important. This was evident during participant observations when for some families, there was an easy, flexible swing between parents when sharing the practical care of the child. Although such families have a demarcation of roles (such as one parent responsible for the housework, one parent responsible for outside home maintenance) they both smoothly interface to help the child. I observed this during the following interactions on my visit to Simon's home.

Dad comes in to help out. Good timing- the phone goes and Mum answers it. It is about netball- she is very involved helping organise activities for the other kids...Simon finishes and quietly gets up and gives his dad his plate in the kitchen, then runs very fast outside...he is talking to his big brother out on the deck. Mum was boiling an egg for T's [younger sibling's] breakfast. Dad is busy with Simon and his brother and Mum is still on the phone...Dad comes and attends to the egg. Now Dad is checking Simon's face is clean, and also wipes T. Simon begins to practise jumping. "Simon, you'll get hurt". Simon responds and lies back, quiet in the couch while T. gets on with eating his egg on his own. Things are becoming noisy again- Mum is vacuuming, the washing machine is going- Simon appropriately gets up and turns up the TV so he can hear it, and then a little more for good measure. "Turn it down, turn it down" from Dad, and Simon obliges. The phone goes for Mum again- another neighbour. Dad asks Simon if he wants his eggs. "I don't ask for them" he solemnly informs his Dad, so Dad gives them both to T, who eats with little assistance, but spreads egg a fair way around the floor...Dad cleans up while Mum returns to the vacuuming. She comes back to the lounge and checks on both children in about five minutes....Mum and Dad's actions in caring for the kids are choreographed as carefully as a dance. They coordinate their care...smoothly and seemingly without

asking each other. The care is almost continuous, sometimes just a glance to ensure there are no problems. [Simon, Obs]

In this way, sometimes parents work together, or one will step in to help the child with an occupation without being asked, instinctively sensing a need if the other is busy or needing a break.

We get there too, if one's doing something, the other one just keeps twice the eye on him, so you can have a bit of time out. [Donna, I2]

Yeah, Evan and I will both will just sit with him. Read or, you know, cut things out or... [Theresa, I2]

There is also a consistency between the way such parents work to Hold Things Together, and parents talked of the benefits that resulted from “*backing each other up*” in the way they did things with the child.

Like we always back each other up on everything and support each other and yeah, talk about things and work out strategies, how we're are going to deal with it next time... [Theresa, I1]

This Close Support means both parents are familiar with a set way of doing things, such as the order of tasks in the morning, or dealing with problem behaviour.

### ***Actions and Interactions: Protecting***

Driven by the bad experiences of Black Days, and with growing awareness of the dangers, parents act to Protect the child. Protecting in this sense is interpreted broadly, including both physical protection (eg. from running out in front of a car) and emotional protection (eg. from failure, frustration, or losing it due to fatigue). Protecting actions are made in an effort to Hold Things Together, aiming to prevent further destruction and to contain things.

Probably the priority would be keeping her safe. And, so that she's not going, when she's in a particularly impulsive mood, that she's not going to harm herself. [Pam, I1]

Parents expressed the ways the children were “*out of control*” following the brain injury, and how their usual strategies no longer seemed to be effective

to help them. Protecting actions were encouraged by clinicians, but also emerged as parents began to learn from experience. As caregiver's understanding of what is going on increases, positive interactions begin to emerge with the children when efforts are focussed towards managing the child's activities, the environment, and time. This indirectly limits the children's fatigue, confusion and frustration, and also provides safety and opportunities for achievement.

Protecting was immediately observable in the parent's interactions with the children, and was also a word that came up time and again during the interviews. Parents were noticeably very close (physically and emotionally) to the children, and encouraged particular ways of doing activities by working and playing jointly with the children. The places they would take the children to were carefully considered and limited. Additionally they were very clear about the temporal arrangement of the children's days, with activities carefully organised at particular times to fit with the child's own energy levels.

Mary James [psychologist] explained that strict routines...are much more important, that they need boundaries and they need that comfort zone around them and they need to know exactly what they are going to do next and those sorts of things, so we tried very hard to do those and not taking her into places where there was lots of noise and lots of people and lots of busyness, to minimise the fatigue. [Pam, I2]

Two of the families, Bailey's mother and Lucy's father found it very difficult to Protect their children all of the time. Bailey's mother, Pam, worked full time and had no partner to support her in Protecting Bailey. Additionally there were several other children in the family, and her desire to meet their needs created further limits on the time she had available to Protect Bailey. Lucy's father, Grant, also worked, had no close support and had other children in the family. For both of these parents, other demands on their time, and the lack of Close Support combined to place constraints on their ability to Protect the children as much as they would have liked, creating a "*dilemma*" [Pam, I1].

...I have been told is to have such a strict routine at home that she feels like she is at school, but it's very hard when you have got other siblings too to continue that strict routine. I mean, Bailey herself can have a strict routine, like bedtimes and meal times and those sorts of things, but there are times the routine goes out the

window...because of the other kids. You know, one child is running late and has to be picked up later than Bailey, and there's no baby sitter and Bailey has to be put in the car and taken. [Pam, I2]

Although John's mother also worked full time, there were no other children in the family, and she had a high level of Close Support from her husband. In fact, John's parents had made a conscious decision not to have any other children. Protecting their son was their priority.

Yeah, I mean he's my only child and he's already had a helluva life that, you know he's got to be protected basically...we were told not to have any more children, so we haven't for that reason, and I don't think we would have been able to cope with another child, because having another child and watching him and you know, that sort of thing, would have probably been too much really. I wouldn't have coped. [Theresa, I1]

### ***Protecting: Doing With and Doing For***

The parents in the study valued the time they spent with their children assisting them and joining in with their occupations. This shared occupation, Doing things With the children and Doing things For the children is a strategy parents use to help Protect them. *"She's just used to me being around all the time. Her and I are always together"* [Rona, I2]. This characteristic was very evident during the participant observations, when the children seldom went off and played alone, but remained close by the parents, who would only endeavour to fit in household tasks at times when the child didn't need them. Parents seldom relied on standing back and giving verbal instruction to the child, but followed through with hands on demonstration and support. While prepared to be just be part of the activity or nearby if help was not needed, they were also immediately responsive to the child's needs for physical assistance. During interviews, parents frequently talked of their child's occupations using the pronoun "we" (e.g. *"we get dressed, then we might play with this."* *"We go swimming."* *"We read a book"*). This notion of "we" captures the closeness parents feel to these children, the special bonding that comes about through the accident and which is strengthened in joint occupation.

The amount that parents participate in occupations with their children is along a continuum. At times, parents carry out an entire occupation for their

child such as getting them dressed, showering them or feeding them their breakfast. Sometimes the parents do things side-by-side with their children, such as being part of a ball game, or looking at a special play-thing together. At other times, the child is assisted to carry out the occupation or does it themselves, with the parent close by taking an active interest in what is happening, stepping in quickly to help if there is a problem. At the furthest end of the continuum, parents back right off, giving their children space to be alone, but remaining emotionally close and monitoring their needs from a distance.

Two of the caregiving families described the way that after the accident they were continuously with the child, not even separating to sleep, and even carrying the children when they moved around. This level of shared occupation was more difficult for parents who were also in paid employment; however these people still talked of doing things together, and interacted with their children in occupation throughout participant observations. In general, as time passes, the children increase their ability to carry out occupations independently, but regress after a busy day, if unwell or stressed. At these times, caregiving shifts from Doing things With them to Doing things For them. Whatever the case, parents are closely tuned into what their child is doing and where they are, never far out of reach and ready to be right there with them.

She was very clumsy. I was always scared she was going to yeah trip. So we did a lot of carrying in those early days. [Rona, I1]

We'd sleep with him. We'd lay down with him....We laid with him to put him to sleep. [Simon, I1]

The children are at times demanding or needful of shared activity with the adults, but at other times the parents join in for enjoyment and interest. The parents Do things With their children and Do things For their children both in families where there are siblings and in families where the child with the injury is the only child. This emphasis on sharing and supporting their child's occupations creates several interrelated zones of protection.

Firstly, parents Do activities With the child to ensure their safety and success. Interest in the occupation is maintained, and frustration resulting from failure is avoided. Frustration inevitably leads to the child Losing It turning the occupation into a “*battle*”, with extremes of emotion and behaviour creating danger. Shared occupation in this respect is preventive.

You sit because he gets frustrated when he can't do it.... if you ignored it they're gonna get shitty, they're gonna lose it and you have to stop and go and sort them out and it takes twice as long to get back into it. [Donna, I2]

Pam played a ball game with Bailey during my visit. Being there with her daughter was about sharing an enjoyed activity, but also it was about ensuring Bailey didn't run off or go out onto the road.

Bailey is pleased at the chance to play a game with her mum, and also at the chance to show off her prowess at kicking. She starts throwing the ball- very high. It goes straight into Pam's carefully planted bed of lupins, and Bailey begins to tramp in after it. “Bailey, take off your socks” Pam instructs Bailey comes and sits on the step beside us and takes them off, then gets back to the game. “Be careful” Pam instructs again- she is worried Bailey will kick the ball through the fence or over into the neighbour's garden. “Keep your voice down” as the noise levels rise. The ball goes from one end of the garden to another, narrowly avoiding the danger zones. It is as though Bailey is unable to monitor risk situations for herself, and doesn't think things through...Mum is constantly monitoring these things and instructing her of risks. [Bailey, I2]

Secondly, parents Do things With the child to retrain skills and to teach new skills that are going to be difficult to achieve. This might involve learning how to do up buttons, how to ride a bike or swim, or how to put on shoes and socks, or it might be about encouraging the child to sit at the table for long enough to finish their meal. This is also a way of Protecting the child from future failure.

...she normally brings her clothes down near the kitchen, so if she needs help I can help her. It's putting her socks on, she sometimes she can't get her feet into her socks, or she puts them on the wrong way round, and she doesn't realise. [Pam, I1]

Thirdly, Doing With and Doing For is about teaching and reinforcing safe ways to carry out occupations, such as learning how to cross the road, or always wearing a helmet if you ride your bike. Although all parents do these

things with their children, these families cannot rely on words to get the right behaviour, they need to stay right in there with the children, Doing it With them and Doing it For them to ensure safety and reiterating safe routines through practice.

...the thing that I am doing at the moment is teaching him how to dive. So I think, well, I would rather him learn how to do it properly about, you teaching about you can only dive in the deep and you think “oh God if I get that into him”, because he is going to do something somewhere. If he learns how to swim properly...[Theresa, I2]

Fourthly, at times, the occupation just needs to be done. Sometimes it is easier to save time, and avoid a battle by just Doing it For them. This is particularly important if the parent is under time pressure, or if the child is tired.

Oh he loses the plot. There is screaming, crying and that sort of thing, so I always probably do, I don't want him getting too tired so I will put on his clothes and dress him and I mean I still brush his teeth and he is five.... [Theresa, I2]

During my observations with Bailey, the family needed to go out in the car to take a sibling to a dance lesson. Bailey, at 7 years old, was put in the vehicle by her mother. Doing For in this case was about time pressures.

The kids and [the dog] bundle through the doors and into the lounge. Someone is picking up L.'s bag- out, out, through the front entrance. Mum struggling to keep dog in, holding on to Bailey as she rushes out down the steps, and getting the van open. L. gets in herself, but Bailey suddenly doesn't want to. There isn't time for discussion. Pam lifts her up and puts her in, dealing with bags, doors, and seatbelt all at once. [Bailey, Obs]

Finally, parents have repertoires of “quiet time” occupations that they Do With their children or Do For their children when they are tired. This might be sitting together to read a book, preparing special food, watching a favourite video, doing stickers together, or just having a lie-down together

She is usually really tired after the morning at play-centre so she usually watches a video or we, play sticker books or play with her babies or something like that. [Rona, I1]



I probably do too much for him Because it might be like he's you know, lying on his beanbag and he's "mummy can I have some toast", or something in the afternoon. I always run out and make him toast. And I think good, he's lying on the beanbag. He's resting, right, you know what I mean. It's like this treading on eggshells to make sure that he has as much rest as he can and he doesn't get too worked up. [Theresa, I2] .

In this way, rest is assured, and the child is supported in learning about the need for quiet time through repetition of familiar routines alongside the caregiver. Becoming overtired with unsafe behavioural outbursts and regression to Black Days can be avoided.

### ***Protecting: Guarding***

Guarding was another strategy used by all the parents to Protect the children and help to Hold Things Together. Guarding strategies are preventive, and involve being vigilant, remaining close to the children, and are also achieved by containing the environment. Parents are concerned the children are unable to look after themselves and are unable to rely on them for any degree of responsibility for their own safety. Guarding is seen as "*extra care*" necessary to Protect the children from the physical and emotional threats that parents are learning about, including the risk of physical injury, running off, becoming tired or overloaded, and frustration. Parents in this study stressed the rapidity at which the children would act on an impulse, using words such as "*taking off*" and "*escaping*", and describing their own actions in terms associated with surveillance, restriction, constraint, and shielding.

Because at times, I feel like I have to close her away. You know, not close her away sort of put her in a cupboard.... So I suppose I at times don't take her where I know she's not going to be well behaved or she's going to pick up on the hype vibes. [Pam, I1]

...when she first started going to the extended session she went with my caregiver who was just by her side all the time...the supervisors are just that little bit more aware of Katie. Just if she climbs something, they are there or they take her down...they're just that little bit more careful with her. [Rona, I1]

Direct guarding actions include the deliberate use of the senses such as vision and hearing, evident in parent's use of words such as "*observing*", "*watchful*", "*keeping an eye on her*", "*never let her off my sight*", and "*keep my*

*ears open*". Guarding is a full on job, not "*once in a while*" checking. Other household work is rarely the central focus, only slotted in around this essential activity. Caregivers do not allow their vigilance to lapse. This heightened perception results in increased awareness, with parents assured that they know where the child is, how they are, and what they are doing. Several times during my observations, while engaged in conversation, I would lose track of where the children had gone. Without exception the parents would pinpoint for me where the child was and what they were doing.

I just have to keep my ears open all the time. [Pam, I1]

I suppose observing him and his needs as far as watching for signs of tiredness ....  
Watching for all those signs and symptoms of fatigue. [Theresa, I1]

At an increased level of vigilance, parent's Guarding incorporates closer physical presence and actions such as "*holding on*" "*being there*" and being "*by her side*", or "*right beside*" the children. This increased level of Guarding is more evident when parents are in an unfamiliar or high-risk environment, such as the street or a shopping mall, and is a response to the parent's reduced levels of control over the environment.

I hold onto her. She'll just run ahead. Miles ahead. So you're sort of, at 7 years, and at shopping centres Bailey just gets it in her mind she's going to go somewhere and she'll go. You know you could be doing supermarket shopping, look round to see where Bailey is cause you think she's right beside you, and she's gone. [Pam, I1]

Guarding is also used indirectly, through restricting the children's access to particular physical and social environments, and through careful management or set-up of the environment. Limits might be imposed, such as not being allowed off the section, staying at home, securing windows or a door, or shutting the child out of certain areas of the house. Added attention is paid to the set-up of objects presenting safety worries, such as kitchen knives, lowering beds to prevent falls, clearing a bedroom to provide a safe, quiet place, or removal of fire-hazards like lighters. Restrictions are made for the amount of noise and stimulation through TVs or music.

Nailed the windows shut. Took everything out except a mattress on the floor and a blanket. [Theresa, I1]

That's the original doors in that corner. And she came in behind the car there, so I couldn't see her when she came down the steps. So we just put these doors on here and shut that door off. We said we didn't care how much it cost. It's just going to be done. [Rona, I1]

Families described seldom going out anywhere, particularly in the early days after the accident. This was a response to the overstimulating and fatiguing effects of other environments, and also was due to a concern that others might not be as aware of the need to guard the child closely, or that the environment might present physical hazards.

And I never took him to places like parks or anything like that. I couldn't. So he probably didn't go to too many places ... Yeah, Didn't go out. I mean Evan and I never went out for absolutely ages and ages and ages. We never even went out together. [Theresa, I2]

And it's, it's hard. We don't get to do as many things as a family as we'd like to. Because a lot of places we don't go because of the noise or too much travelling. [Donna, I1]

In the case of Bailey's mother who was renting a house, and who had moved house several times, it was particularly difficult to adequately Guard her child. Careful consideration was given to the suitability of different rental houses, limiting the options for accommodating the family. With compromise came a less than optimal environment, and limited ability to change things to provide the Protection needed.

One of my main priorities at the moment is trying to save enough money to get a deposit on a house. So we can all be secure and she can be as safe as possible. You know she's not going to ever be 100 percent safe, but as much as possible. [Pam, I1]

Direct Guarding actions of this mother were more intense to compensate for the reduced safety of the home environment, but were impossible to sustain 24 hours/day. A central goal for this mother was to purchase a home that could Protect her child from danger, and that would be there for the long-term.

### ***Protecting: Safe Routines***

Routines are established by parents as another important way of Protecting the children against dangers. Routines not only involve set times of

the day for doing things, but also specific patterns of behaviour for doing things, and for some, specific layouts of the environment. The whole of family life becomes deeply enmeshed within these Safe Routines, weaving together time, tasks, and space. The constant repetition of the Routines provides a Safe framework for the children's days, where they can begin to understand their own needs, helping them to know what happens at particular times, and to gain some independence. When Simon's mother was asked about how she contained his safety and fatigue and behaviour, she responded

It's just getting into a routine.... knowing what you've got to do when you're doing something ..... we're still getting into it now. [Donna, I2]

This statement also shows the way that the Safe Routines are not instantly established or enforced, but are something that happen within a learning context. They are something that parents and children "*get into*" like wearing new clothing until you know it and it becomes familiar and comfortable rather than having something strange and uncomfortable put onto you. Good routines flow smoothly "one thing after another", "*step by step*", "*day by day*," "*minute by minute*," and are punctual. They are not ready-made, but tailored to fit the child and their needs.

She planned his outings realising that this is his best time of day. This is the time that he needs rest. He needs his dinner at 5 o'clock on the dot which she always has ready for him, and when I come home it's just easier, it's like, cool, thanks, right into the shower you know, routine, so. [Theresa, I1]

This smooth routine carried out by John's paid attendant carer was in contrast to his mother's own routine before he had the accident.

I used to work glide time, so it might be you know, 3 or 4, go and get something for dinner. Everything was disorganised. [Theresa, I2]

The routines are all encompassing, enveloping every aspect of family life; "*It's every day life. Even going to do your shopping .... Because if you want to do the shopping and he's tired, you can't do it*" [Donna, I2]. This can be very hard on other family members at times, but is necessary in order to Hold Things Together. Early on, routines are fixed and rigid, and parents

talked of the routines feeling “tight” or “tense”, and that there could be little give.

All day, all week. We try not to vary it. If we’ve got something on, we try and have one of us stay. [Donna, I1]

As time goes on and the Safe Routines become better established, this “basic structure” provides the foundation for a little more flexibility, say, at weekends.

No, I suppose not so much structuring in the weekend but we just watch for the signs... play it a little bit more by ear.... I think we just follow that some routine right through the week- doesn’t matter what.... It’s so automatic now. We don’t even have to think about it. It’s just the way our lives are. [Theresa, I2]

Safe Routines are used in a variety of ways by the parents in response to the children’s needs. Quiet time routines are used by the parents to help prevent the children becoming tired, and to manage fatigue. Quiet time routines also encourage the children to recognise their own signs of tiredness and what to do. Quiet time was an activity that John’s mother Did With him.

Mum goes into a mode for dealing with tearful behaviour- it feels like a well-used recipe. “Where’s your blanky and bean bag?” She fetches the blanky. “Let’s have a video and a quiet time.” She cuddles John to her on the couch, and they talk of video options...”Let’s get some books. Which one? Mummy will read you some stories from the big blue book.” John gets down, then comes back with a story book. “Do you want a tissue?” He lies back against Mum with his blanky again, and Mum reads to him quietly. The house is very quiet. This is quiet time. This is what happens when John gets too tired. [John, Obs]

Parents emphasised the role routines played in assuring safety, establishing safe habits to Protect the children from further injury. While teaching their children about safety is something that all families do to different degrees, this is a particular focus for these families. Both John’s and Bailey’s mothers explained the need for ongoing repetition of behaviour with their children to build safe habits for crossing the road. Simon’s father and John’s mother stressed the safe patterns of behaviour they were building around bike riding, including always wearing a helmet, and never riding a bike unless an

adult is there. These Safe Routines are more than just spoken rules, they are actions that are carried out between the parents and children every time the situation is encountered. This need for joint action is necessary every time, as the children cannot be relied on to follow through with simply telling.

Simon's parents and Bailey's mother also used Routines of behaviour to teach their children how to handle things Safely when they were becoming stressed and "Losing It". This would involve having a special room to go to. Simon's room was set up so that if he were throwing things, there was nothing there that he could do damage with. He had got to the point that if he was becoming upset, he would recognise it himself, and head off to his room until he felt better.

T. is swinging the ruler at Simon (he was asking for it, he pushed T. first). Simon heads back to his bedroom, and after a few seconds, Dad heads down to check him. Simon's bedroom is packed- a bed and a bunk and toys everywhere, but this is where he chooses to go to calm down. [Simon, Obs]

Routines are also used to support the children's success when learning new skills and to prevent frustrations associated with failure. These routines are often supported by objects, which then became an integral part of the way the activity is done. For example, Simon had his own special chair and table kept in the same part of the lounge that he always had to sit on to help steady his hands for writing or drawing activities. Bailey's mother always used special cards with her to cue her how to get ready for school, helping to Protect against disorganisation and failure. Her words elicit a sense of the fragility of her daughter's success, and her continued need to Hold Things Together before they fall apart.

...different cards for different situations in different parts of the day, so she can be reasonably independent in like packing her schoolbag, and um, when she gets up in the morning, the order of things she has to do it, and she can refer to the pictures on the card, and that's been great..... I think if she didn't have the cards, then it would all fall apart again. [Pam, I2]

The three strategies that parents develop to give care to these children are Doing With and Doing For, Guarding, and Safe Routines. Through these strategies, parents endeavour to Protect the children from physical danger, the

risks associated with becoming tired or overloaded, and the emotional trauma of feeling frustrated or experiencing failure. For parents who are able to manage these strategies effectively, there is a sense of progress, which is called Getting Through.

### ***The Consequence: Getting Through***

The parents expressed varying perceptions of progress, or Getting Through. Getting Through is not necessarily time dependent; as the name suggests, it is a consequence that is in process (Getting), with a sense of emerging from a cloud or darkness (Black Days). It is not a static state or point of having arrived at, and all parents expressed concerns for the ongoing progress of the children, with ups and downs and changes occurring.

Families expressed different degrees of Getting Through. This was conveyed by a sense of having “*moved on*” in some way, or of being on a journey from one place to another (“*getting there*”), more particularly those families with higher levels of Close Support who felt able to Protect their children effectively: “*I’m happy now*” Mum tells me. “*We’re in a good place now.*” [John, Obs]. Families conveyed that it would have been easy to take a wrong turning “*I think that he could have gone a completely different way*” [Theresa, I1], and sorting out backwards steps were seen as getting things “*back on track*” [Theresa, I2].

Getting Through was not immediately observable, but was something the parents talked of. During their interactions with the children when Protecting them, the parents are developing an intimate or detailed Knowledge of their children. Parent’s also conveyed a sense of Seeing Progress in the children, and of different degrees of Handling their caregiving role.

### ***Getting Through: Knowledge***

During their caregiving interactions, the parents all showed very detailed Knowledge of their children which they used to understand what was happening, what could happen in particular situations, and how to help their child’s safety and success in their various occupations. This Knowledge is growing rather than static, continuing to build and change as their child progresses and develops. Knowledge is both learned and experiential, gained

through interaction with therapists and the child, through comparison with siblings, and through observation, with a focus on the parent's own child and how they functioned. Donna showed her special Knowledge of Simon's level of understanding during my visit.

Simon is wanting attention from his mother- he stands beside her and asks something. She responds promptly, treating his request as important. "How much longer?" I hear from Simon. "Four hours" Mum replies. "That long" she demonstrates with her hands a certain distance apart. Simon accepts her response immediately, and with a smile of good things to come, returns to the lounge. "We promised him a spacey game" Donna explains to me. "He doesn't understand time very well, but understands the measurement when shown by Mum and Dad's hands.".... Simon wants to know from Mum again how much longer until he gets his game. Mum patiently explains to him again. I can see she understands that he really needs to know, that it is hard for him to focus on anything else. She explains that if you say something to him you really have to follow up on it. He doesn't understand if you don't [follow up]. [Simon, Obs]

The Knowledge is very refined, and is an outcome of parents being in the context where they are Learning about Dangers. Knowledge also evolves through the parents' close interactions with the children when they are Protecting them. The Knowledge seemed to emerge whether the families had Close Support or not, but contributed to an overall sense of Getting Through. Parents employ the Knowledge to "*predict*" levels of success or failure for their children, and to know safe boundaries. By being able to predict the likely outcomes, parents are able to adopt looser routines, and can deal with problems such as fatigue or anger before they ever happen. Tensions reduce as some of the day-to-day uncertainty over dangers can be eliminated.

I think you can see the antecedents a whole lot more. Like you can see things before. You can predict things ... It's not I don't wake up and have to wait till a time that he loses it. It is like he can have a whole day of not losing it, if, you know, if his day is managed in the right way. [Theresa, I2]

So I think that's a big thing is tiredness, if you can pick the signs up early and counter them before they get extreme, that's a big part of it. [Neil, I1]

Our routine isn't as tight as it used to be... Yeah, and we now know the signs before it. It's that before thing, you can pick up, it's a lot of it. [Neil, I2]



Immediately apparent during interviews and observations was the parent's high level of awareness of the way their children did things. This awareness extends from the way a child moves, their colour, or subtle changes in their facial muscles, through to a careful analysis of the way they carry out particular occupations such as getting dressed, pedalling a bike, or attending a sports day. Parents use their own abilities or the abilities of other children as a reference point. Comparing in this way helped parents to understand what the children might need help with, and how they might cope in a situation relative to their peers.

She's able to sort of do her own pyjamas up and she sort of props herself on the edge of the couch or the chair, and she puts her clothes on that way. She can't actually stand there and do one leg at a time, but then I don't know if other kids can of her age, you know, it's probably quite a skill. [Rona, I1]

He puts a lot more into doing that same little thing. Like, his brother would pick it up in half the time Simon would. You know, not really the age difference, but I mean if you put them both on the same scale age limit, he'd pick it up in a couple of days, Simon might take a couple more. You know, something that's quite hard that's new. [Neil, I1]

Related to this awareness of their child's physical function, parents are also developing an acute awareness of the child's body rhythms, knowing their "tired times", their "grizzly grumpy times", when they will be ready to wake up, or when they will need food: *"Not so good and she just get...by the afternoon she come in and like soon, 12 o'clock, will come in and just lie down for a while."* [Grant, I1]. Utilising this awareness of their child's function, the parents are highly attuned to subtle signs and responses or variations in behaviour in their children. These signs can signal the early onset of a problem, allowing parents time to deal with it. The possibility of beginning to fit family activities in around these rhythms and signs is also created.

If he's got thinking things, if he has to think too hard, he'll start scratching his head. So you know, stop. It's time to rest. If his cheeks go bright red, you know you've got to just completely stop. And if he comes up in like little milk spots all over his arms, you know that he's getting shitty! Things like that. It's just things that you just, little quirks that you notice, with his toe, how he swings his leg, when you're walking you know he's getting too tired. [Donna, I1]

During interviews and observations I was struck by the very close emotional bonds that developed between the parents and this child who had had the brain injury. The parents would often seem to almost be inside their children's heads, interpreting their unspoken thoughts, understanding their reasoning, and Knowing what they were feeling.

You know how he works things out. Like ... when he was up at the netball waiting there he couldn't find anyone. Must of stood there for quarter of an hour waiting cause Donna thought that her girlfriend that she was with him. He went to where they were, and ... they weren't there, and he went out, car was gone, so he went back and he reckoned he stood there for a bit, and he thought, "Ohh, I'm walking home", he reckoned he knew his way home. Well. So he was happily walking along...[Neil, I1]

...she thinks that she wasn't good enough for up there sometimes. Affected her very badly, and she just couldn't focus because of um, she knows these things that she's done, but she doesn't know how to put it together to get it right I think ... And then she gives up easily on it. [Grant, I1]

In addition to Knowledge of their child's function and feelings, parents also understand how their child carries out particular activities and how they respond to particular environments. Parents intuitively begin to put this knowledge together to work out how their child might cope in particular situations. Simon's father described his concerns for Simon in playing rugby. He is aware of Simon's desire to be involved, but is concerned for his fatigue, and his protective reactions, and their affect on his ability to manage what happens during a game. The language denotes the way Neil has taken on board the terminology used by therapists ("*coordination*", "*reflex*"), but is combining this with what he knows about rugby ("*gonna hit ya*", "*tackle*", "*bump into ya*") and the way his son operates ("*he likes to be involved*", "*he's tired*", "*he might get his arm up but it's slow*").

...if he went up to where K's place up the road, they play rugby and that, he'd be straight in there, and you know, and get barrellled....Cause he doesn't like having to watch, he likes to be involved. He likes to be part of what's happening.... Especially for Simon, cause he's tired, his coordination isn't so good, it's not like you can stick your arm up all the time if someone's gonna hit ya, like in a tackle or something, or you know gonna bump into you, once he gets tired he can't get his arm up as fast as

you or me, you know it's a reflex.....Oh, even he might get it up, but you know, it's that half second too slow. [Neil, I1]

This knowledge is also used to work out what might be going on when the child is having a problem. Katie's mother explained the things she felt made it difficult for Katie when she went for an assessment.

She was in a strange place with strange people you know, and it was like right into it, and then you were there for 2 ½ hours, and I just thought it was all a bit much. [Rona, I2]

Rona is using Knowledge she has attained of Katie's wariness of different surroundings, her concentration span, and her need to be prepared, to understand the situation.

### ***Getting Through: Seeing Progress***

Families are aware to varying degrees and in different ways of Progress in their children. Progress is consistently interlinked with both time and with the parent's ability to Protect their child, as though the child is moving along a pathway hand in hand with the parent. Along this pathway, parents often turn and look back, measuring their Progress. However, the children's function is not often compared to their seeming distant pre-injury function, which can bring sadness. Donna took care to avoid traveling back that far.

...you try not to think that. That's the worst I can ever do is think it, to compare...sometimes I do, but then I try and "this is how he is, and to improve this, this is what we need to do", rather than if I went back to before, I would just get really depressed. [Donna, I2]

Parents instead measure their children's Progress against the time just after The Accident, or the starting point on the road for this new child. Discussion around how the child was doing often referred to these time frames: "*A year ago it probably would have been too much*" [Donna, I1], or "*She was so much more fragile at the start*" [Rona, I2]. Comparisons from the start point of The Accident are helpful to parents, as the differences from those early days to the present are often quite dramatic, particularly for those children who sustain more severe injuries. Theresa described the journey with her son.

Like now with some years down the track, if you had asked me these questions three years ago it would be so much more different, because then it was hitting and biting and that sort of thing...He was 18 months old and he is 5 and a bit now ... So now he's different from then. [Theresa, I1]

Using the time just after The Accident for comparison therefore can be very motivating. Simon's mother would remind herself of his progress in this way when she was feeling discouraged, looking back to see how far they had come: *"Sometimes when I get down, that's when I'll think when I first brought him home"* [Donna, I2].

Despite looking back to The Accident, parents referred infrequently to progress in terms of healing. Mending within the brain and the concept of healing is vague and cannot be seen or measured. The assumption is that something is recovering; *"...six months ago...everything was a little bit more raw then"; "another whole year of healing and growing"* [Rona, I1]. Parents are clearest about Progress when they see the changes for themselves; *"...he recognises the numbers a lot better...he went four plus four and he'll do it on his fingers and get eight...he sees that shape and he knows what it is"* [Neil, I1]. *"So he can get through a whole day without lying on the floor screaming"* [Theresa, I2].

For parents who are struggling alone to Protect their children, symptoms such as Losing It are still very evident. These parents are uncertain of their child's progress, in spite of the child making some gains. Lucy's father who also found it almost impossible to Protect his daughter did not talk at all of seeing her Progress, while Bailey's mother did not feel Progress was assured. In addition, both of these children had sustained their head injuries as the result of less severe, repeat accidents, and their lives had not been at immediate threat at the time. Improvements in their behaviour across time were less marked than for those children who had for example been hospitalised and unable even to walk. Gains were not seen as stable or steady, and both parents seemed worried and unsure for their children.

At second interview Pam talked of Bailey's Progress as identified by neuropsychologist testing, *"she scored quite well in certain areas"* but could not see any certain improvement in symptoms such as fatigue and difficult behaviour, *"fatigue is still a major for her, and that's probably what hasn't*

*improved in her is the fatigue and the memory loss, and when she's fatigued, the bad behaviour and the impulsiveness". Pam pondered over the possibility that any Progress might just be the result of growing older: "it could be a maturation thing too, so as she has grown", and "I suppose because of the fatigue, I suppose then you could say maybe a lot of repairing hasn't gone on in the brain". She felt that Progress, as measured by healing was not really happening, and that any improvements were possibly only evidence of external supports. "...the other side of Bailey is still there. She is still a fast quick child that is impulsive. ... and I don't know if that's ever going to change. I just think maybe there's things put in place to protect her". Much later in the interview, she discussed some signs of Bailey's increasing awareness of her own feelings, suspecting that this could perhaps indicate some Progress: "I suppose sometimes because she's saying she's got a sore head, she's recognising.... I suppose that's progress"*

In contrast, other families are confident about Progress, taking pride in their children's firm achievements. Caregivers are increasingly familiar with what is going on for their child, and respond readily to early signs by preventing problems before they arise. Progress for these families is seen in part as a reduction of symptoms from the time of The Accident. Reductions in symptoms such as fatigue, impulsivity, or episodes of Losing It were often simply and briefly described as "*better*" or "*getting out of that*," flagging relief, but also an easy acceptance of the child's own improvement. Parents noticed that the onset of fatigue or the time it took the children to calm down or recover from fatigue had "*moved up the time scale*" [Theresa, I1].

No, I mean every day it improves. It is just amazing, like every month I can look back and go, right, we have got through, you know, this is a little bit better or you know this is a little bit better ... [Theresa, I1]

...make sure he gets a good sleep and that. He does take a bit to come right. He's sort of shortening that up a bit, he can do a lot more now without wearing down. [Neil, I2]

Of greater concern to parents is their child's increasing ability to "*know*" and "*recognise*" their own levels of tiredness or anger, and to do the right thing about it. For parents, the child's familiarity and understanding of their own feelings is a clear sign along the road. This awareness brings about

greater two-way interaction between parents and children. The children increasingly listen to parents and talk with them about how they are feeling, while parents have positive interactions with the child when they try “*reasoning*” and “*explaining*”.

...lately we have actually been talking about his fatigue, which is great- his tiredness, and a couple of times recently he has actually acknowledged it, which normally he would fight about it, but he has acknowledged that he is tired and we need to do something restful about it. He’s got to the point now he can understand. [Theresa, I2]

Building further from this, the children who are seen as Progressing begin to stick to safety rules, and begin to manage themselves at times when they become tired or angry. With the constant repetition of Safe Routines, when the children begin to realise that they are, for example, Losing It, they know where to go and what to do until they calm down, and follow through. Katie’s mother was finding that “*She knows that she has to have a rest*” [Rona, I1], while Simon’s mother reported that he was organising his own time out: “*Yeah, he goes in and everyone just stays out.... He just goes in and he’s just, you know, yeah, he knows that it’s his, yeah.*” [Donna, I2]

Progress in the children is also seen as the development of skills. Children begin to regain earlier skills, lost as the result of the accident, and families also refer to the building of new skills. At one level, children begin to “*master the basics*” such as eating or sleeping, or getting dressed, and further along, they begin to play more independently, or learn completely new skills such as telling the time, or swimming, or riding a bike.

...after 6 months of having the head injury, he learnt those skills back. The walking got better, like he couldn’t walk up and down stairs and things like that, but he took 6 months to get back to where he sort of had had the head injury...he has just started running properly and stuff now. [Theresa, I1]

...his nanny just bought him a calculator, one of those like the playschool one...he recognises the numbers a lot better ... Yeah, it’s sort of teaching him what the look like ... He knows how to do it in his head off his hands...Now on with pressing the buttons he’s picking all his numbers up. [Neil, I1]

Mum encourages her to draw her name. Katie does this- almost all in mirror writing. Mum is proud of Katie's writing and praises her. She gently encourages her to start on the other side of the page. [Katie, Obs]

This perception of Progress motivates families to continue to act to Hold Things Together, and in this way, the process is ongoing. Progress is moving forward, feeling positive about the future. Although parents who are Protecting effectively feel certain of the gains, they are always on the lookout for things that might threaten the continuation of their child's Progress. Setbacks are feared as they might mean Progress coming to a halt, or reversing back down a difficult path. When Simon's mother was asked why she was worried about him bumping his head again, her response was "*In case it stops the progress...he's done so well. That there's already that thing of what you've already been through*" [Donna, I2]. Taking pride in his achievements, Donna feared a return for them both backwards into Black Days.

Katie's mother was also frightened of the possibility of setbacks to her daughter's Progress. People had commented to her on Katie's increasing difficulties with balance. Watchful in case this might signal that her daughter was losing ground, Rona arranged for Katie to have a developmental assessment so that any real difficulties could be identified and "*sorted out*".

...my heart was like Kaboom, cause she (the therapist) was saying things that I was like, it made me panic. And um, and she basically said that Katie wasn't where she should be considering where she'd been the last visit. And so I found that quite hard to deal with. I felt up tight.... I thought "Oh my God, she's really freaked me out and made me feel that, that something was going wrong, and that Katie was going backwards or something was going on in her head. She just gave me a fright.... Cause I was just a little bit upset, just sort of deep down, that she didn't get all this glowing report ...But I'm really pleased that [the physiotherapist] is coming. Fortnightly, til Christmas. [Rona, I2]

Rona's words following the assessment spelled out her high level of apprehension that Katie might be moving backwards rather than forwards along the path, that she needs to be watchful of her Progress.

### ***Getting Through: Handling It***

The parents all expressed different degrees along a continuum of their ability to Handle the caregiving, and of how well they were Getting Through. Handling It is about “*coping*” with things, or managing. It is not only about what the parents are feeling, but also the amount of hands on Protecting that they have to do and the effectiveness of that Protecting.

Parents who have high levels of Close Support, who are able to implement tight, effective Protection for their children and who perceive Progress are quietly confident of their ability to Handle It. At her second interview, John’s mother felt pleasure in how well things were going, talking about her feelings, and also what she needs to do. She uses the pronoun “we”, emphasising that the process of Holding Things Together is happening with the Close Support of John’s father.

You know it’s starting to become pleasant, probably in the last maybe six months it’s started to become more pleasant. You know, it’s okay and we can cope and we will just work our way round it and if there are some issues, we will deal with it one at a time. [Theresa, I1]

A little further back along the continuum, Simon’s mother and father had experienced ups and downs in their ability to Protect Him and in their levels of Close Support. Although they were pleased with Simon’s Progress, they described things as “*strenuous at times*” [Simon, I1], flagging that there were instances when they weren’t Handling It. Donna explained this further, showing the way her Close Support helped Get her Through these times.

Sometimes you just think “right, I’ve had enough”, but then when you get like that, that’s when you have you have your people to help you and just go “time out, Bye!” [Donna, I1]

Further along the continuum again, although Lucy’s and Bailey’s parents did not feel as though they were completely “Losing It”, their words certainly conveyed the unremitting demands they felt they were facing in their efforts to Protect with little Close Support.

Yeah, I never get, I mean, it’s this full on all the time. You get used to it. [Pam, I1]



I've got Lucy to focus eh, and, oh, she keeps me on my feet. That girl gets me. [Grant, I1]

...we stuck to, we just hang in there. But she gets me going though. She gets me going. Jesus Christ. Have to run to the school, run here, flying there... [Grant, I1]

Life was spent scrambling and struggling to Hold Things Together, without let-up, things continually slipping out of their grasp.

### ***Holding Things Together: Summary***

The parent's need to Hold Things Together is prompted by Black Days, which refers to the experience of disorder and darkness engendered by the events of The Accident, the A-Z Changes that this brings about and concerns that both they and the child are Losing It.

Parents are Learning about the Dangers facing their child. In this context they are Becoming Aware of the effects of the brain injury, and are on the Alert to Threats to their child's safety. Parents begin Recognising Signs that the child is becoming tired or stressed, and are constantly Fearing Further Knocks to the child's head.

Instigated by Black Days and while still Learning about the Dangers, parents begin Protecting their children. This is achieved through Doing things With the children and Doing things For the children. Parents also Guard the children and establish Safe Routines.

Parents' ability to carry out Protecting actions and Hold Things Together effectively is mediated by the levels of Close Support surrounding them. Close Support helps by having somebody who is seen by the parents as Going Through the same experiences Together with them, and someone who is also able to Work Together closely with them.

As a result of Protecting their children, parents experience, to greater and lesser degrees, a sense of Getting Through. They attain a close Knowledge of their child and their capabilities, begin to see Progress in the child, and feel they are Handling their caregiving role.

Although parents are Holding Things Together, they often feel alone in their role, and both they and the child are isolated from others in the

community. The need to be part of things again is the force driving the second caregiving process, *Joining My Child With Others*, and this process is described in the next chapter.

## Chapter Five: Joining My Child With Others

This chapter examines the second caregiving process that emerged during data analysis, Joining My Child With Others. This term refers to the things that are involved when caregivers endeavour to integrate the child with other people in the community. Again, Strauss and Corbin's (1998) conditional paradigm is used to represent the relationships between the categories and subcategories comprising this caregiving process, and these are shown in the table below.

**Table 3**

**Joining My Child With Others**

Paradigm Component	Categories	Sub-categories
Causal Conditions	Needing to be Part of Things	Isolation Child's Wants Other Demands
Contextual Conditions	Using Knowledge	Predicting the Risks Weighing Up Planning
Intervening Conditions	Family and Community Support	Understanding Involvement
Actions/Interactions	Setting Up	Having a Routine Getting What's Needed
Consequences	Occupation With Others	Letting Go Fitting In Monitoring Sorting It Out

During the process of Joining My Child With Others the parents actively work to integrate their child successfully into occupations with other adults and children in their local community. The parents are endeavouring to prevent the child experiencing failure through negative interactions and Losing It. Not all parents perceive that they are successful in their efforts, and in certain situations which are discussed in the following sections, parents find it very difficult to Join their Child with Others.

Parents find this caregiving process restrictive and frustrating at times. Although it places limitations on the family's ability to do things together spontaneously, nonetheless parents see it as necessary: "...*I mean we're a normal family, but at times we're not. You know we can't do normal things as a family. Cause somebody always has to get left behind. Or you have to structure it really tight*" [Pam, I1]. Successful social interactions were highly valued by parents in this study, who all voiced concerns for their children's ability to be with others successfully in the future when they were no longer there for them.

Everybody likes to have social interaction, you know, good times with other people, so I think you know it is important. I think it's important that she does and she does have some good times... you notice some children are on the outer all the time and what a stress it is in their lives and how they become almost picked on .... I'm not saying she has to be the most popular person in the class, but it's just if the other children can understand what ...because I think if she's going to live in isolation, then the frustration and violent side might come out more later on when she is a teenager. [Pam, I2]

They try to help Lucy fit in, to be at school. That's all I ask to have for my girl. [Grant, I1]

The Joining My Child With Others process was apparent during interviews, when parents described "going to" and "coming to" and "doing with," referring to times when the child was spending time with others. This might have been going to do the shopping, or other children coming to the home to visit after school, visiting a grandparent, or joining in a game with siblings. On a more formal level, children were going to pre-school and school, or attending swimming lessons, or taking part in sports activities. However it was evident that for the children to do any of these things, varying degrees of organisation were involved. At times it appeared that a deliberate decision might be made for the child not to be part of an activity. As part of a considered strategic process, this ensured the child was not set up to fail in their interactions, or did not become overtired and require further restrictions the next day.

...because you know it's going to be a long day, then I get someone to come with me. Otherwise, if I know it's going to be really hot, then I leave him with Neil or someone who I feel comfortable leaving him with. [Donna, I2]

The Joining My Child With Others process occurs concurrently with and is interdependent with the process of Holding Things Together, although at different times there is more emphasis on one process than the other. For example, shortly after The Accident, parents of younger children focus more on Holding Things Together, largely Protecting the children at home, with very little interaction with other people. As these children progress, or grow old enough to attend school, the emphasis shifts to Joining My Child With Others, although the parents continue to Hold Things Together in order to optimally support this second process.

Although the two processes are side-by-side, they are very different. Joining My Child With Others is less emotional than Holding Things Together. The process is logical and methodical, focusing on practical goals around the child's participation in particular circumstances. Parents are using information and resources in planning, reasoning, and organising. Interactions with other people are involved throughout.

The Joining My Child With Others caregiving process arises from the child Needing to be Part of Things. In this context, caregivers are Using Knowledge in order to Set Up for their child to be included in Occupation With Others. The process is mediated by the amount of Support available from the rest of the Family and the Community. The remainder of this chapter discusses each of these categories and subcategories in greater detail.

### ***The Cause: Needing to be Part of Things***

The parents' actions in Joining their Child With Others are instigated by a Need for the Child to be Part of Things. The parents in this study all placed high value on their children spending time with other people in their community, and were aware of the Isolation from the rest of the world that had occurred after their child's brain injury. In many cases, the Child expressed that he or she Wanted to Do Things With Other children. At other times, parents acted in response to Other Demands. These included things such as the

requirement for a child to attend school, the need for the parent to go out and do the household shopping, or in some instances, to improve the child's interactions with their siblings.

It was apparent that for the Child to experience success in these types of interactions, it was not enough for the parent to just take them along or to have others visit the home. Outings or other children visiting involve changes to the Safe Routines that the parents are managing as part of Holding Things Together, with increased levels of noise and activity, possible interruptions to quiet routines and increased opportunities for the child to experience frustration. There were many instances described of the child Losing It during these interactions, and the parent having to curtail the outing.

At Touch, one of the boys hit him and Simon come away and then the boy teased him and Simon just ran after that boy, didn't you Simon, and when I said "Stop!", Simon got wild at me for stopping him, and attacked me, so I had to pick him up and go right away until he calmed down. [Donna, I2]

I mean the number of times I have walked out of that place, just leaving the things in the shopping trolley, just walking out. [Theresa, I1]

At other times parents described needing to manage the "*roll over*" effects [Pam, I1] through the next few days if the child became over-tired: "*three days consequence of one night going out!*" [Theresa, I2].

Some of the differing levels of success in Joining the Child with Others come about through conflict within this causal condition. In Lucy's situation, although her father didn't want her to be isolated at home, Lucy didn't Want to go to school at all, based on her feelings that she was seen as stupid and that the other children were laughing at her. However there was a legal requirement (Outside Demand) for her to attend school. Despite strenuous efforts on her father's part and also on the part of staff at the school, her interactions with others were unsuccessful, and she rarely attended.

Joining My Child With Others successfully becomes harder as the child becomes older and has increased motivation and ability to get about in the community. This is again illustrated in Lucy's case, where she would run off from school and make her own way down to the local shops, hanging out there until her father came home.

I got her to the school for the interview early this year. I got her looking nice at the beginning of the year. Not so long after that her schooling just dropped. Yes, just dropped, and got so bad that now I come home, get Lucy ready. We've got so bad now we've got taxis that pick her up in the morning and taxis to bring her home after school. And that's a very good help. The thing is I thought Lucy could hop on the taxi here and go to school- but when she gets off at school, she goes the other way- she took off. There've been a few other times where we thought she was at school but she wasn't. She knows to wait like till when school finishes before she comes home. Afterwards she comes from school, but I found out afterwards that she wasn't. [Grant, 11]

Additional problems arise with older children for whom there are greater expectations for their participation, creating higher levels of fatigue, and an associated increased tendency to run off. For Bailey too, if she decided she wanted to visit a friend, even if her mother didn't want her to due to fatigue levels after school, she would just take off down the road, and her size, speed and ability to undo latches and locks made it difficult to restrict her.

### ***Needing to be Part of Things: Isolation***

Many of the families feel Isolated after their child's traumatic brain injury, and parents are concerned not only that the child is missing out on the company of others, but also that others in the family are restricted in their ability to spend time with others in occupations outside the home.

There are two overlapping parts to the Isolation. Firstly, parents are aware of their child being Isolated. Parents are concerned by the physical limitations the injury places on the child, such as difficulty walking, or nausea, and also by the child's tendency to Lose It when tired or stressed. These concerns lead to the parents themselves Isolating their child from some activities. Further parent-related restrictions on the child's activities stem from Protecting actions, such as the parents limiting the child's environment, Guarding them from dangerous activities, or enforcing Safe Routines around meal-times and rest-times.

Lucy is not very, she gets car-sick very fast. It just knocks her around a bit. ... She's not a very good girl to take along far. That's the other reason she's not going with the other kids in the holidays. [Grant, 11]

And she can't understand why she can't do it. On a playground, not letting her play on the higher equipment, and she feels left out, so it's all that explaining again. [Pam, I1]

Yeah, it's the routine, and you can't really do things on the spur of the moment and you always have a caregiver around so you can't do some things, and really people still not understanding when you're out in public.... The routines are still there, but I suppose, I mean she just comments more if she gets left home when she wants to come. [Pam, I2]

As this quote from Bailey's mother shows, the child's Isolation also comes about through other's reactions. Sometimes siblings exclude the child from their play. *"They just yell at her and shut their bedroom doors and she feels really sad because she thinks they're there to play and...she comes to me or just, she'll go away and cry"* [Pam, I1]. Bailey's mother was also saddened that she was seldom asked anywhere by other families, and that she was avoided by others.

At the moment... which I find very hard is that she doesn't get invited out. And some people don't want to come to our home. And she can be a neat kid as well, you know. But, whether they're scared of her epilepsy, or are scared of, I don't know. [Pam, I1]

Secondly, and related to the child's Isolation, parents feel Isolated themselves. Early on, due to the caregiving demands imposed during Holding Things Together, including the need to Protect the child, some parents feel that it is almost impossible to go out, even to the point of having difficulty getting out to do the shopping.

... it's taken 3½ years before we could go to [the shopping mall]... I used to go every day and just get one or two things. Couldn't do it, or if we couldn't you know do one big bulk shop, one of us would just go [Theresa, I1].

At the start we never went anywhere. We just stayed home. Because of his condition of how he was, you know. Because, we were still holding him to stand when we came home and ...and, yeah, it's really, you just feel isolated. [Donna, I2]

It is often therefore a conscious decision to exclude the child from outings. However along with feelings of relief for the parents if the child stayed at home with somebody else, came feelings of remorse at not including them. Parents were faced with the conflicting desires to adequately Protect their



child, to meet their own needs and the needs of siblings to be in the wider community, and also to prevent the child's Isolation.

It also meant that the family as such, couldn't function like a normal family I suppose because we had to leave Bailey at home all the time...Yeah, it was very hard. I mean there was two minds there because she was difficult, you know it was like "phew, we don't have to take Bailey, and we don't have to worry about her in this situation." And we can just get on with it and do it and she'd be home, but then I felt guilty that she was being left out of all these activities. [Pam, I2]

Because he's not allowed to go off the section, like other kids can go over to the neighbours and play, but he can't, so we have to compensate by going other places with him. [Donna, I2]

But the conflict we have is if the rest of the family and I want to go out and do something that's probably not a good idea for Bailey, like going into a shopping centre, she always wants to come as well. And I suppose it's getting the fine balance of letting her enjoy things with the family, and not letting her miss out on too many things. And I suppose, we have to expose her to those sort of things, even though I know it's quite, probably an unsuitable place to take her. [Pam, I1]

The tension brought about through these conflicting factors means Isolation becomes a motivation to ensure the child is successfully Joined With Others whenever possible.

### ***Needing to be Part of Things: Child's Wants***

Another condition driving the families to Join Their Child With Others is the child's own needs and desires. Almost all of the parents spoke of their child Wanting to go to particular places or activities such as a sports training, or to kindergarten, or Wanting to be part of family occupations such as the other children's games. This was particularly obvious in families where the child had other siblings, and the child would Want to be part of whatever they were doing.

He doesn't like getting left out. He loves going to things like that and watching them and running around with the ball and that. [Donna, I1]

We're going to have to give her swimming lessons this summer. But she wants to get into everything that Daniel's doing. Like she wants to play soccer, and she wants to do this...She does want to play soccer. [Rona, I1]

The child's Wants create challenging situations for the parents. For these children, Wanting to do something is a very strong emotion or yearning, and for them to be thwarted in their desire can lead to sadness, outbursts or Losing It. Pam described the way Bailey would build up an image in her mind of how wonderful a particular activity would be, and how she was unable to understand when her image couldn't happen due to risks to her physical safety or the risk of becoming overtired.

Like people just saying, or asking Bailey, "do you want to come to the pictures?" And not realising that, that is she fatigued, is it a good day for her, because then if she can't go, she just gets pictures in her mind and wants to go. Or places like Rainbow's End, and things like that.... She just wants to do it. That's it. And it becomes, it's just chaotic. And in the end she just ends up in a crying heap really. Thinking that she's been left out yet again. Not going, but, it's a whole huge drama. [Pam, I1]

Conversely, the child not Wanting to do something also creates challenges for parents as discussed above with Lucy who didn't Want to go to school. The child not Wanting to do something therefore is also a motivating factor for the parents to devote time and energy to Join their Child With Others. Simon also had a time when he didn't Want to attend school, and Donna and Neil described the way they organised for him to walk to school with the other children because this was something that he did Want to do.

I walk him to school with the other kids because he is playing up and wouldn't go. So if we walk with the other kids, he'll stay at school for that hour. Yeah, I think a bit of a play because he wanted to, he'd been saying for ages he wants to walk to school with the kids, and then he played on it a bit so he could get to go with them eh? You know rather than you picked up and take him. I think. Because he enjoys going to school in the morning with them. [Donna, I1]

These parents modified the way they did things, capitalising on their child's Wants in order to successfully Join Him With Others at school.

### ***Needing to be Part of Things: Other Demands***

In addition to concerns over Isolation and the Child's own Wants, there are also requirements that are external to the parent and child which compel them to work towards Joining Their Child With Others. The most obvious of

these Other Demands is the need for the child to attend school. The participants all discussed this requirement and their feelings about it.

Katie was still at kindergarten, but her mother expressed concerns for the time when school would inevitably need to happen. The words used by Katie's mother point to her worries over who would be there to provide the "extra care" that Katie had always had to Protect her, and feelings that this would not be possible at school. John's mother also described the anxiety around this time and the issues that had concerned her.

And like even now, like she's just turned four, I thought "oh My God, she's going to be going to school next year," and I'm sort of getting a bit sort of up-tight about that too even now a year out. And like "Oh My God, she's going to be at school, and no one's going to have that, no one is going to be there to do that extra". Because they just can't at school. And it's a fantastic school and everything, but I'm thinking, ohhh. But luckily, it's another whole year, that's another whole year of healing and growing...[Rona, I1]

I think that the big anticipation was him starting school and for me, I've just got this great sense of relief because I've been so anxious about how he's going to go, how he's going to go in the noisy classroom, how he's you know going to cope with the day and the tiredness and um, touch wood, he's you know, he's coping well. [Theresa, I1]

As well as parents needing to plan how best to Join Their Child With Others when they start school, external demands such as changes at school sometimes force adjustments to existing routines. Examples of this include moving up a class, changes to the amount of time spent at school, a new activity at school such as swimming, a sports day or concert, moving to a new school, or school holidays. These changes all trigger caregiving efforts to be directed towards arranging things to ensure successful participation with the other children.

Usually at school she normally, she was only doing a half a day at school. Now she's doing, on some days she's doing slightly longer hours. But she um, has a rest at school. She doesn't go home at lunchtime, and she has a sleep at school in sick-bay. And during the school morning, when her caregiver can see that she's probably losing concentration, she'll take her out for five or ten minutes just to have some quiet time before she brings her back into the classroom. [Pam, I1]

If you've got something coming up though, like if, there's going to be on a Friday, their school assembly, and they want the kids to get up and sing, Simon never, because like, you go into class and the kids in two days would learn a song. Simon, we'd have to come home for two weeks and practise and practise and practise. [Donna, I1]

As these excerpts illustrate, at times there are Demands for the child to be part of something that bring about caregiving actions to Join The Child With Others. At other times, there are demands for a parent or sibling to attend something, such as a sports practice, or dance lessons. This also means that plans may need to be made for the child to be Joined in for things to run smoothly at the activity.

Even with Nettie's sports...because like at the moment, Nettie's going out West, so for us to be there the whole day, and enjoy it... because you know it's going to be a long day, then I get someone to come with me. Yeah, otherwise if I know it's going to be really hot, then I leave him with Neil or someone who I feel comfortable leaving him with. So now we're trying to get Simon to be happy to watch them, and because he gets upset because he's not doing it, we find something he can do there, that, while they're doing it. [Donna, I1]

In this case, sports practices for Simon's sister and Simon's wants were both conditions that caused Donna to set about Joining Him With Others.

### ***The Context: Using Knowledge***

The caregiving actions involved in Joining My Child With Others occur in a context of Using Knowledge about the child, the environment and the tasks that will be involved. This Knowledge is being gained as a consequence of Holding Things Together (refer to Chapter Four, Getting Through), and is one of the ways in which the two caregiving processes interlock and support each other. In the Joining My Child With Others caregiving process, the Knowledge gained is being used to Predict the various Risks (both physical and emotional) of the child being with others, to Weigh Up the options and benefits, and to Plan or identify things that might help bring about positive outcomes.

Early on after the accident, the risks of the child being with others often out-weigh the benefits, and parents Know less about things that they can do to enable successful interactions: *"It's just not worth it. It's not worth the crying"*

[Theresa, I1]. At this stage, as discussed in Chapter Four, the child tends to be Protected close to home, with only limited contact taking place, such as a visit to a grandparent, or a short walk to the local playground. For Bailey, a child who was already at school, attendance at this time was limited to a few hours a day. At times, Other Demands such as a need to do the shopping necessitate Joining Their Child With Others, and as described previously, many of these early interactions are unsuccessful.

As time goes by, with parents becoming more confident at Protecting the Child, Seeing Progress and better able to Handle their role, increasing Knowledge means the Risks are better able to be Predicted. Driven by the Need to Be Part of Things, the benefits begin to outweigh the risks and with Knowledge, the parents are better equipped to Plan and focus more on Joining Their Child With Others.

Because you're in more of a routine and you know now- like we know if we want to go shopping, it's going to tire him out. And if we go in the morning it's better, so you sort of just plan well in advance. More in advance than you would before. [Donna, I2]

Lucy was the exception in this case. As described in Chapter Four, her father had Become Aware over an extended period of time of the ways in which the brain injury was affecting her. Consequently, Lucy was attending school without her father having and Using Knowledge to Join Her With Others effectively. Lucy had great difficulty Fitting In, experienced negative interactions, and therefore did not Want to be at school. As a result, further efforts to Join Her With Others were hampered.

...a couple of months back, she started to "don't want to go to school", Lucy just doesn't want to go to school and I won't push her, because if I push her- I drop her off, it goes, I see her, I take her to the office, they take her to her class, I leave school, Lucy leaves through the other door. Gone...It's totally a waste of time. And so me and the school understand that, look, if she doesn't want to come, please, I know. [Grant, I1]

Parents who have limited Knowledge about a particular environment or the way their child might respond to unfamiliar tasks express fear and anxiety. Unfamiliar environments or occupations made it difficult for them to predict how their child will respond, and to know what they can do to help them.

Like a woman rang me today saying, “I would really like to have John over to play on Friday”, and I’m going “Oh, I don’t want him to go and play” because I don’t know what that place is like and is he going to be safe enough, and what happens if he’s naughty, and what do I say to them. You know what I mean. I still don’t feel like, I’m not relaxed about it yet. [Theresa, I2]

Theresa’s words show that when parents have insufficient Knowledge, they revert to Protecting, but the problems with Isolation remain.

### ***Using Knowledge: Predicting the Risks***

The families described the ways they were able to increasingly Use Knowledge to Predict the Risks to their child in particular situations where they would be with others. These might be physical Risks such as the Risk of falls and Further Knocks in a school playground. Equally, it might be the Risks of failure, such as Losing It due to frustration over inability to manage a classroom task, or due to overtiredness. This ability to Predict is built out of the foundation of practical Knowledge of the child’s abilities, their signs of tiredness, and their rhythms such as the times they required rest, or the length of time they can concentrate for. On Katie’s visit to her brother at the primary school, Theresa had good knowledge of Katie’s ability to cope with the stairs there, and let her negotiate them on her own.

Mum has to pick up some things from the school office which is upstairs. Katie makes her own way upstairs. Mum is carrying M. Katie waits quietly while Mum talks to the office person, then we all make our way downstairs, Katie leading. She is hesitant on the stairs, judging her foot placement carefully, but also looking around frequently. Mum seems unconcerned and says she manages the stairs safely. [Katie, Obs]

At my second interview with her, John’s mother described the risks she could foresee when he began swimming at school. She could clearly Predict Risks, raising a number of questions she needed to address. Predicting creates worries for parents, but also sets the scene for knowing what needs to be done.

I think “oh gosh... what’s he going to do at the swimming pool if he’s tired and grotty like this at the school swimming pool. He’s going to jump on someone. He’s going to bang. He’s going to slip. He’s going to fall, because he’s clumsy”.... The other day I took him to the swimming pool, he lost the plot because he couldn’t get his tog top off. He was screaming, yelling, lying, you know, just hysterical. I know it’s because he

was tired, but I kept on thinking when he has swimming at school, how is he going to get his tog top off without losing the plot...Because they have to do it by themselves. [Theresa, I2]

As the time came closer for Katie to attend school, Rona was beginning to Predict the way her daughter would manage, based on the way she responded to activities at kindergarten. However, uncertainty over Katie's progress in recent developmental testing made Predicting difficult, and continued to create some anxiety. Predicting was also hampered by insufficient knowledge about what Katie would be required to do at school.

By the time she goes to school in eight months time or whenever it is, she will probably be just as ready as David was, I don't know.... I think I am concerned with Katie, it is going to be a little bit different with her. Even though she goes off to pre-school, she loves it and fits in there.... Because she enjoys that whole structure and with mat time, and the singing and the worksheets and stuff they do there. Hopefully they don't do maths there like they send home in their homework book. So I guess she will probably click into it just the same. I don't know. [Rona, I2]

John's mother described the way her knowledge of his physical signs and his rhythms enabled her to Predict a bad outcome for him on a weekend visit. In this instance she didn't take him.

We just watch for the signs, watch for them, the rubbing of the eyes, or the grizzling or the crying, and just play it a little bit more by ear. So like he was invited to a party on Sunday, but he was too tired. He had already started crying by 9 o'clock that morning, so I just didn't take him to the party. [Theresa, I2]

Using her Knowledge of her child and the activity enabled Theresa to Predict The Risks of him attending. Her decision was made after Weighing Up the Risks against the benefits, and this process is described next.

### ***Using Knowledge: Weighing Up***

While considering the Risks, parents also use their Knowledge to Weigh Up the relative benefits of the child being with others, and to Weigh Up the options around such an event. Weighing Up involves careful consideration of the options and likely consequences. Judgement is made of the value or worth of the event. Weighing Up enables parents to come to the best decision about

whether or not to let the child participate, and to make appropriate choices around such participation, such as timing or venue. The parent's words during interviews indicate an active thinking process that occurs around opportunities for the child to be with others, and a need for the parents to make an informed decision one way or another.

This Weighing Up might involve consideration of the child's levels of tiredness, their skills, the demands of the occupation, other events that might be scheduled, and the child's own wishes. At times, as with John's mother in the last example, it was a relatively straightforward process. In other instances, the parents found it difficult to make decisions and were very aware of the importance of the decisions they made. Pam Weighs Up here the relative importance of Bailey attending swimming lessons on a Friday when she is tired after school.

I mean sometimes she does swimming on the Friday afternoon and if she's really, really fatigued, then she can't go to swimming. The teacher doesn't understand, you know what it's like. You've paid this money. You really want her to go, but now she's fatigued, is it worth it? You know she needs to know how to swim, so...[Pam, I2]

Weighing Up was an ongoing part of the families' lives. For Pam, further Weighing Up took place over the decision to organise things ready for Bailey to play netball. In this case, Weighing Up had to this point resulted in the decision that she wasn't ready. However, Pam, her mother, had recently decided that it was the right time for her to have a go. This decision was based on Bailey's improving ball skills, the availability of her older sister, and Bailey's desire to play netball like her sister. Nevertheless Pam had some remaining concerns about her fatigue.

I want her to go. This year she's going to start playing netball. Her older sister does netball, and they can go to the practices together as part of the school team, and she won't initially start playing the games in the league, but she's always wanted to do that, so she can be part of the team. Hopefully she can be taught the rules and stay within the rules, and go on the netball court.... If she's going to go and join and become part of the team, then the fatigue part, and it might be contrary to the fatigue part. [Pam, I2]



Parents sometimes expressed the burden associated with this kind of decision-making. Consideration is needed of so many aspects of the participation, and the wrong decision can have serious consequences, such as a return to Black Days, or problems with participation in the future. Simon's parents, Donna and Neil, faced the need to Weigh Up the options around how many days a week he was ready to cope with at school.

...like at the moment him going to school three full days a week. They're trying to push him for five days a week, and if I said yes, I think it would just overload him and he could go backwards, and so it's like being able to talk with the teacher, with his physiotherapist, and them and say how I feel and they tell me how they feel, and know that your decision has been right for him. That's really scary, making those sorts of decisions. [Donna, I2]

Both parents felt very aware of the responsibility that their decision would carry. Weighing Up entailed careful balancing of information about his fatigue, his learning, and his physical skills in the face of other's opinions and demands.

### ***Using Knowledge: Planning***

Families also Use Knowledge to identify things that will be needed for their child to Do Things With Others successfully. Planning involves time and energy. Information is processed about all aspects of an event. Any concerns for the child are identified and ways are worked out to address them. Forethought and organising occur in advance of the event. Plans might involve finding out how special equipment could help, working out a time when the child has adequate energy, checking what the child will need to do, or ensuring enough support people will be available on an outing. Donna, Simon's mother described her use of Knowledge for Planning as "*getting into a routine*". She summarised for me what she meant.

Knowing what you've got to do when you're doing something or when you're out... knowing how you want him to be while you are out. Yeah. So if you want him to be in a good mood, so you can stay where you are, it's knowing that the others keep talking to him, give him jobs to do, like when we go to Kool Kidz Club at the school- because I go up and help after school sports. Because Simon can't play, he helps ref and he helps with the gear. [Donna, I2]

In this instance, Donna and Neil were Using their Knowledge of Simon's abilities to Plan before Joining Him in With Others in a sports practice. They Knew what he would and would not be able to manage at the event. They planned the energy levels he would need, who would be available to assist, and what activities he could do when he got there. Planning ahead means parents and children are prepared in advance of the activity. Problems can be worked through, there is time to Get What's Needed, and the child has a greater chance of successful participation.

### ***Intervening Condition: Family and Community Support***

The Support of family members and of people in the local community is an intervening condition for Joining My Child With Others. The Support that parents receive influences their decision-making and their ability to carry out the caregiving process effectively. The levels of others' Understanding intersects with the degree of their Involvement with the child to create the Support, either smoothing the way for the parents when they are Joining their Child With Others, or, at the other extreme, hindering the parents.

During my first interview with Bailey's mother, she discussed how difficult it was to go out. When she was asked what was helpful, she responded *"As far as friends go, just people understanding where Bailey is, and having her into, you know taking her and letting her sleep overnight cause they understand."*

It is important that anybody who is Involved with the child in any capacity understands about the brain injury and the child's difficulties, in order to support successful interactions. This requirement extends from neighbouring children who are visiting the family home, through to a landlord, or a checkout operator at the supermarket. However, for people who are more closely Involved with the child for greater periods of time, such as a teacher or sports coach, the greater their degree of Understanding, the more the parents are assisted in their endeavours to Join their Child With Others. On the day of my observational visit, John was anxious about the school sports day. However, Theresa was reassured that he would cope because of the Support provided by a teacher who knew him well.

“Mum, do you know how long I’ve been wearing that hat for? Home time to here.” He’s been outside practicing for the sports day. “I’m not going to go in [the sports day]. D’you have to be in a line?” Mum responds “All the other children will be doing it. Miss Young will be there.” [John, Obs]

The support in this intervening condition links and overlaps with the Close Support for the Holding Things Together process, but the features of the support are different. The Holding Things Together process is mediated by Close Support while the Joining My Child With Others process is mediated by Family and Community Support.

Within the Holding Things Together process, Close Support for parents involves a person who has Gone Through the experience with them. The experience means the Support person has Understanding of what it is like for caregivers, of the child’s signs, and of what to do, in order to Work Together closely. Within the Joining My Child With Others process however, the need for Understanding centers on the child. It is important for *all* people who have any involvement to have Understanding of *the child*. This implies practical knowledge of the reasons for the child’s difficulties, and how to help

There is often overlap across the two caregiving processes between the two types of Support. A person who provides Close Support is also able to assist in Joining My Child With Others. However, this Close Support is little help when Joining My Child With Others if there are still people present in the family or community who don’t Understand what is going on for the child or who don’t Understand what needs to be done. On the other hand, over time, good support people in the Family and Community who are very Involved with Joining My Child With Others may come to be seen as part of the Close Support and are able to help with Holding Things Together.

### ***Family and Community Support: Understanding***

The Understanding of people in the Family and Community is important to the parents’ perception of Support when they are Joining their Child With Others. The need for Understanding is focussed on the child. People who Understand recognise that there is a reason for the child’s behaviour. They are accepting of the child, and open to their inclusion. They help the parent to

Protect the child, and are open to providing practical assistance to Join the child in activities With Others.

For the child to do things with other people, Understanding is needed from both the wider family and from the public. Not all people are Understanding however. Parents struggle with the limits inadequate Understanding places on their ability to include the child successfully in settings such as sibling's play activities, school, shops, sports activities, and visits to friends. Parents feel judged for their child's behaviour, and overwhelmed by other's intrusive comments. This creates reluctance to repeat the experience.

The difficulties with others' Understanding seems to stem from the lack of the usual "markers" signaling the child's disability, such as a wheelchair, differences in gait, or signs of cognitive impairment. Even siblings find this difficult to cope with at times: "...*he looks fine, why can't he be fine?*" [Donna, I1]. The children with traumatic brain injury in this study were all able to walk independently, could all speak, and had no obvious injuries to their faces such as scarring, but all needed Protection and help to participate with others in the community. Coupled with their "normal" appearance was the fact that they were children, and problems with behaviour such as Losing It tended therefore to be interpreted as naughtiness, and as resulting from poor parenting.

You know, because he looks normal, he is reasonably intelligent. You know what I mean, and they just see it as bad parenting. That's what they see all the time. I mean people would say, "give him a smack. Give him a hiding. That'll fix him" and I would be going, "Oh, God," you know, they don't understand, and no matter how much you explain to those sort of people, that, that's just a bad child that needs to be taught a good lesson. [Theresa, I2]

...not going around in public, and people not understanding and sort of making comments, or looking at you or looking at the family, and thinking, "why can't you control your child" or "what's wrong with you" and then "Naughty Girl" and making comments to her, grabbing her by the arm and telling her off and, you know, sort of overstepping the boundaries a wee bit. [Pam, I2]

Families experience the greatest levels of support in familiar communities, where other people are aware of what has happened and of what the issues have been for the child over time. Katie's family were still living in

the same small semi-rural community that they were part of when she had the accident.

She still is treated as a special person at places like playcentre and people still freak out if she trips over or whatever... No, people still have a knowledge of Katie being just that little bit different than everybody else... but nowadays, like I've been going to playcentre for nearly five years now, so there's lots of newer people having her who have no idea if anything had have happened to her, so to them she's just a regular four year old girl. [Rona, I2]

Simon's family had also stayed in the same neighbourhood after his accident, and neighbours and their children were familiar with Simon and what had happened.

But we're lucky 'cause the kids around here like, "why's Simon got that [*special pedal on his bike*] on?" "Oh, cause he gets too tired and his leg falls off", "Okay", and they're quite happy. I think, because they're just all used to him .... Most of the people have been here for a while. So they know what's happened the last few years. [Donna, I1]

For families who move to a different neighbourhood, this same level of understanding is not automatically present, and takes time to establish. Lucy's family had moved to a new suburb some time after her accident, and the people there were unfamiliar with what had happened to her. It wasn't until after an incident when Lucy's father had to explain to them about her brain injury that they Understood the reasons for her behaviour and began to look out for her.

And then I explained to him about Lucy. How my girl is this and that. Because most of these people round here thought she is just a naughty girl. Lucy is just a naughty girl, and now some of these people are starting to understand that Lucy is not all right. She is not naughty, but she is not okay, so now they are beginning to reach out and talk to her and say, "hey girl, you all right girl?" [Grant, I1]

Understanding involves knowledge of the child. At a basic level, this involves awareness of the child's disability, and tolerance of behaviour. Parents often talked about this Understanding using negative examples, where people were not aware that anything was wrong. Donna described to me how difficult it was to take Simon out to the shopping center early on after his accident due to others not Understanding.

I used to find a lot when I went shopping, if he didn't have his helmet, people would just push him out of the way - push him over. Even when I had to hold him, they would try walking between us or they would walk past and they would just...[Donna, I2]

At a higher level, it is also helpful for other people to realise what some of the dangers are and what to do to Protect the child. At this level, people are described as Understanding when they show a genuine desire to do something to help the child be part of things. This level of Understanding is sometimes termed “*caring*” by parents, and is about a person being committed to taking care of the child and to including him or her. People who are caring are very receptive to changing things or doing whatever is needed at a practical level to help the child participate.

His class is really well, they're awesome, because the kids know to be careful of him running around when they're running around and that so they take extra care. It's neat, they call a Wednesday “Simon” day. So that they re-adjust everything for while he's there. So that's really good. [Donna, I1]

Understanding is also seen as people's expertise and skills in knowing how to best assist the child to participate. This includes experience, specialised training, and skills in working jointly with the parent. This level of Understanding was something that was described in connection with teaching staff helping Join The Child With Others in the classroom.

She's been a really good teacher. I like her style. She's a praise the positive, ignore the inappropriate behaviour. She's one of those types. And I like that style, so he's done really well there. He likes that. She gives cuddles and he's quite an affectionate cuddly child... [Theresa, I1]

Because she's gone through all the training, she cares, eh Neil. He gets on well with her kids. Cause she's home-schooled her children for the first two years, so, you know, she's quite into it. It's quite good because the home-schooling group that she was with, Simon gets on really well with them. And I've gone through play-centre with them and everything. So they are really understanding. And some days she'll take him to the home schooling group to do his school-work as a change. And because they know how he is, they adjust their things to suit him. So we are just like really lucky. [Donna, I1]

### ***Family and Community Support: Involvement***

Different people are Involved at different levels with the children when parents are Joining them With Others. The amount of support perceived by the families is built on the level of a person's Involvement relative to the amount of Understanding they have.

On an outing, there are often other people around or passers-by who have minimal Involvement. Their basic understanding of the child's disability is helpful, such as when Donna takes Simon shopping. In this case, it is a Support when people on the shop floor are familiar enough with the child and their situation to mind the family's trolley if they have to leave suddenly. More support than this is not necessary in this situation.

...if he [Simon] wants to go, unless you hold him and explain to him, then he'll just get up and go. You get used to shopping at the same shops for that reason. I only shop at [a particular supermarket] at [suburb]. If he needs to go, he'll just walk off. He'll just say, "I'm going!" Yeah. So I just say to them, "I'll be back soon," park my trolley up, and I go. And they just, ... "Got it!" But they're used to him. Yeah, those things become a big thing. [Donna, I1]

For a regular event where the child will be spending more time with others, it is supportive if those Involved know enough about the child to help the family to Join Them With the Others in some capacity. Pam was confident that Bailey's elder sister knew enough to be able to help to Join her In With netball practices, even though she wasn't fully involved with Bailey's team.

I mean her sister is in a different age group when it comes to league- she's in the intermediate age group and Bailey will be in the primary, but the actual practices are run together... So her older sister will be able to keep a little bit of an eye on her... like even though they will be practicing in different teams, she will keep an eye on her. [Pam, I2]

Similarly, Simon's mother felt that her friends who were Involved with him during Touch practice on a weekly basis Understood enough about his needs so that they could effectively help him to be part of a game.

We've got such a awesome group of friends, that when I do play touch, he can come, and they'll say "oh, we'll have a little game with you". And they'll be really careful so he thinks "oh well he got to play. " [Donna, I1]

At a high level of Involvement with Lucy's integration into the class programme, the teaching staff at her school used their expertise to develop her a specialised programme. Lucy's father recognised their support, but sadly it wasn't enough to assure Lucy's participation, due to Lucy's own dislike of attending school (not Wanting to be Part of Things) and Grant's difficulty establishing Safe Routines (Protecting).

She's got her own programme. Her own programme. They set it up for her. Away from other children. That Lucy got her own programme. Her own stuff that, she's got to go swimming, she's going to cooking, she's got her own, she's got a computer, she's got her time out. That's her sort of thing, and for the whole school to do that for me, for my daughter. I was, that's amazing. That's so good. [Grant, I1]

Despite Lucy's difficulties, Grant clearly perceived a high level of Understanding from those closely involved at her school, and felt supported in efforts to Join Her With Others.

### ***Actions and Interactions: Setting Up***

When Joining their Child With Others, parents are concerned at the possibility of their child failing in their interactions with other people, involving a return to Black Days and ongoing Isolation. Because of this, caregiving actions and interactions are directed into Setting Up for their child to Do Things With Others. Based on the Risks parents have predicted and the decisions they have made when Weighing Up the options around their child's participation, they go about implementing a Routine and Getting What's Needed to promote success: *"He still doesn't like failing. Remember how he used to get shown something down in the physio room. Go back to the room and practise - he still does. But he gets it. He gets it in the end"* [Donna, I1].

Setting Up describes organising, obtaining things, and establishing procedures. As the name implies, parents are erecting a framework to support the child's interactions. Pieces and patterns are matched and interlocked together. Missing parts are found and fitted. Information is communicated and networked to other people. Things that are needed are sourced and patterns of behaviour are adjusted to fit the new situation. Actions and interactions for Joining My Child With Others are preparatory and preventive. *"It's that*



*routine thing of knowing that if you want to do that, you do all of this in advance, so that you can do that*” [Donna, I2]. The parents conveyed the way they try to “*anticipate*” problems before they develop, and act in advance of their child Doing Things With Others. There is a feeling of working through all the issues until things are ready.

Because the children’s Doing Things With Others is in many instances ongoing (eg. attending school), these actions of Getting What’s Needed and Having a Routine are not necessarily a static piece of work. Parents also need to Set Up again in response to change (eg. a new class, moving home), and to address issues that arise before they escalate.

I don’t want to [move house] till we get it set up. ’Cause like now we’re going through all the process with the schooling, then if we move away we have to start again. So, once we get everything out of the way, we’re getting there. It’s like, even with his schooling, because he takes a lot longer than the other kids to learn, that we are still working out the best way for him to do things. And we’ve, Neil and I have always said the computer is better for him. Because he can’t write. And all that... So now we have to go through all the forms and everything of getting that done. Which so far has taken six months. And we are still at the same stage as we were six months ago. Because everyone has to do their assessment. And if one person forgets to do it, you have to go back and remind them. And so by us waiting and getting it all done here, once we get it set up we’ll be right. [Donna, I1]

In contrast to the parents’ actions when they are Protecting their child, Setting Up involves a high level of interaction with other people. Time is spent in providing information to other adults and children, and negotiating the things that can be put in place for the child to participate, such as special equipment, environments, or routines. Documentation is involved as when completing forms to obtain funding for items. Assessments are often needed, requiring hand-over of information regarding their child’s function to health professionals. Time is also invested in preparing the child, ensuring they are physically ready and have adequate energy to Do Things With Others.

Setting Up was harder for some parents than others. Donna and Neil described in very physical terms their struggle with the documentation and liaison required to obtain things they needed for Simon.

The phone goes again- this time about Simon's rehab programme. When Donna gets off she explains to me that the paperwork around Simon's accident remains an area of stress. It is hard, and it takes time to understand what to do to get the help. They find people who help them to push for what they need, but they don't need the pressure. They think it would be hard for a single person. Donna describes fighting for what you need, pushing things through, pushing. [Simon, Obs]

Not all parents were active in Setting Up. Lucy's father, Grant, had been to meetings at the school to help with Setting Up for Lucy. However, this seemed to be largely at the school's instigation, and the emphasis was on the school requiring him to be present to help with keeping his daughter at school, or giving him advice on how to manage things. Grant did not talk of things he had done himself to Set Up for Lucy to participate, other than being present at the school to encourage her to stay there, a thing both he and Lucy felt uncomfortable with. In spite of Grant's knowledge of Lucy, he did not know What Was Needed to improve the situation, in the face of Lucy's refusal to attend school at all.

In contrast, Theresa was actively involved. She described her actions when she began Setting Up for John to begin school. She was explicit in her instructions to staff as to the way she wanted her son to be Joined In.

We had a meeting. We had lots of talks and talks and talks about how we were going to do it. What we were going to say. How we were going to approach it.... So I suppose it was like four people that I talked to and Evan and I talked and we talked and we decided how we were going to do it and what we were going to say and you know that sort of thing. So we had a meeting with the deputy principal and his class teacher at the school about...a couple of weeks before he started and just explained to her basically the situation and what had happened and told her this is how we are going to work it and this is what we want to do. [Theresa, I1]

### ***Setting Up: Having a Routine***

When parents go about Setting Up for their child to do things With Others, one of the things they do is to carry over and interface the child's routines that have been established in Holding Things Together. These routines are the Safe Routines that are necessary to Protect the child from things such as physical injury, fatigue, or Losing It. Often, the routines required adjustment, either at home, in preparation for the activity With Others, or if there is a

change such as moving up a class. Negotiations with other people as to how the routine can best be fitted with what is already happening may be necessary.

Because your routine is like, so that you know that okay, if he goes into another class, his routine that he is already in- can I stick with that or do I have to change it because I have a new teacher who might not like what you're doing. So that if that's the case, then you have to, before he gets there, is know his routine and what you have to change so that his doesn't change going into that class. [Donna, I2]

John's mother described this carry over as "*tying it all together*" [I2]. There is an emphasis on promoting similarity in the way things are done, and on the follow through with temporal aspects of the child's day, such as times for rest or quiet time, in order to continue Holding Things Together while Joining My Child With Others.

It's tying it all together. Yeah, it's keeping the kindy together and doing the consistent thing and keeping the caregiver together, yeah so there's consistency of us all. It's about all managing it in the same way and all having the same goal. [Theresa, I2]

Simon's mother also identified that actively ensuring carry-over of routines between school and home is essential to successful time with others. She referred to this as "*backing each other*".

It's really hard, because this term we've both decided we're going to get stricter and we're backing each other up. That to get it to work at school, we've both got to back each other and see different things. If things aren't happy at school, it comes back at home, and if he's not happy at home, it goes to school with him. So you've got to keep it on an even sort of thing all the way through. [Donna, I2]

For Katie, her routine was largely about meeting her physical safety needs in the pre-school setting.

When she first started going to the extended session, she went with my caregiver who was just by her side all the time, but now she doesn't need a caregiver any more, but the supervisors are just that little bit more aware of Katie. Just if she climbs something, they are there, or they take her down. [Rona, I2]

The routines that Katie's parents had established around Protecting her from falls and further injury were carried over into the play-centre by staff there.

### ***Setting Up: Getting What's Needed***

When the children are going to be involved in Occupation With Others, in order to Set Up for them, the parents are active in Getting What's Needed in place for them. The parents have a Plan for successful participation. This based on the context of their Knowledge of the child, discussion with others such as therapists or teachers, where the child is going, what the child will be doing, and the Risks involved. Parents then set about working with other people and Getting What's Needed to eliminate those risks and to ensure success.

The things that are Needed are wide ranging, and include the child's own skills or energy levels, assistance at an event, equipment, a special environment, special activities, or transport. Sometimes the parents take responsibility for Getting What's Needed themselves, and at other times, someone else who is involved can help to Get What's Needed.

It is common for the parents to Set things Up carefully before a special outing or event to ensure that the child has enough energy, doesn't become overtired and Lose It. Getting What's Needed involves some restful time before the event takes place.

He knew a song from play-centre, so he went to school, and he taught the class to sing it. So at their assembly they're singing the song Simon knows you see. So for this assembly, we're going to all that week have to just keep everything nice and quiet and stay home and just so that he'll be able to last the whole assembly without walking out. [Donna, I1]

Look, if you're going to this Halloween party you need to have a quiet afternoon. You need to chill out and do your stuff in your room, or just watch a video and go to the Halloween party and you need to get straight into bed when you get home. [Theresa, I2]

For John, his mother routinely wanted to ensure he had enough energy for school, and during the week organised things so that he had early bedtimes and no other activities that could tire him out.

I think we just follow that same routine right through the week- doesn't matter what... And the other thing is if I put him to bed late, he is only going to be really tired for school, that then you know all of that stuff is going to come out, so you have to do it. There isn't any choice unless you want to keep him off school. [Theresa, I2]

Sometimes, Getting What's Needed involves the child developing a special skill to enable him or her to be part of an activity with others. At this point, there is overlap with Doing With the child, as the parents do in order to Hold Things Together. In this case however, the focus is not on Protecting the child, but on training a specific skill that is Needed to be part of an activity with others. Before he began school, John's parents focused on improving his concentration for school-work activities in order that he would be ready to learn in class.

Like before he started school I bought hundreds, spent hundreds of dollars on those activity books with the stickers, and I did them for a year. You know, book after book after book. We used to take them on holidays, try and get through you know a couple of books and just increase that he could actually sit there and do, concentrate on the sticker activity book, you know, draw a six and then colour in the flower and you just stick it, and you know, over that whole year we increased his concentration on that kind of actual, you know, almost like school work type stuff. It would have gone from you know, a couple of minutes to a good half an hour. [Theresa, I2]

John also Needed to learn how to manage his own clothes before and after a swim at school without Losing It. To Get What Was Needed in this situation, Theresa bought a top with a wider neck, and spent time with him practising until he could do it. Before joining a swimming group, Simon Needed to learn how to put his face in the water and how to continue to float if there were other people around him. His parents were supported by a friend and her children and used a noodle flotation aid to practise with him until he achieved this and was ready for the group.

We had him in the end on a noodle. And you could tow him and tip him and he's sweet as. So then I had a girlfriend who used to bring her kids down so that he got used to other kids in the water with him. Cause he'd just stop. He just stopped, and like watched them and then he'd start sinking, and forgetting. You know, it just took him back to the start. So they came every week with us cause they were happy to be going for a swim, and after a few months, eh Neil, like he got really good and it didn't bother him that they were there. [Donna, I1]

Simon's parents were also concerned about the Risk of his aggression towards his brother and other children, and focused on training him to respond appropriately if he was feeling angry.

You know how the older kids say, “oh just hit him back”, but they don’t realise that he’ll actually do it. But no, otherwise, Simon will just get up and run away. He will head from the furthestest [sic] point away from them. ...Like at the moment what we’re trying to teach Simon is his strength. That when he hits Tim, he’s not to belt him. Right, that if Tim hits him, he can smack him back like that, but not really hard. [Donna, I2]

The children themselves often Need special preparation if something is going to happen that is a variation to their Safe Routine. Getting What’s Needed in this instance involves a special explanation about what will happen. It is important to gain the children’s attention, to take care to spell out for them step by step, and to repeat things if they haven’t been taken in. Katie’s mother routinely does this with her every evening before she goes to sleep, walking it through, preparing her for what is going to happen the next day.

Katie’s a child that needs to have things explained, like you can’t just say “right today you’re going blah”. She needs to, like every night we’ve got to say “Now tomorrow... Mummy’s going to go to work, and blah blah’s going to look after you and this is going to happen and that is going to happen.” Or “tomorrow you’re going to play-centre and this is going to happen and that’s going to happen.” And she is fine. But if you try and just throw something at her with, unannounced, she just doesn’t like it. [Rona, I2]

While I was interviewing John’s mother, she had the following conversation with him about an outing that would take place after my visit. Although this conversation served the dual purpose of encouraging him into an activity during our interview, it also illustrates the way she walks him through the specifics of an activity. Information is repeated carefully with detail, and his understanding is checked.

“Mummy has to take that Beethoven video back, or are you going to watch it one more time?”

“Take it back now and get a new one. Please?”

“No, we can’t do it now. I will do it after Margaret has gone. How’s that. If you watch it one more time, we will take it back and swap it for another one.”

“If I watch it?”

“If you watch it now.”

“Mmm”

“And when you have finished watching it-“

“Mmm”

“we will take it to the video shop and swap it for another one. You can take your shoes off and just have a chill out on the couch. Okay....And then watch the video and take your shoes off and when you have finished that video, mummy will take you to the video shop. Good Boy.” [Theresa, I1]

Getting What’s Needed sometimes involves the cooperation of others, and other adults or children may Need information before the child can be successfully included. Families often use a helmet with the children, not only for Protection, but also as a sign to inform strangers that there is a reason for the behaviour should the child Lose It. The helmet is used to flag a special safety Need. Information about the child is delivered indirectly, preventing the possibility of hurtful criticism spoiling an outing.

I suppose he used to wear his helmet all the time. He used to wear his ACC helmet... Whenever he was out at any sort of physical, you know at the park environment, anywhere. He would always have that on, so that was probably a good indicator, but not you know maybe looking, his behaviour wasn’t just being just naughty. [Theresa, I2]

Parents also communicate their concerns face-to-face with those involved. People may be directly informed about the child’s special Needs in the classroom or about their particular safety Needs. Important information for school personnel is often passed on at a meeting, and is formally recorded in written records; *“We had the files and I talked to the teachers. And because I know the staff here, it was sort of a bit easier. And we had an IEP [individual education plan meeting] with everybody when a new teacher came in...”* [Pam, I2]. John’s mother always explains the issues to people, and makes certain she is always available. Plans and processes are put in place; *“I still have to say that I can’t bear the thought of not saying that he banged his head. So everywhere he goes, like we’ve been to school and said that if he bangs his*

*head, you know, we've got to be contacted, and we always have our phones on and that sort of thing...*" [Theresa, I1].

Parents are involved in Getting What's Needed when modifications to the physical or social environment are required, or if an activity is changed so that the child can join in. Simon got tired at school and had difficulty concentrating in the busy classroom. He Needed a quiet place at school where he could go to rest and study. Donna and Neil talked with staff, who Understood his difficulties, and a mattress, desk and chair were set up in a special room with a sign. These arrangements had to take into account Simon's interpretation of his environment and what he felt he Needed.

He has a special room at school that got cleaned out and she takes him in there and she just says "here's the mattress, go on"....We thought we could use the sick-bay for him for time out, but when his teacher aide went to take him there for a rest, he ran outside, clung to this pole, and wouldn't let go. "It's a sick-bay, it's not my time out room!" Okay, so now they've got a resource room which is Simon's. We put a sign on the door "Simon's sleeping". No-one comes in. Simon can go in there and do extra work with his teacher aide. [Donna, I2]

Sometimes, the child Needs somebody with them in order to help them be part of an activity. In this aspect of Getting What's Needed, the parents have a high level of involvement at events, facilitating their child's interactions with others and making sure they are Protected. Neil knew that the school sports day would be very challenging for Simon in terms of activity and noise. He attended and stayed with his son, not only to watch, but also so that Simon could take part while being Protected with quiet time.

We went up to their sports day, 'cause he did all the sports with the kids and that, and when they have to sit down in their lines and that and it's just full on, you know what kids are like, it's everyone of them's got something to say at the same time, so it's just a endless noise. He went and sat down with them and he sat there for a couple of minutes, and he got up, come over, and sat with me. It was too much. He wanted to go and sit down somewhere else where it was quiet. [Neil, I1]

Getting What's Needed involves parents acting and interacting in diverse ways with their child and with other people to bring about their child's



success. As a result of their involvement, their child spends time in Occupation With Others.

### ***The Consequences: Occupation With Others***

As a consequence of the parent's caregiving actions of Setting Up, the children join in Occupation With Other children and adults in the home and wider community. Parents talk not only of the children *being* With Others, but also of what they are *doing* With Others; the interaction is usually around an Occupation, ranging from delivering newspapers to playing species, going shopping with their parents, through to swimming, or doing schoolwork.

The success of this shared Occupation is dependent on the Children Wanting to be part of things, the Support of others, and the actions of Setting Up. The success of the children in this study varied across time and across settings, and this affected the way the children felt about themselves, the way parents felt about their participation, and also affected the parents' ongoing actions.

The children are Occupied With Others in a variety of settings and are included to different degrees. Some children at school spend their time in the classroom with other children, while others spend extensive periods of time working alone with their teacher aide. Interactions with siblings within the family vary. Some children have a great deal of positive interaction when playing with their brothers and sisters, while others have less interaction or negative interactions. Visits to shopping malls or public places such as swimming pools and playgrounds also vary in the amount of participation that takes place.

Sometimes, the children have Occupation With Others acting on their own, without the parents Joining Them. This might happen if they ran off, and was something that happened for the two older children on the study. These interactions caused the parents grave concerns for the children's safety, and in response, caregiving actions became more focused around Holding Things Together.

### ***Occupation With Others: Letting Go***

Letting Go is one of the consequences of the caregiving process of Joining My Child with Others. Letting Go is something that happens when the child has Occupation With Others, and is about the parent Letting Go of the caregiving. When something has been Joined securely, you can take your hands away a distance, and it stays together, it stays in place.

Letting Go happens at both an emotional and at a practical level for parents. At a practical level, Letting Go means the parent not being with their child, and somebody else taking responsibility for the hands-on caregiving while the child is Occupied With Others. At an emotional level, Letting Go is about the parent feeling confident to release the child away from their own care. Parents in the study talked of “Letting Go the reins”, using metaphor to indicate a removal of their caregiving hands and loosening of their links with their child. The child is still connected however; the parent is still the driver, moving along through time with them, and watching out, on the ready to pick up and grasp tight the reins again.

Letting Go for these parents therefore is not a clear-cut relinquishing of the care, and they tend to Let Go gradually. Parents express different degrees of Letting Go of their child, and also different feelings about this happening. Letting Go is harder close to The Accident, when Joining is still underway, things not yet fully fastened. *“At the beginning it was hard to let go. But um, no, now it’s fine”* [Donna, I1], and became easier with the passing of time. Early on, Theresa saw herself tensed, with her hands still grasping tightly, but gradually Letting Go a little as time moved on: *“I don’t think I have let go of the reins yet. I’m not relaxed about it yet. I think there’s been an improvement where I can take him places”* [Theresa, I2].

Some Occupations with Others require greater degrees of Letting Go, such as full days at school, while other Occupations such as playing with a sibling or a friend require minimal Letting Go, albeit giving the child some space to let this happen. Theresa acknowledged Letting Go at a physical level while John was at school, but emotionally was not confident of his safety there. Here, she felt she still needed to keep hold, picturing his movements in her

head. She felt differently about Letting Go when he spent time with his father or with his grandmother, both of whom she saw as Close Support.

Yes school has been good for him. Yeah. But I still feel anxious about his safety, behaviour, where he is, what he is doing. I don't feel it when he's with Evan. You know, obviously, but I still feel that, and I don't feel it when he is with my mother. [Theresa, I2]

Letting Go happens most easily when the parents have a high level of Family or Community Support. When this support shifts to be Close Support, a high degree of trust evolves, and Letting Go happens confidently, as was the case for Theresa. Along with this, Letting Go also reflects parents' feelings about their ability to Set Up. In the way a rider relies on well buckled harnessing, Letting Go is more difficult when the parents are unfamiliar with the environment, or are unsure of the child's safety; things are not able to be Joined together properly. When I asked Simon's mother if she felt she was Letting Go the reins yet, she responded:

Ah, yeah, cause I leave him at school. You do a little bit. It's learning to have more trust in other people...because like at school, I've got to trust the teacher aide to know when he's tired, because if he gets too tired, then the next day, that's wiped out- it's having that trust in others when they've got him. [Donna, I2]

Letting Go can be frightening for parents. There may be falls, rough landings, and pain. However, as time passes and the children become older, parents become more accepting of Letting Go.

So hopefully I'll let her go a little bit easier. Because I'm going to have to at some stage. So. But it is basically you know a scary thought. [Rona, I1]

I think that in the end, I probably let her do more things than I ever thought that a year ago I would let her or eighteen months ago that I would let her do. But I think it's a lot of that is too is cause you have to in the end, you can't, I can't be there all the time, I can't wrap her up in cotton wool all the time so I'm going to have to. [Rona, I2]

As the parent and child move forward into the future, Letting Go is inevitable. It is easiest however, when parents are certain their child had been Joined With Others securely.

### ***Occupation With Others: Fitting In***

When the children do things with other people, their parents gauge the success of their interactions in terms of their Fitting In. This is a term that was used by several families. Katie's mother also referred to the success of such interactions as "*clicking in*", while Bailey's mother talked of "*dynamics*", and John's mother talked of her concerns for his ability to "*cope*", and "*play cooperatively*". The words all indicate a sense of the child having a place with others that he or she belongs to, the way that this place is formed in part by others, and a feeling for the child's movement into, interconnection with, and feelings of acceptance into this place.

They all play pretty well together. I think that's a big part, a really big part of it is getting him to be able to play with other kids. Oh, in particular having had an accident. That's a big thing, for him to fit in. [Neil, I1]

Fitting In therefore involves both the child's and others' feelings and responses, and generally occurs in the context of an occupation. Parents talk of the way their child is Fitting Into a variety of situations. These range from small interactions with siblings in the home situation, through to interactions with teachers or classmates. The child's success in doing the occupation and also the relationships they are forming with others are both important to the sense of Fitting In. Not all children Fit In, and this can be due to the parents' difficulties Setting Up, or sometimes due to inadequate Family and Community Support.

Bailey's mother at the first interview described the difficulties Bailey had Fitting In during visits with family friends. This was about Bailey's responses to her mother and other people, and their responses to her. Pam felt that the change of surroundings may also have contributed to her challenging words and actions. Bailey's responses involved changes in her behaviour, such as acting out, or seeking attention, and people found this intrusive.

And I find if people are visiting, or we're out visiting, her behaviour goes off as well. I think she's always more demanding. Whether it's just the dynamics, cause she's not getting my attention, or her sibling's attention all of the time or she just can't handle the strange environment...[Pam, I1]

Later in this interview, Pam described the difficulties Bailey also had Fitting In with her older siblings' play activities. This was an instance of Bailey having difficulty with an occupation (Lego). Pam talked about how it was for Bailey, but also how it was for her brothers and sisters. She described the other children's reluctance towards routinely creating space for her to be doing things with them because of her difficulties and the frustration it caused them. The lack of Support and Bailey's lack of skills created negative feelings about her ability to successfully Fit In.

And sometimes she cries so much that you know, that she's really remorseful. You know, she just, if she's gone and wrecked something, I mean, I sometimes remind the children that... they were seven once as well, and so that they wanted to play with their older brothers and sisters. But she consistently goes in and touches and wrecks and destroys. You know, if they've built a Lego car or something, she'll climb up onto a shelf and get it down, and try and rearrange it, which is really, you know, so there's all those things that come in to the dynamics as well. [Pam, 11]

During observations with the families, it was noticeable that these children were dominant in many of the interactions they had with others. Although it was possible that I focussed more on their part in interactions, the parents too seemed very aware of how this special child was getting on with the others at any point, and family life seemed to center around these children. Fitting In was compromised because the others felt left aside.

Because we gotta give so much with Simon before the other kids, we're not doing as much for them... So now we're trying to get Simon to be happy to watch them, and because he gets upset because he's not doing it, we find something he can do there that, um while they're doing it.... You have to watch because sometimes you get so focused on him, that for a while there I lost the progress of the other kids. [Donna, 12]

At times it is too much for the other children. Having this special child there is like a piece of a jig-saw puzzle that is a bit too large for the hole, but is being pushed in anyway, forcing other pieces apart and out of their place, then jamming in too tightly.

She has different relationships with her siblings. She finds them as a group together at times hard to interact with, but you can see the special side of each relationship when she's on a one-to-one and nobody else is round. But sometimes it's

overpowering for them because all she wants to do is be with them, and they might want to do something else, but she has to come, tag along and do everything with them. Getting stuck. [Pam, I2]

Fitting In is not a given. It does not happen automatically, but is dependent on Setting Up. When Setting Up is ineffective, the children have more difficulty Fitting In. Sometimes, parents are not able to Set Up for their child to be with others, such as when the child ran off on their own, or lack of time due to work demands. At other times, despite parents' efforts at Setting Up, these actions are ineffective in the face of other more complex issues. Lucy's father talked about the way he and the school worked together Setting Up so that his own presence at school might encourage Lucy to stay there. Unfortunately, Lucy did not see herself as Fitting In at school, due to repeated failure at lessons and falling so far behind her peers. The Setting It Up did not help matters, as Lucy perceived this as yet another factor that prevented her from Fitting In, seeing herself as being singled out and made fun of.

I go up to the school now and again, just to...I know that I am there and keep, so I can feel like it's something they try to work out if I can be there, in the hour in the day or late in the afternoon, to go with Lucy to some of her subjects. I did that for a wee while, but, I felt stupid. Looks silly sometimes. And to me I think my girl just doesn't want that kind of thing. It looks to her. It looks to the other kids that they are sort of teasing her up. [Grant, I1]

Additionally, there are many instances where the child is Fitting In initially, then there is change and they no longer Fit. John's mother told of what happened when John became overtired towards the end of the school term, and he was no longer able to Fit In with the demands of work in the classroom. The teacher was aware of what was happening for John, and the decision was made with his parents for him to stop the school term early.

It's like school last year, he got asked to leave school at the end of last year. Yeah, lost it...completely. They asked us to take him. He had a huge brain overload. She [the teacher] would say to him "John, go and sit on the mat" and he would look all confused and sit on the chair and look at her. I mean, it had been so successful you know, and I told you he got the Principal's excellence award, and she said "Look Theresa, he has just done so, so well, I just don't want it to turn to custard".... It was just fatigue and she would say "sit and do this" and he would do the opposite, not

being non-compliant, but he was obviously doing a whole lot of other naughty stuff as well...[Theresa. I2]

Families are frightened of what might happen in the future if their child does not Fit In. Theresa talked of things “*turning to custard*”. There is a perception that the problems might turn into a future mess which cannot be sorted out or unscrambled. The child could experience ongoing Isolation or a return to Black Days. Katie’s mother voiced this fear in relation to her daughter beginning school next year: “*So I guess she will probably click into it just the same. I don’t know. But I have that little fear that she is going to be my one [child] that’s really difficult*” [I2]. This fear of not Fitting In is related to another consequence of Setting Things Up for the child to have Occupation with Others. This consequence is called Monitoring.

### ***Occupation With Others: Monitoring***

Families remain involved by Monitoring their child when they have Occupation With Others. Monitoring entails finding out about and keeping track of the child’s success, safety and progress when he or she is doing things With Others. It is associated with maintaining awareness, constant review, and processing information. As well as overseeing that the child is Fitting In, parents’ Monitoring necessarily includes watching out for any dangers that might result from Occupation With Others, such as “*roll-over*”, Further Knocks, and Losing It. Thus, the caregiving process of Joining My Child With Others has links at this point to the Holding Things Together caregiving process, and parents are now Learning The Dangers that can occur in different situations.

The way Monitoring is achieved varies across families. Some parents are physically present during the child’s Occupation With Others, and can monitor very closely, as in the case of family sports practices or a playground visit. Sometimes the effects of doing things With Others are noticed by the parent on the child’s return home. In other cases, parents rely on feedback from other people, as in the child attending school. When the parent has not Set Up for the Occupation With Others, such as the child running off from school or taking off down the road, Monitoring is impossible, and this is a situation

where parents are very frightened and must rely solely on feedback from other people.

Rona discussed her Monitoring of Katie's participation at pre-school, and the way that changes in her physical abilities became apparent with her falling over more. Rona described the way that she felt more vigilant of Katie's progress than for her other children because of the accident, conveying her fear of failure for her daughter. She also spoke of the way the issues were first noticed in the situation away from home, giving her a scare when they were brought to her attention.

...as it goes along the line you get a little bit more relaxed. But with Katie it's completely different because, because I monitor her because I want to. Because I'm worried that something's, that she's not going to achieve because of this...and so, and I always think now if anything's going on I want to know about it so we can get it sorted... like the whole clumsy thing came about more so from one of the supervisor's at playcentre said to me "Oh I don't want to alarm you blah blah blah" so sometimes I think I'm watching and being vigilant, but actually I don't notice because I'm with her all the time. And someone else brings it to my attention and I think "Oh my god"...[Rona, I2]

On the other hand, it was very evident to John's mother on his return home from school that something was going wrong, affecting his ability to Fit In. Like Katie's mother, Theresa also got a jolt when this happened, showing the way that the families could never allow themselves to become complacent. They could not assume that their child was completely over the accident and could Do Things With Others with no problems.

...but then, you know we have had a week last week where we had a horrendous week where he wasn't sleeping properly. He was crying every morning before he went to school. There were tears, there was, he just you know completely, I don't know why particularly that happened, but we got it back on track, and that was fine. It was more like, "Oh my gosh, we are back to this old stuff again" so it was more like a shock. [Theresa, I2]

At one stage, Lucy's father was unaware that she was cutting school and going down on her own to the local shops where she had begun smoking. Because he had no idea what was going on, this was a situation that Grant could not Monitor at all, and he found out what was happening through his



neighbours. After this, feeling wary of her safety, he began Monitoring Lucy very closely to see exactly where she was going and what she was doing. His words “*tracking*” and “*catching*” relay an almost vigilante approach to his monitoring.

...people were telling me that Lucy has been, like down to this little shop around the corner here. Our local shop. She just goes and picks up cigarette butts from the ground to smoke, and she walks into the shopping centre, walking round picking up butts...And I didn't believe them, until the day I followed her. I tracked her down. She took off from school, I caught her then, in the centre and I watched where she was going, and she was picking up butts. [Grant, I1]

Managing difficulties with Fitting In is an ongoing, two-stage process. When, as a result of Monitoring, parents identify that there is a problem with their child Doing Things With Others, follow through is required to Sort Out any issues.

### ***Occupation With Others: Sorting It Out***

If concerns become apparent when the children are doing things With Others, parents act to address the problems, or Sort It Out. Sorting It Out is about confronting and remedying issues such as failure, physical dangers, “*roll-over*”, and Losing It. Parents also talk of “*getting it back on track*”, “*dealing with it*”, and *working with it*”. Sorting It Out is about moving in on a problem situation and getting a job done. Sorting implies that things have become tangled, or confused, and Sorting It Out applies to untangling the way the children feel about things when it is all going wrong, and also to untangling a situation that has become messy and isn't working. Simon's interactions with his brother were Sorted Out twice during my visit and observations, small tangles, deftly smoothed out by Donna.

There is another meltdown with Simon and T. I think one pushed the other. Mum seems to know instinctively who is at fault. “Say sorry to Simon, T. Tell him. Tell him. Later another small disagreement; T. hits Simon with a spoon. This causes tears, and is also dealt with... Now a ball game has stopped, and Simon is teasing T. again. “Hey T, I got your doggie.” “No!” Mum takes the dog away and gives it to Simon. “You take it out on me” from Simon. “No.” “Alright, my fault.” I guess this is a great practice arena for Simon to learn social skills. [Simon, Obs]

A number of different strategies are used to Sort It Out, depending on the issue. Often, problems require increased Protecting actions to manage fatigue resulting from Doing Things With Others. This involves a shift back to Holding Things Together, with increased emphasis on Safe Routines. At other times, further Setting Up is required, with changes of plans, or adjustment of a routine. When John started having difficulties Fitting In at school, his routine was pulled back, and his mother encouraged his paid attendant carer to Hold Things Together more closely with Safe Routines: *“So we stopped school in the last two weeks, three weeks I think. He went like a couple of half days a week and that was it. I think he went one half day.... Just quiet time. Really good, quiet time”* [Theresa, I2].

When Simon showed reluctance to go to school in the mornings Donna changed the routine they had put in place for taking him. Rather than taking him in the car, they arranged for the other children in the neighbourhood to stop in at their place, and Simon walked to school with his peers, boosting his feelings of Fitting In.

...and when he didn't want to go to school for a while, so now we walk with the kids to school. The other kids and his friends come over here in the mornings, wait for us and then we all go to school together. [Donna, I2]

Sometimes, the parents intervene directly with the child to Sort It Out. The issue is talked through, and punishment such as time out might result. Physical punishment such as smacking is avoided. Rather, if immediate action is needed to ensure safety, the child is physically removed. Bailey's mother used this strategy when Bailey Lost It with one of her siblings and hurt them. Pam explains how difficult it was to discuss it rationally with Bailey initially, and the importance attached to following through and Sorting It Out. She explained that time out was not only a punishment, but also a time when Bailey could calm down and unscramble her thinking about what had happened, ready for reasoning.

And she's very remorseful about it. Like almost like she blocks what she has done out or that her mind gets in such a state that she doesn't realise what she's done... But she's still got to be disciplined for it and she's still got to have time out. She's got to realise if this is what you're like and this is what you've done, then it can't happen

again...you know... Because you know you have to get her out of it, and you can't reason with her for any other punishment. I mean, you can't hurt her so we usually have time out and she will get "you're not allowed to watch TV". When you can reason with her, "you did do this Bailey. Yes, you know you said you were really tired and you lost it, but you have done this, so no TV". [Pam, I2]

When there is a concern over the child's progress, parents discuss the issues with their Close Support, and often seek professional advice. This process takes some time, with appointments to be made and attended, overlaid by the worry for the child's future. When there were worries over Katie's balance, her mother and father talked this over together. Appointments were made with the paediatrician and a developmental assessment was scheduled. Rona uses the word "triggered", indicating quick responses to concerns, and the chain of events that followed.

...the therapist said "oh well, I'm not so happy with her this time, and my heart was like Kaboom, cause she was saying things that I was like, it made me panic... I mean I was the one that triggered the whole thing, and the reason why we wanted to get Katie's clumsiness sorted out. Cause I actually had spoken to her paediatrician and said that I'd noticed that she's been more clumsy, so you know they're doing something about it and that's great. [Rona, I2]

Sorting It Out is often necessary as part of the Joining My Child with Others caregiving process. However, for Grant, who had not widely involved himself in Setting Up for Lucy's Occupation With Others, Sorting It Out was the dominant caregiving action. Much of Grant's time and energy was directed into addressing problems with Lucy in the community, only to have still more things go wrong. Thus, Sorting It Out is a secondary action that takes place within the caregiving process, but is a dominant action when primary caregiving actions seem ineffective or are not present. Additionally, Sorting It Out is limited in its effectiveness when these primary actions are not present.

Because Lucy's father was often at work while she was supposed to be in school and after school, Lucy was often left to her own devices.

...the lady down the road here, she knows Lucy doesn't like her daughter. So Lucy goes out. She takes off. If the lady hangs up her daughter's clothes on the line, like tops and nice things, Lucy will take them off and takes them down to the creek and just chucks them in the creek. So now she doesn't hang her daughters' clothes

out...well the worst part of it, Lucy threw rocks at their house. She went up to the shop with a rock and kept on walking. She smashed their windows... I didn't know. I didn't know this 'til very late. The window is all smashed and she never came to tell me. I found out from my littlest boy that Lucy was throwing rocks. I hit the roof. I went down there...and I said, but you got to tell me, you got to tell me, tell me so we got to do something to stop it. [Grant, 11]

Lucy's actions were distressing for many of the neighbours, but also upset her father. Sorting It Out became the focus for Grant.

### ***Joining My Child With Others: Summary***

This chapter has described the second caregiving process that the parents are involved in, Joining My Child With Others. This is a process that is focused on interactions with others. The process is triggered by the child Needing to be Part of Things outside of the relationship with their parents, sometimes due to the Child expressing their Wants to move away from the Isolating constraints of the Holding Things Together process, but also due to Other Demands such as the need to begin school. This caregiving process occurs in a context of Using Knowledge, where parents are able to Weigh Up choices around their child's participation, Predict the Risks of participation, and make Plans.

The process is moderated by the levels of Family and Community Support, which either facilitate or hinder parents' actions in Setting Up for their child to have Occupation With Others. Letting Go of the child can be difficult for parents, particularly if there is limited Support. Ongoing input is needed from parents to Monitor how their child is Fitting In and to Sort Out issues as they arise.

The next chapter will provide an overview of the findings. The chapter defines the central category Structuring For Security, and examines its key relationship with the two caregiving processes Holding Things Together and Joining My Child With Others.

## **Chapter Six: Overview of the Findings**

### ***Structuring For Security***

The two previous chapters utilised Strauss and Corbins' conditional paradigm to help explain the two caregiving processes that parents and children were involved in, Holding Things Together and Joining My Child With Others. The overarching theme of the study is captured by the central category Structuring For Security. This category encompasses the essential elements of both of the processes of Holding Things Together and Joining My Child With Others, and conceptualises caregivers' efforts to achieve both safety and success for their children. This chapter will provide an overview of the findings, based around this central category.

The chapter opens with an explanation of the way the researcher arrived at the central category Structuring For Security through analysis of data. The central category is defined, and terms are interpreted for the reader with explanations and examples. Using a diagram depicting the central category, the present chapter summarises the two caregiving processes and integrates the relationships between them, explaining how each process responded to change, and addressing the variations seen between participants.

### ***Making Sense of What Was Going On***

The commitment of the research participants to the study by creating a space in their lives for the researcher to "be there" and discover what was happening proved invaluable, in that multiple avenues were provided for gathering, analysing, and thinking about the data. Almost all of the families nominated to hold the interviews in their own homes at times that fitted with their schedules, and also welcomed the researcher into their homes during participant observations. The combination of interviews and observations with the children present imparted a wealth of information. This derived from what parents were willingly able to talk about, and also from the opportunities that were created in which to observe interactions between children and their

parents and siblings, and the way the parents and children were interacting within their own physical and social environments.

This variety of information was pivotal to the researcher arriving at the central category of the study and obtaining a more complete picture of what was going on for families when they were caregiving. Initial interviews and observations with families were a time when the researcher was quickly disabused of the understanding that data gathering for this project would be a calm, orderly, and unpressured process. Interviews and observations were carried out in the midst of caregiving and housekeeping or employment activities, and transcripts and narratives are marked by phone calls, comments and inquiries from the children, and the need to attend to them. It was very apparent that caregiving for a child with traumatic brain injury was about much more than routine family life.

The amount of activity was overwhelming at times for the researcher, and created an impression of haphazard pieces of information, with multiple colours, shapes and sizes, all scrambled together as though a child had tipped out a container of building blocks onto the floor. Early on, these disjointed pieces of information made little sense. With the ongoing sorting and sifting of data analysis, certain patterns and similarities, or themes became increasingly recognisable.

Structure was a word that came up repeatedly in conversation. Parents often articulated structure as one of the first things they were doing, and applied this term broadly to temporal aspects of the day as well as particular ways of doing things with the children. Discussions revealed that early after the brain injury, this structure wasn't present. Instead there were feelings of disorder and confusion. Structure was something the families learned to do. As well, the researcher came to realise over time that the hustle and bustle of activity observed in the families was characterised by an underlying logic or structure that was guiding the parents' actions.

Another theme frequently articulated by families was that of fear. Memories of the accident were still vivid, and although the parents did not focus on the past, the fear was associated with a need to protect or shelter the children from further physical injury and the emotional trauma of failure. Fear was heightened for situations that were unknown, where parents would have

less ability to protect the child, and was therefore often about the future, as well as the immediate present.

The actions and attitudes of other people were another recurrent theme. Parents saw their child's future not in isolation but as being linked with other adults and children. The children themselves saw doing things with other people as important. Other people could either facilitate or hinder the caregiving processes, dependent on their knowledge, level of involvement, and ability to assist, and were also seen as having a direct part to play in the child's future success in society through their responses and interactions.

Finally, the fact that the parents were constantly doing things with their hands when they were caregiving was very apparent during observations. Looking after these children was very much a hands-on job. During the researcher's visits, hands were being used to do things with the children, such as making a cake together, making a hundreds and thousands sandwich together, colouring in, exploring special toys, playing ball with the dog, getting a drink, or working in the garden. Hands were used to do things for their children, such as lifting them, carrying them, feeding and dressing them when they were too tired, holding on to them to prevent falling and running off when they were out, doing up seat-belts, setting up furniture, holding a book, or providing physical comfort when they were tired or overloaded. At a second interview with Bailey's mother, when she was talking about managing the routines as Bailey became older, I realised that when she talked of the caregiving, she held her two open hands up together as though symbolically supporting something between them.

As more information was gathered during theoretical sampling, and assisted by memos, diagramming, and Strauss and Corbin's conditional paradigm (1998), the ways that these scattered blocks of information interlocked to form a whole became more evident. Structuring for Security is the phrase that emerged out of data analysis that conceptualises what is going on for parents when they are caregiving. The words Structure and Security embrace parents' efforts to provide frameworks for their children under which they will be protected in the future in their interactions with other people, and draw on the analogy of building blocks. Structures are not there by accident, but are deliberately built, and as such require the use of hands in their

formation. The meanings of Structuring and Security are considered in the following sections.

### ***Structuring***

Structuring is a word that was frequently spoken by parents during interviews. They tended to use the word as a receptacle in which to gather together all the things they did with their children: *“Keeping his day as structured as possible” [Pam, II]*. The word was often linked with other words such as coordinating, controlling, managing, and organising, and was applied to time, space, and ways of doing things. Structuring involved deliberate arrangements such as particular points in the day for doing things, ways of responding to signs and behaviours, special ways of doing things to prevent further injuries, or setting things up carefully before visits and events. Structuring encompassed the caregiver actions of Protecting, where parents Did Things With and For their children, Guarded Them, and developed Safe Routines to prevent the child Losing It or sustaining further injury. Likewise, Structuring encompassed the actions of Setting Up, where caregivers were Getting What’s Needed and Having a Routine to support the child’s successful interactions with others.

The Chambers 21<sup>st</sup> Century Dictionary (Robinson & Davidson, 1996) defines the verb to structure as “to put into an organized form or arrangement” (p. 1399). The word derives from the Latin word *struere*, or to build. Thus, Structuring is about building something, and arranging and organising things. Buildings have organised arrangements of foundations and frames that are connected together. Upon these arrangements, people use their hands and tools to erect more complex features such as claddings, stairs, partitions, and windows, to provide shelter from the elements, movement, places to be with other people and to do things, and a way of seeing out. In the context of caregiving for children with traumatic brain injury, Structuring can be seen as arranging an organised, cohesive framework for protection for the child, and a foundation on which successful future development and interactions with the outside world can be established.

John’s mother responded in the following way when she was asked to describe the sum of what she was doing. Her words denote the way the



Structure links everything together securely, providing a framework for everyone involved to work consistently within. For Theresa, the Structuring involved great detail, specifying exactly what needed to be happening for every minute of the day, in all areas of John's life.

It's tying it all together... Yeah, it's keeping the kindly together and doing the consistent thing and keeping the caregiver together...so that there's a consistency of us all. It's about all managing it in the same way and all having the same goal... And it's taking it step-by-step, day-by-day. Taking it minute-by-minute almost. You know, trying to plan it minute-by-minute. If something changes you've got contingency situations that you can put in. [Theresa, I2]

Structuring such as this did not come about by chance. During the darkness and chaos of Black Days after the accident, or during the period of isolation when the child was unable to cope with being with other people, Structuring was not immediately present. Rather it began to emerge as parents increased their knowledge and developed strategies to address these issues for their children. Structuring involves purposeful efforts towards Holding Things Together, and Joining My Child with Others, bringing about order in the face of confusion and blueprints for the child's successful participation with others.

The literature around traumatic brain injury also holds themes of Structure. Ruth Johansen (2002) wrote of her experience of her teenage son's severe traumatic brain injury that took place in a horrific car accident. Here she incorporates a similar concept to describe the impact of her teenage son's injury on his essential being and his future development. Although Johansen does not use the word Structure here, she draws on the theme of building to describe both the way the accident affected her son and also caregiving actions. Like the parents in this study, she and her husband strove to bring order to disorder, to draw things back together, and to integrate their son back with other people. Her description is rich with metaphors that convey the way her son's life was shattered apart, and the need for Structures to be put back in place to reestablish her son's function and growth. She describes her son's first visit home (pp. 118-119).

He was in some ways like a house deserted while still under construction: the architectural plan had been laid in his genes and our dreams, a foundation lay in the

womb of the unconscious, and a framework in consciousness had been taking shape through his childhood development and choices. With the accident and coma, all visible work on his “house” had ceased. Now, back in his family home, some confusing array of biological, psychological, cognitive and spiritual elements that we still called Erik wandered, in and out among the two-by-fours, the studs and girders, and unfinished floors of his self. It was as if he had been shaken upside down and inside out; sometimes it almost seemed as if “he” had flown out of his house. Could this child’s framework ever be filled out with walls and windows and doors, with life-giving water and electrical current flowing to all parts, with rooms for inquiry and reflection, with plentiful touches of beauty and spaces for music and laughter? Could all these ragged and disarranged elements cohere?

... we sent a letter to our near neighbours and friends describing Erik’s condition, encouraging them to reintroduce themselves to him when they saw him outside and informing them that, though he would be sometimes disoriented or impassive, their engagement with him was important for his ongoing rehabilitation. We were trying to normalize and gather the disjointed pieces of a situation that could only be described as shattered.

In an interview for this study, Simon’s mother summarised her feelings about why she felt it was essential that she and Neil were proactive in Structuring things for their son. She is stating an absolute need for parents to put in place Structure so that their child with traumatic brain injury can make gains. She uses the word control not in the sense of having mastery over things, but to express a way of managing or arranging things. Control is not applied *to* the child, but to what happens *for* him (his life).

I think that’s the hardest thing... his life is your control...Your control is his life... You know, if we had just followed behind, he wouldn’t have improved how he is. I don’t think so. I don’t think he would have improved. [Donna, I2]

“Life” is also used by Donna to convey the way Structuring applies to everything and everyone concerned with the child, in the present and in the future. Structuring is all encompassing, incorporating the whole family, and extending to others such as teachers and agency caregivers within its framework. Theresa stated *“It’s like a huge coordinated event, and it’s like a whole team working together to ensure that it’s successful”* [Theresa, I2]. The Structure is there throughout the day and night, and is enduring, the way that a building provides shelter from the outside world and becomes part of our lives.

If the Structure appeared less conspicuous with time, this was only because it had become so much a part of the family life, that it was instinctive, providing an unobtrusive background framework on which life proceeded.

It's so automatic now... We don't even have to think about it. It's just the way our lives are. It's the way things are structured. [Theresa, I2]

### ***Security***

The desire to achieve Security for their child with traumatic brain injury was the reason for the caregiving, summing up what was driving the parents' actions. The Collins Concise Dictionary (Makins et al., 1995) defines Security as "the state of being secure", and also as "assured freedom from poverty or want". As an adjective, to be secure is to be "free from danger", "free from fear, care" (p. 1216). Taking these definitions, Security is therefore broadly about caregivers feeling confident that their children's wants and needs will always be successfully met. These definitions of security are in line with the particular concerns of the parents in this study, fitting with their endeavours to prevent further trauma and failure for their children, and thereby promoting their safety and success.

I suppose that to be successful is that he can go to places I know that he is sensible enough to be safe, to act appropriately. I don't mean perfectly. Five year old boys will still chase cats around the garden with sticks and stuff. I mean that's sort of boy stuff. But he won't get tired and lose the plot... For him to go off and be successful and have friends and be appropriate and to be like a 5-year old boy in a normal kind of way and not having me worry the whole time where he is, what he is doing... I suppose it's a hard thing to explain all of that... I think that I will get to the point where I think, you know, he really is quite independent to do things for himself. [Theresa, I2]

Theresa describes here the way safety and success are both components she sees as necessary for her child's Security. Safety and success were often intermeshed in this way in parents' thoughts, and were not seen by the parents as being achievable in isolation from each other. Neither were they seen as being achievable in isolation from other people. Interactions with others are an essential part of human life, and parents all saw the children's Security in the context of society, alongside other people. Parents in the study were concerned that further physical injury could trigger a return to Black Days, jeopardising

the children's behaviour, and their ability to be With Others successfully. A lack of success in their children's Occupations With Others could result in Losing It, Danger for the child and others, and ensuing Isolation. Equally, an unfulfilled Need to be Part of Things might trigger children's unsafe behaviour such as running off, or instances of Losing It. Theresa described her need to protect her son from failure.

I think I'm just, it's like the risks of him going there, what could happen and what could be the outcomes if I took that risk and I think that's a little bit too paranoid, but I want him to succeed and to be successful and to grow up and not have a whole lot of negative, I'm overprotective about the negative stuff for him...I'm just afraid of failure for him, and afraid that it's not his fault if negative things start happening around, he's tired, you know he's tired, he's fatigued and he's done something, and then it's like it's all going to be this failure stuff and I just feel like I still need to protect him. [Theresa, I2]

Similarly Pam articulated her fears for her daughter's acceptance by others in society as she became older and the risk of her becoming isolated. For Pam, Security was about Bailey having successful relationships with others and preventing the unsafe fallout from loneliness. As discussed in Chapter Five;

Everybody likes to have social interaction, you know, good times with other people, so I think it's important that she does, have some good times. You know, you notice some children are on the outer all the time, and what a stress it is in their lives and how they become almost picked on. ...because I think if she's going to live in isolation, then the frustration and the violent side might come out more later on when she is a teenager. [Pam, I2]

The future was unknown and uncertain. Arguably this is the case for all parents and children. However, for these families, the impact of the brain injury on development created even greater concerns. The past of the accident was not the focal point for parents, but could not be forgotten as it was also intertwined with their children's future. Thus, Security was also about a need to address their children's wants and needs for the future.

I can never be assured until I don't know, she's an adult perhaps. That everything is okay. Because we don't, still don't really know. I mean enough is, enough is okay to be happy. But there's things that you're still learning and striving to do when you're a

child you know. Getting to those teenage years and things. That we still don't know whether everything is quite right. [Rona, I2]

Yeah, I'm looking more towards the future. Sometimes I just think "oh, what's the future going to hold" and I get a bit, well going back and being scared of the future. But it's more that, than looking back and going, "Oh I wish the old Bailey would come back." Sort of got beyond that. [Pam, I2]

The parents were all fearful for the future, not only because it was uncertain but for the time when they could no longer be there to assist their children. Donna articulated her wishes for her son's future Security. Her desire is for him to be actively part of society, and to know that his Security will continue to be achieved as he grows up. Independence from her is not only Simon doing things on his own, but is seen as him knowing the processes to follow in society in the future when he does have a want or need.

That as an adult, he can look after himself. That's our biggest worry. Because we know that you know, one day we're not going to be here and that's quite scary. Living! Being able to live, to have a life where he doesn't have to have us with him all the time. To know that where he can turn to for help, and what to do when he needs help. [Donna, I2]

Although the two concepts of Structuring and Security have been considered separately here, in *context* they were interdependent. Structure was put in place to provide Security for the children, who were young and still had a lot of growth and development ahead of them. The Structuring provided the foundation and framework upon which could be built the child's future Security in the world. Structuring for Security was a dynamic process that shifted and adjusted as the child moved through their life.

### ***The Structuring For Security Process***

Structuring for Security conceptualises the things that go on when parents are caregiving for their children with traumatic brain injury. Structuring is used in the present tense to emphasise the ongoing and dynamic nature of the caregiving for these children. Rather than being a limited set of actions carried out repetitively by parents each day, or a sequence of different stages, the

caregiving is continuous and evolving, responding to change with the passing of time and touching every area of family life.

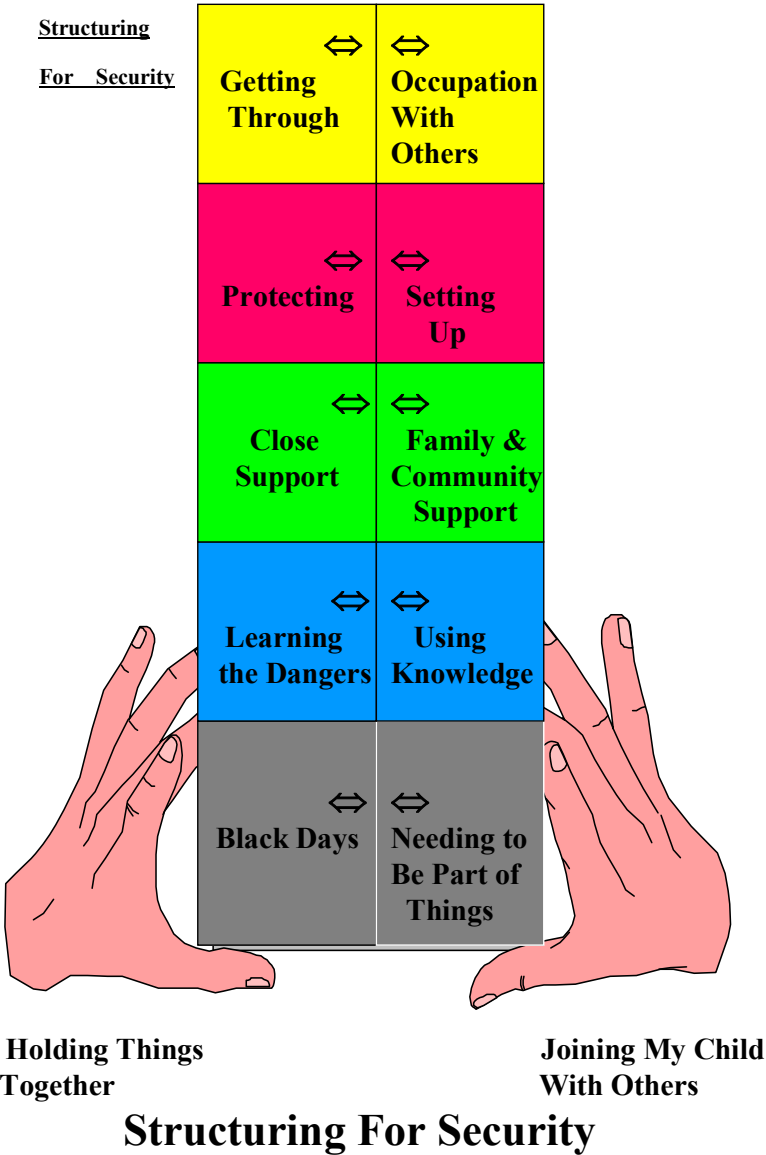
The phrase Structuring for Security encompasses both caregiving processes of Holding Things Together and Joining My Child With Others. These processes happen simultaneously, although there is wide variability in the emphasis given to each process by different families at different points in time. There is interplay between the two processes, and each is necessary for the support of the other. Imbalances create instability and create threats to the child's Security.

The following diagram, Figure 1, is an abstract representation of Structuring for Security. It depicts the hands-on nature of the caregiving, and the way the caregivers are continuously working to bring about Security. Towers of building blocks symbolise the Structuring that caregivers are using with their children, and also show the way that the two caregiving processes are built from the conditions of Black Days and Needing To Be Part of Things. Arrows represent the interplay and shift between the two caregiving processes. Like children's blocks, the towers became unstable if standing alone, if one of the blocks shifts or is too small, or if the parents' hands are removed from their position where they are Holding Things Together and Joining My Child With Others.

Figure 1:

Change

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### ***The Holding Things Together Process***

Holding Things Together is the caregiving process that emerges as a response to contain the turmoil and life-shattering events surrounding the accident. Hands are used to Hold Things Together when Structuring the scattered pieces of a building kit, bringing about order and creating cohesive, Secure frameworks that will last into the future. This process is represented by the blocks on the left hand side of the tower.

The base point of the process is Black Days, which refers to the nightmare of the accident. Families' lives are blown apart at this time, and parents' ability to care for the children is lost to them in the face of total change. Parents feel they have little choice but to set about picking up the pieces and forming them together the best way they can for their child.

Parents are precipitated into a process where they are Learning of the Dangers that their child now faces. With increasing awareness of the causes for their child's changed behaviour, parents are on the alert, watching out for threats to their children's safety, and coming to realise the signs that foretell of behavioural outbursts. Parents are fearful of further injuries for their child, but find that these are now a reality.

Close Support is gained from other people who are able to go through the process side by side with parents. This support creates feelings of trust and connectedness. It assists caregivers through the process, buffering their emotions through a mutual understanding of what is going on for the child and the family, and sharing the load of the caregiving.

Instigated by the need to move beyond the horror of Black Days, and with increasing understanding, parents embark on a course of action that is mediated by the quality of the Close Support they receive. Activity is directed towards putting together Structures to Protect the child from physical and emotional trauma. These protective Structures involve specific arrangements for the child's occupations, the environment, and the timing of routines.

Within these Structures, parents direct increased energy into their children's occupations, doing things alongside them to Protect against failure, and completing an occupation for them if they see the child is unable. The children are guarded against risks arising from unsafe environments, impulsive



behaviour, and fatigue. Building from the child's own temporal rhythms and energy levels, parents establish set daily routines that Protect against fatigue and outbursts. Routines are also used as a way of training habitual patterns of safe behaviour in the children.

Parents begin to perceive progression in the Holding Things Together process in response to their increasingly effective ability to Protect their child. A sense of Getting Through emerges with increasing knowledge of their child's needs, feelings about their own competence, and the perception that their child's ongoing physical and emotional wellbeing is more Secure.

The circumstances of some children's accidents meant that those parents took much longer to Learn the Dangers that were present. Children who had a series of less severe brain injuries were not subjected to the immediately apparent and devastating consequences of a severe brain injury where the child had required immediate hospitalisation in life threatening circumstances. The effects of a child's mild injury were less obvious, and the parents' learning occurred more slowly. This meant that this part of the Structure was a less sturdy foundation for the next levels of Close Support and Protecting, and the sense of Getting Through was less Secure.

Two of the families had less Close Support. Neither of these parents had the support of a partner through the process of Holding Things Together, and also did not express the consistent presence of a therapist or grandparent who had been routinely present. Although all parents had to work hard at Holding Things Together, these parents particularly emphasised the ongoing difficulties they were having, feeling unable to adequately Protect their children and also juggle this with their other roles. The block symbolising Close Support was much smaller in scale for these families, making the structures above unstable and likely to fall, with the risk of a return to Black Days.

Grant had times when he was completely unable to Protect Lucy because he simply couldn't be there. In the absence of Grant's hands to hold the structure, and without Close Support, Lucy was unable to Protect herself. Grant described several instances where she had put herself at extreme risk while he wasn't there.

In contrast, Rona and Colin had extremely high levels of Close Support from the start of the process. The family lived in a smaller, close-knit

neighbourhood, with extended family nearby who were actively involved. The therapist who was working with Katie had been visiting regularly over a long period. Rona described this support as a “*buffer zone*” around the family, where Katie was Protected to the point of being cacooned [Rona, I2]. The block forming their Close Support was solid and strong, creating a secure base for Rona and Colin to Protect Katie.

The uppermost block in the tower is dependent on the stability of the blocks beneath it. The parents who took longer to learn about the dangers for their child, who had limited Close Support, and who had difficulty Protecting their child had not experienced a clear sense of Getting Through. Fears for the future Security of the children were more apparent. Conversely, parents who were forced into a position where they more quickly and thoroughly learned about the dangers, who had good Close Support, and who were successfully able to Protect their child had a strong perception of Getting Through, with children clearly making progress and the parents confident in their ability to Handle the demands.

### ***The Joining My Child With Others Process***

Joining My Child With Others is the caregiving process that forms in response to the child’s need to spend time in activity with other people. People use their hands for joining one thing to another, fitting and pressing until items are assembled into a whole structure. This process is represented by the blocks on the right hand side of the tower.

Joining My Child With Others commences when parents respond to their child’s social Needs. Children can become isolated following a traumatic brain injury, with tiredness and difficult behaviour limiting the times and places that they can do things with other people. As children grow and develop, society places expectations that they will attend school, play a sport, or go on family outings. Families are compelled to set about meeting these Needs for their children.

As time passes after the accident, families are increasing their Knowledge about their child, about the ways the environment can support or hinder their child’s endeavours, and about the challenges that different tasks might present to their child. Within the process of Joining My Child With

Others, this Knowledge is being put to use by parents, as a basis to support their caregiving actions. Parents are becoming more able to predict the physical and emotional risks associated with different environments and tasks. Knowledge enables them to weigh up the relative worth of their child going somewhere, and to consider the different choices that might be involved in a visit. Plans for attending can be developed based on this Knowledge.

The Support of other people in the Family and in the Community is an intervening factor in the caregiving process of Joining My Child With Others, with higher levels of Support from the people involved contributing to the success of the process. Support is achieved through others' understanding of what is difficult for the child, and of what to do to help them to be involved.

Armed with Knowledge of the risks involved, and having made decisions and a plan, parents proceed to Set Up the structure for their child to participate. Routines that support the child's safety needs and energy levels are organised around the event, and often preparatory work is needed with the child, such as explanations, special training, or increased rest time. Sometimes special equipment needs to be obtained, or other people need explanation about what to do.

As a result of things being Set Up for them, the children are ready to participate in Occupation With Others. When things are well Set Up, parents feel more confident about letting their child go, and the child fits in more Securely with others. Parents remain active in their role, monitoring the success of their child's participation. If parents feel their child is failing in their interactions or if the situation became physically or emotionally unsafe they deal with it through further Setting Up or Protecting actions.

Lucy's Need to Be With Others had shifted and altered over time. This base block of the caregiving process of Joining My Child With Others was weakened in that Lucy had repeatedly experienced failure at school, and no longer wished to be there. In spite of high levels of Support at the school, and her father's Knowledge about why school was proving difficult for her, no amount of Setting Up seemed effective. Provision of transport to school, special programmes, and special equipment was not enough to prevent Lucy's perception that she was not fitting in with the other children, and possibly even emphasised her differences. Lucy continued to play truant, and Grant was left

with the ongoing task of dealing with this. Frustrated, he was reduced to attempting to Protect Lucy by instructing her to stay at home and not leave the house. The Joining My Child With Others Structure was failing.

In contrast to this family, Bailey experienced success in her Occupation with other children and staff at her school. She had an intense need to Be Part of Things, and at age seven there was an expectation that she would be attending school. Her mother had achieved good understanding of her needs by this stage, and worked with staff at school to Set Up the routines that best supported her. Bailey responded well to this level of Structuring and Support from staff members, and Fitted In securely there.

It was more difficult for Bailey to achieve success in her Occupation With Others in the home setting. Although she keenly wanted to Be Part of Things with her siblings, it was difficult for them as children to always be understanding, and this Family Support level of the Structure was less Secure. Pam endeavoured to Set It Up for her to join them in their activities, but with the other demands on her time at home and Bailey tired after school, she found it difficult to provide the level of Support that Bailey needed. The reality was that the other children continued to become frustrated with Bailey at times. Pam frequently had to deal with the emotional fallout from these failed interactions, spending time explaining to the children and endeavouring to get Bailey to understand what she had done wrong. The uppermost level of the caregiving Structure was frequently insecure, and the block below it was repeatedly needing to be repositioned.

### ***Interconnecting and Interdependent Processes***

The two caregiving processes did not stand in isolation, but interacted and supported each other, with the parent's hands in place, Holding and Joining throughout to stabilise. Metaphors for the way families need to continually hold and join structures together after a child's traumatic brain injury are used too by DePompei and Williams (1994). Their view is of a fragile family structure, like a house of cards, falling, and needing rebuilding, the cards dependent on each other and on people's hands for support. They convey a sense of hands in place, bracing the structure against blowing apart, and of the

need for hands to be constantly holding and joining while crafting and further strengthening (pp. 68, 79).

A house of cards is built one card at a time. Each card is supported by and depends on the other. When stress affects one card, the entire house may lean. And sometimes the house falls. Traumatic brain injury is a sudden and unexpected intrusion in a family system that can cause extraordinary challenges. All of the family members may be called on to steady the leaning house of cards and to support the structure so it does not collapse.... A house of cards can be cared for in a number of ways. It can simply be moved away and isolated from any danger. It can be sheltered by building a strong wall around it. It can be glued together so that no card can slip or move. It can be attached to a strong foundation that will not allow it to fall. Or it can be strengthened from within by developing internal supports. And it can be strengthened further by building a community of houses around it so that each supports the other. Families responding to life altering traumatic brain injury may need to use a variety of strategies at one time or another.

One tall structure on its own can sway and topple over, but when another structure is placed beside it, the structures become steadier. Parents were often involved in the two processes simultaneously. Even early after the accident, interactions with other people such as visitors were inevitable, and many parents needed to begin *Joining My Child With Others* while they were just beginning to *Hold Things Together*.

Sometimes however, parents focused entirely on *Holding Things Together*, before there was a need to *Join My Child With Others*. Early after his accident, John's mother *Held Things Together* very tightly, and was not yet ready to begin *Joining Him With Others*. At other times, parents would be *Joining My Child With Others*, and were not yet able to *Hold Things Together*. This is what occurred for Grant, when Lucy began school before he was fully aware that she was having difficulties as a result of her brain injury. Inevitably, a focus only on one side of the structure created instability, with either *Black Days* or *Needing To Be Part of Things* stimulating a need to begin *Structuring* for the other caregiving process.

*Holding Things Together* and *Joining My Child With Others* are interconnected through the Knowledge parents attain. Knowledge gained during the process of *Holding Things Together* forms an important background context to the *Joining My Child With Others* process. When *Holding Things*

Together, the parents are in a context where they are new to and still Learning about the Dangers that are present. Knowledge emerges as a consequence of that process. When Joining My Child With Others, the Knowledge that parents have already attained is now used to Weigh Up options, Predict Risks, and Plan. Naturally, parents also gather further Knowledge from the process of Joining My Child with Others, and this Knowledge is used further to support them in ongoing Setting Up activities, and as a context to more Protecting actions that might be needed.

There is also a high level of interaction between Close Support and Family and Community Support. Close Support sometimes shifts over into the Joining My Child With Others process, where someone who is close to them can assist parents in Setting things Up for their child. However, it is the more general concept of Family and Community Support that specifically influences the success of the parent's ability to Set Things Up for their child. Without the support of involved others, who understand what the difficulties are and what to do to help, it is not possible for the child to have Occupation With Others successfully. Conversely, someone closely involved who had provided effective Family and Community Support may end up also becoming a Close Support to parents. However, it is the quality, and consistency that is inherent to Close Support that is the factor mediating the outcomes of Holding Things Together.

The Protecting actions that parents use in the Holding Things Together process were also incorporated into their actions in Setting Up for their child to have Occupation With Others. Ways of working with the child as they did things, promoting their safety, and their safe daily routines were carried over and adapted to support the child's interactions with others. Additionally, some of the things that were attained when Setting Up could then be taken and used to Protect the child. This might be a special skill that the child learned such as how to cross the road safely, what to do when they got tired at school, or using a special helmet to prevent bumps to the head in the playground.

Structuring for Security is not static. Both of the caregiving processes Holding Things Together and Joining My Child With Others are growing and changing, building up from their foundations of Black Days and Needing To Be Part of Things. There was not a point where the parents in the study saw

that they would stop their involvement in these processes. Once built, parents' involvement in the processes continues, and this ongoing nature of Structuring for Security is driven by Change.

Structuring for Security is about children who are continuing to grow and develop, and this developmental change is one of the things that leads to the ongoing nature of Holding Things Together and Joining My Child With Others. As children became older, there are new challenges to be faced.

Katie's mother was well aware of these challenges when Katie became old enough to begin at a new kindergarten. Although Katie had been Joined With Others at Play-Centre, the things that had been set up for her there were adapted to meet her needs in the new setting. The new kindergarten made bigger demands on her learning skills, and energy levels. Tiredness when she got home necessitated adaptation of the Holding Things Together structure to allow for more rest afterwards.

Changes in the physical and social environment also brought about ongoing action on the caregiver's part to Hold Things Together and Join My Child With Others. Bailey's mother had shifted to a new rental home. The new house brought about a whole new set of dangers, such as proximity to busier roads, and stairs to Bailey's bedroom. New ways of Protecting Bailey were established by Pam after the move, and play with siblings in a new environment meant that things such as safety rules needed to be Set Up differently and taught to Bailey.

### ***Structuring For Security: Summary***

This chapter has drawn together the research findings using the overarching central category, Structuring For Security. The chapter has defined this category, and, utilising diagrammatic representation, has explained the category's core relationship with the two caregiving processes, Holding Things Together and Joining My Child With Others. Variations and interactions between the processes have been summarised, and an explanation has been provided of the way the processes respond to change.

The following chapter, Chapter Seven will move on to consider the issues arising from this study with reference to existing literature. The strengths

and weaknesses of the study are considered, and the implications that the findings hold for practice and policy are outlined. Recommendations are made regarding directions for further research in this field.



## **Chapter Seven: Discussion**

### ***Introduction***

This chapter considers the strengths and limitations of the study findings in relation to its context and current literature, and the implications of the study. The findings are firstly discussed in respect to their fit with the philosophical understandings of symbolic interactionism that were introduced in Chapter Three. Consideration is next given to the New Zealand context of this study and the implications arising from this. The findings are then considered relative to existing literature in the field, and the similarities and differences between the findings and the literature are examined. The contribution of the study to the body of knowledge is explored. Reference is also made to relevant understandings from the wider field, including trauma, and occupation. The relationship of the study findings to these constructs is outlined.

The chapter follows on with a discussion of the relative strengths and weaknesses of the study. Maxwell's (2002) framework for understanding validity in qualitative research that was previously introduced in Chapter Three is referred to again here in consideration of the rigour of the study findings. The chapter concludes with a review of the implications of the study for families, professionals, and future policy development. Recommendations are made regarding directions for further research.

### ***The Findings and Symbolic Interactionism***

The impetus to undertake this study arose from an intuitive concern on the part of the researcher over a lack of substantiated knowledge about what caregivers for children who have had a traumatic brain injury are doing as they look after the children on a daily basis. The study asked the question "what is involved in the day-to-day occupations of caregiving for a child who has had a traumatic brain injury?" Using a grounded theory methodology (Strauss & Corbin, 1998), the study aimed to contribute to the development of a theory which explains the processes involved in the day-to-day occupations of

caregiving for the child with traumatic brain injury, and to identify things that assist and things that hinder families during these occupations.

Symbolic interactionism is the theoretical approach that underlies the Grounded Theory methodology utilised for this study. The approach assumes that people's actions are based on the meanings that things hold for them, and that this meaning evolves from interaction with these things within particular social contexts. The approach also holds that meanings are interpreted and changed as the individual deals with the things that they encounter (Blumer, 1969). Central to the researcher finding out about what caregivers were doing therefore, was the need to gain understanding of the way caregivers thought about and defined objects, events, actions, interactions, and ideas in their world, and the changes that these definitions underwent.

During the researcher's interviews, observations, and ongoing analysis of the data, theory began to emerge that provided answers to the research question, and explained the processes and changes that were taking place during caregiving occupations. The way parents interpreted the things that were happening proved pivotal in the development of the theory, as was gaining understanding of the physical and social contexts in which the caregiving actions and interactions were occurring.

The meanings that the parent attached to the accident event, their child's behaviours, and the resulting isolation were central in driving their caregiving actions and interactions. Contextual factors such as the behaviour of the child, the parent's knowledge, and the perceptions and support of other people all influenced caregiving actions and interactions. Additionally, it was seen that these caregiving actions and interactions underwent a process of further interpretation, leading to shifts in the parent's understandings of the situation and changes in their actions. The parent's day-to-day actions were found to be part of two interrelated caregiving processes, Holding Things Together and Joining My Child With Others. These processes were encompassed by a central category of Structuring For Security.

Structuring For Security describes and draws together the key elements that are taking place when a parent is Holding Things Together and Joining My Child With Others. It is a concept that captures the parent's need to create a safe and successful future for their child, in a world that they now interpret as

being both dangerous and as presenting their child with the risk of future failure. The parent's actions are devoted to establishing frameworks or structures for ways and times to do things that support the child's occupations and interactions in this world. Progress and development in the child, and environmental changes drive the ongoing involvement of the parent in the processes, by creating the context for further structuring that responds to the new situations and demands.

The first process, *Holding Things Together*, explains the things that are happening when a parent endeavours to contain the turmoil they perceive after their child's accident. The parent feels as though life has been shattered apart by this event, and this understanding impels them to act to Hold Things Together. The environment and their child's behaviour have been re-interpreted as dangerous, meaning physical and emotional risk for their child. Supported by those they perceive as close to them, the parent feels driven to pick up the pieces and draw things back together, acting to prevent ongoing physical and emotional trauma. As the parent becomes increasingly able to protect their child using actions and interactions such as guarding, implementation of safe routines and doing activities closely with their children, their perceptions undergo further change. They experience a sense of getting through, with developing knowledge, feelings of confidence in their ability to manage the role, and increasing awareness of the child's progress.

The second process, *Joining My Child With Others* involves the parent's efforts to bring about their child's success in occupations with others at school, at home, and in the community. Parents respond to the isolation experienced by their children and themselves, due to the child's behavioural difficulties. Value is attached to the child being able to do things with other adults and children in the immediate family and in the community. The parent draws on their increasing knowledge as a basis to act and set up the things that are needed for their child to participate successfully. This process is mediated by the knowledge and practical understanding of others that they interact with. The parent interprets the child's interactions with others in terms of them fitting in. As time passes, the parent's ability to let the child go changes. However, the parent remains involved, aware of and reflecting on the safety

and the success of their child's ongoing interactions and, when necessary, adjusting their actions to deal with any problems that arise.

### *The New Zealand Context*

In any discussion of this study, it is important to acknowledge its location in a New Zealand context. Rehabilitation services for accident victims in this country are delivered under the umbrella of the Accident Compensation Corporation (ACC), which is a Crown entity. New Zealand citizens, residents, and temporary visitors who have an accident involving a serious injury have a legal entitlement to be provided with appropriate levels of training, educational support, counselling, and psychological services. Other supports such as funding for attendant care, equipment, and housing modifications are also provided in response to an assessed need. The Accident Compensation Corporation holds contracts with agencies that provide attendant carers to support parents in the caregiving role as needed. Further to this, people who are assessed as having a permanent impairment may qualify for payment of an independence allowance or lump sum compensation. Lodgement of a claim is usually completed at the time of initial consultation with a medical practitioner. Following this, case managers and lifetime rehabilitation planners within the ACC system are proactive in informing people of their entitlements and ensuring that they are delivered (Accident Compensation Corporation, 2002, 2003a).

This immediate and ongoing level of support may not be not as readily available in other countries (Cronin, 2001). Claims with private insurers may take time or legal involvement before being accepted. Strict limits may be placed on length and costs of rehabilitation. At other times, services may be constrained by geographical location, or may emphasise service delivery through the education setting. Much of the literature acknowledges the additional strain placed on caregivers of children with traumatic brain injury by the need to fund and/or access the supports they need for themselves and for their children (Conoley & Sheridan, 1996; Cronin, 2001; Gronwall, Wrightson, & Waddell, 1990; Kolakowsky-Hayner et al., 2001; Tomlin et al., 2002;

Waaland, 1998; Waaland et al., 1993; Wade, Taylor, Drotar, Stancin, & Yeates, 1997; Willer & Corrigan, 1994).

The results of this study are reflective of the New Zealand Accident Compensation system for meeting rehabilitation needs, and provide some initial insights into the ways in which the system relates to caregiving processes. Mentions by parents of support received through case managers, therapists and psychologists were frequent, and only one of the five participants expressed difficulties negotiating the system. Assessments were another theme that frequently cropped up during interviews. It is possible to view assessments as a means of the medical profession exerting control over those with disabilities (Munford, 1994). Although the New Zealand parents in this study tended to see assessments as stressful at times, they also saw them as a way of Getting What was Needed.

During data analysis, the concept emerged of ACC funded caregivers who are contracted in from an agency. Several of the families had such paid attendant carers looking after their child for certain parts of the day, often while a parent worked. Sometimes these paid attendant carers appeared to fit within the caregiving processes. At other times however, in line with the researcher's concerns before commencing the study, their involvement seemed to have little relevance to what the parents were trying to do, or was perceived as a hindrance. The parents' use of a paid attendant carer to do the caregiving for them particularly affected the Holding Things Together process. This occurred in two ways.

Firstly, if the paid attendant carer was able to follow very closely the Structure that the parents had put in place, had good understanding of the child's needs, and had been with the parents over an extended period, they came to be seen as Close Support, and became part of the process that brought about a sense of Getting Through. Alternatively, if the paid attendant carer failed to follow through with the Structure that the parents had put in place, because they were the person providing the caregiving when the parents were unable, this meant that nobody was Structuring for the child over these times. Parents became concerned as they could see that things were not being Held Together.

Families of children with other types of disabilities in New Zealand have expressed similar concerns over the need for caregivers to understand what the important issues are and to be consistent in working to the parents' structure (Carpinter, Irwin, & Rogers, 2000). These parents also acknowledge the time it takes for agency caregivers to fully understand what is going on for the child. Such parents expend considerable time and effort in training caregivers, only to experience frustration when they fail to recognise signs or don't follow through with established routines.

### ***Situating the Study Findings with the Literature***

The following sub-sections review the findings and discuss their fit with existing literature. The names of the categories are used as sub-section headings to assist the organisation of information.

#### ***Black Days and Needing to be Part of Things***

Families on this study experienced the events following their child's accident as Black Days, a time of darkness, upheaval, confusion, and absolute change. Feelings of fear and losing control pervaded not only the way they perceived themselves and their ability to cope, but also the way they viewed their child's behaviour. The depth of parents' feelings varied in response to the circumstances of The Accident, the time since The Accident, the extremes of the child's behaviour, and also to events that were going on at the time. Although these feelings improved as time passed, parents identified returning to Black Days when things broke down, such as when a child became over-tired or ran away from home, and they continued to fear returning to these times. Thus, Black Days remained as a force over time that impelled the parents to act.

The description of Black Days matches the emotions that parents are typically held to experience as they adjust following their child's transition from hospital to community living. Such feelings are said to include fear, confusion, frustration, and being overwhelmed (Polinko et al., 1985; Rivara, 1994). For parents who are caregiving for adult children, there is then a progression over time through the emotions of grief, involving anger, discouragement, guilt, blame, depression, and then mourning for the person

their child was before the accident. At two years after the accident, many families accept that the person their child was has gone, and they begin to re-interpret their relationship in a way that allows them to disengage (Gronwall et al., 1990; Lezac, 1986). Parents who are caregiving for young children are also said to experience grief, and to mourn for their child who, although still alive, has been lost to them through changes in their personality and behaviour. Such grief is exacerbated at the time of developmental milestones such as beginning school or joining their first sports team (Conoley & Sheridan, 1996).

Unlike these descriptions of grief in the literature, some families in this study were unclear about the losses that had occurred. While wondering about “*what might have been*” [Rona, I1], these families were uncertain whether ongoing changes in their child were due to the injury, or perhaps just normal development. This lack of clarity about possible changes is consistent with the fact that children make relatively rapid early recovery of function after the injury (Conoley & Sheridan, 1996). It is possible that stages of emotional adjustment for these families were blurred by this recovery and also by the ongoing, albeit slower, developmental gains that occur, as proposed by Rivara (1994).

In addition to some of the parents on this study being unclear about their loss, there was also a contrast to this literature in that the parents did not describe lingering with their grief, and did not disengage. Although they sometimes talked of thinking back to how things were before the accident, they also focussed on doing what was needed with the now changed child, and looked forward to the future, setting up structures that would support their child as they grew and developed: “*You know there was always that hope that the old Bailey would wake up in the morning, so yeah, I mean, I’ve just got on with it. I mean, that’s how she is, and we love her how she is and we just have to support her*” [Pam, I2]. As Guerriere and McKeever (1997) found in their qualitative study, the parents in this study felt they had little choice but to get on with the job. This direct engagement with the caregiving role and view to the future is in line too with the recommendations of Gronwall et al. (1990), who advise caregivers to adopt a forward focus and to work actively towards achieving short-term goals. Orchison (1997) also describes getting on with the job while adjusting to the changes in her young son who sustained brain

damage after an illness. Although she did experience times of grief, these were interfaced with periods of high activity when she was busy “meeting additional parenting demands” (p.6). Orchison’s descriptions of adjustment mirror the fluctuating but ever-present nature of the Black Days and the focus on action experienced by parents on this study.

Black Days was a time when the parents were faced with significant Changes in their child’s behaviour. Parents were often shocked and frightened by the magnitude of their child’s anger, seeing the child as Losing It, or out of control. They were also distressed by physical Changes in their child, such as a tendency to trip and fall more frequently. This was associated with their own feelings of Losing It as parents, where they felt their existing parenting skills were completely inadequate for the task in hand. They interpreted these Changes in their child’s behaviour and physical function as dangerous, or unsafe. These findings are congruent with evidence that after the accident parents find both the changes in their children’s behaviour and physical symptoms stressful (Ergh et al., 2002; Sokol et al., 1996; Taylor et al., 2001; Wade et al., 1998; Wade et al., 2002; Yeates et al., 2001). However, the findings of this study shed some new light on the processes involved with parents’ stress around these issues. It highlights their concerns over physical and emotional safety, and provides understanding of their responses to this stress in Holding Things Together.

The reactions of family and friends are also commonly identified as being stressful to parents (Taylor et al., 1995; Taylor et al., 2001; Wade et al., 1998; Wade et al., 2002), as are the child’s own difficulties with social interactions (Warzac et al., 1995). Less is known however about the ways in which these type of stressors affect children and their families (Taylor et al., 2001). Although these stressors were also present for families in this study, they functioned as motivating factors for parents to act in Joining My Child With Others. In this study, others’ reactions also mediated parents’ ability to manage this caregiving process successfully. Parents were concerned with the Need for their child to be Part of Things with other people. This need involved a sense of Isolation for both parents and children, deriving from the constraints on outings and visitors placed by the child’s behaviours. Parents repeatedly described how difficult it was even to go out to the shops, or for a meal with



friends, and early after the accident families seldom went away from the home. Parents also voiced a concern at the need of their child to be part of the community, particularly in the future.

Findings from a number of studies demonstrate that children who have had a traumatic brain injury experience this type of social isolation (Burleigh, Farber, & Gillard, 1998; Emanuelson, Von Wendt, Beckung, & Hagberg, 1998; Fletcher et al., 1990; Jaffe et al., 1993; Polinko et al., 1985; Sherwin & O'Shanick, 2000; Warzac et al., 1995). One work that incorporates comments from a parent of a child with a traumatic brain injury rather than the observations or assessments used in other literature particularly captures these same parental concerns for present and future isolation. "Will we ever have confidence that she will be happy as her life goes on? Her old friends don't want to play anymore - such loneliness.... She doesn't interact well, but then she is so upset when they go....How will she ever get back to school or hold a job...?" (Polinko et al., 1985, p. 111).

Isolation for caregivers is also acknowledged in the literature, and while it has been less widely studied, papers do describe reduced participation by caregivers in social and leisure activities. Caregiver isolation is held to stem from the all-encompassing demands of caregiving, and also from the child's behaviour which contributes to awkwardness during outings and which can discourage visits from friends and family (Barry, 1998; Carson, 1993; Degeneffe, 2001; Guerriere & McKeever, 1997; Lezac, 1978, 1988; Sokol et al., 1996). Although Isolation was an issue for families in this study, it differed from the literature in that it was found that parental Isolation was in fact a motivating factor to caregiving action for the children. Caregivers actively worked at strategies for Joining Their Child In With Others in response to their own and the child's present and future need to be with other people.

Less attention has been paid in the literature to the impact of the accident itself on the family. Families on this study recalled vividly exact details of The Accident event and their feelings, using language such as "shocking", and "the worst nightmare". Parents were all deeply impressed by how close their children had come to dying. These descriptions are echoed in the language used by Johansen (2002) when she described her reactions at the time of her teenage son's car accident. Such language is evocative of an acute

stress response to an extreme traumatic event. “Even as I write fourteen years later, I feel my pulse quicken and adrenaline pump through my body.... I try to subdue catastrophic mental images of death and severely mangled bodies... devoured by terror.... on rubbery legs and with a pounding heart” (pp. 8-10). Literature around human responses to trauma describes similar symptoms that can recur over time (American Psychiatric Association, DSM-IV-TR, 2000; Janoff-Bulman, 1992). Wade and his colleagues (2001) reflected on the possibility of acute responses to the accident in parents, involving their avoidance of anything that might stimulate a flashback to the time. Such responses to the trauma of the accident event may also account for some of the ongoing feelings parents on this study experienced, and their perception of the world as a place filled with danger which is discussed in the next section.

### ***Learning the Dangers and Using Knowledge***

Learning and knowledge were important themes in this study and the surrounding literature emphasises the importance of providing families with information (Conoley & Sheridan, 1996; Polinko et al., 1985; Semrud-Clikeman, 2001; Ylvisaker & Feeney, 1998 b). When parents were Holding Things Together in this study, it was evident that this was a time when they were in a state of Learning About the Dangers facing their child. Parents were gradually Becoming Aware of what was going on for their child in terms of their physical and behavioural changes. They were Alert to the Threats to their child’s physical and emotional safety associated with these changes, and they were Recognising Signs of Danger. Further accidents seemed inevitable, and the world was interpreted as a dangerous place.

Families took differing amounts of time to fully understand the changes in their child and the reasons for them, particularly those families whose children had had less severe injuries with less intensive rehabilitation support initially. Knowledge shortly after the accident was very much emergent and still growing. Families described being unable to take on board much knowledge at this stage, and learning was largely pragmatic through trial and error and observation.

The occupational therapist was particularly helpful too. She was really practical...she was a very hands on therapist, like she actually was in there and doing it. Not just

talking to me. So that was good because sometimes you learn from how other people role model, so just to watch her, how she managed things and how she did things made me think, oh okay, he is learning, he can do things. Right I am going to spend more time trying to concentrate on the one-to-one activity...[Theresa, 11].

Texts confirm the importance of education for parents after a child has a traumatic brain injury, and, fitting with the concerns of families in this study, stress the need not to overload them with information too soon (Conoley & Sheridan, 1996; Polinko et al., 1985; Semrud-Clikeman, 2001). However, Ylvisaker and Feeney (1998b) are among the few authors to emphasise the important contribution of experiential learning which was the way families in this study described learning. Smucker's unpublished grounded theory study of family caregiving for young children with traumatic brain injury (1996) also supports the way families in this study learned through experience and observation. Both this study and the study by Smucker found that parent's learning was focussed on the practical day-to-day tasks involved in the caregiving role, such as getting a child to concentrate at a play activity, or what happened when the child became too tired. In line with the families in this study, Smucker identifies the way parents are finding out about their new child and what they need to do to help them. They act on the basis of their knowledge, then reflect on the child's responses, creating new learning on which to base further action.

Other literature does not capture parents' need for practical and observational learning, and proposes that information be delivered variously through group sessions, during face-to-face contact with professionals, via telephone, and in written form (Conoley & Sheridan, 1996; Polinko et al., 1985; Semrud-Clikeman, 2001). The literature is not specific about the type of information to provide to families, variously proposing topics such as the nature of the injury, the rehabilitation process, legal and financial arrangements, the child's medical care needs, the child's functional status, behaviour management, how to manage a child's leisure time, social skills training, support groups, coping skills, and how to manage stress (Albert et al., 2002; Carnevale et al., 2002; Conoley & Sheridan, 1996; Dell Orto & Power, 2000; Hibbard et al., 2002; Johnson, 1995; Kolakowsky-Hayner et al., 2001; Polinko et al., 1985; Rivara, 1994; Smith & Testani-Dulfour, 2002; Taylor et

al., 2002; Waaland et al., 1993; Ylvisaker & Feeney, 1998a). While these medical, legal, and psychological constructs may well be beneficial topics, the more practical aspects of how parents can best support the child in their daily occupations and interactions are not discussed.

In contrast to this literature, knowledge valued by families in the present study was particularly intertwined with the practical need to understand the dangers facing their child and how to manage them. Danger was perceived through the physical threat of re-injury, and also through the child's behaviour, which could lead to further injury or to emotional trauma. Parents talked of gaining understanding of the reasons behind their child Losing It, such as fatigue, noise, or heat, and were learning to recognise the early signs and how to prevent it. Parents were also becoming aware of other dangers for their child such as running off, or tendencies to trip and fall, and they showed increasing ability to identify safe and unsafe environments. No other studies have explored parents' need to learn about managing the safety concerns for their children.

A notable factor contributing to the safety concerns of all the parents in this study was that the children had sustained repeated head trauma. Repeated injuries have serious implications, with the possibility of progressive reductions in brain function (Gronwall et al., 1990). In line with advice given by authors such as Gronwall et al., the parents in this study all displayed awareness of such danger, this heightening their fears for their child's safety. Fears were exacerbated when Further Knocks happened despite their best efforts. Parents became very knowledgeable about their child's physical abilities, understanding that difficulties in walking and balancing compounded the risk of re-injury.

It was at the point of Joining My Child With Others that parents talked more of their children's impairments such as attention, memory, organisation, and balance difficulties. To date, a great number of studies of traumatic brain injury in children have incorporated measurement of such impairments at various points in development and recovery. Studies have investigated sequelae of the injury in terms of children's neurobehavioural function, such as intelligence, memory, attention, problem solving, and behavioural control, and also aspects of children's movement skills such as balance, strength, fitness,

and ability to reach and grasp (V. Anderson et al., 2000; V. A. Anderson et al., 2000; Bakker & Anderson, 1999; Dennis et al., 1995; Donders & Strom, 2000; Dumas & Carey, 2002; Ewing-Cobbs, Levin et al., 1998; Ewing-Cobbs et al., 1989; Fay et al., 1993; Fay et al., 1994; Jaffe et al., 1992; Jaffe et al., 1993; Kaufmann et al., 1993; Kuhtz-Buschbeck et al., 2003; Lewis et al., 2000; Massagli et al., 1996; Rossi & Sullivan, 1996; Taylor et al., 1995; Taylor et al., 1999; Taylor et al., 2002; Verger et al., 2000; Wallen et al., 2001; Yeates et al., 2001). It is possible that this emphasis in overseas literature reflects in part the need to measure and demonstrate the presence of deficits for litigation purposes and to obtain rehabilitation services. For the New Zealand parents in this study, such impairments were seen not so much as an outcome or endpoint, but as obstacles. When parents were Joining their Child With Others, Knowledge and understanding of these obstacles enabled a focus on what could be done to bring about their child's safe and successful participation with other people.

Armed with Knowledge of their child, his or her capabilities, the environment, and the things that the child would be expected to do, parents were able to Predict how safe the child would be, and how well he or she would cope with tasks and social interactions. Parents could Weigh Up the options around the child participating, such as whether it was worth it, or how long they should go for, and could make plans for what was needed to ensure success. As in Smucker's model (1996), much of the parents' Knowledge was gained through ongoing experiential learning, and over time parents demonstrated accurate and detailed Knowledge of their child, their skills and their difficulties. Incomplete Knowledge (e.g. about an unfamiliar environment) made it more difficult for the parents to set about ensuring their child's success, creating fears for future participation. Incomplete knowledge has not been widely investigated as a stressor for parents, and studies have focussed on stress variables for families such as the injury, progress, behaviour, physical function, coping modalities, and others' reactions (Sokol et al., 1996; Wade et al., 2001; Wade et al., 1998; Wade et al., 2002; Yeates et al., 2001). This study points to a possible need to consider more diverse ways of investigating caregiver stress after a child's traumatic brain injury.

The way parents were putting together knowledge about the child, the environment, and the task in order to predict how their child would manage and support them also complements understandings of human occupation. As described in Kielhofner's model (2002), occupational performance results from an interrelationship between the person, the environment, and the occupation. An imbalance or change in any of these components can impact on the person's ability to perform occupations. Conversely, by making changes to any of the components, it is possible to better support a person's performance. This was illustrated by Theresa's reading of the situation when her son was unable to manage his clothing when going swimming. Her response was to alter something in the environment (his clothing) to support his independent performance when his class went swimming.

He lost the plot because he couldn't get his tog top off...He was screaming, yelling, lying, you know, just hysterical. I know it's because he was tired, but I kept on thinking when he has swimming at school, how is he going to get his tog top off without losing the plot. Because they have to do it by themselves. I found a big one with a bigger head...[Theresa, I2].

### ***Support: The Intervening Condition***

Consistent with recent literature in the field, this study found that social support was a factor that intervened to assist parents to manage the caregiving processes (Dell Orto & Power, 2000; Ergh et al., 2002). However this study extended this understanding, finding that it was the quality of the support related to specific caregiving processes rather than the type or quantity of Support that was important to parents.

When parents were endeavouring to Hold Things Together, they valued Support from people who were Close to them, and who could empathise with their situation because they had been through the aftermath of the accident with them. In this way, Support could be provided by family, friends or professionals Someone who had worked closely with the parents meant they could be trusted to know what to do, and could be readily available if they were needed. This level of trust facilitated the person to assist on both a practical and on an emotional level.

When parents were Joining their Child With Others, they described a need for the people who were going to be Involved with their children to Understand their children's difficulties, needs, and how to help. Parents valued greatest Understanding in people who were most closely Involved with their child such as school-teachers, or sports coaches, but also valued Understanding from the general public. Support based on this Understanding indicated the practical nature of the help these people would then be able to provide when their child was participating in activities in the community. For this caregiving process, the essence of the support was different, with a greater focus on the need for the caregiver to have general knowledge about brain injury and how to help.

This study raises the possibility that support valued by parents in this situation may extend beyond the parameters traditionally associated with support such as instrumental (practical support such as respite care or provision of equipment) and emotional support (such as counseling). Literature promotes supports such as counseling, support groups, provision of information, and respite care (Conoley & Sheridan, 1996; Degeneffe, 2001). However studies of such interventions are not consistently able to report significant effects of support on caregiver outcomes (Acorn, 1995; Albert et al., 2002; Hibbard et al., 2002).

Variations in findings between the different studies of social support for caregivers of children with traumatic brain injury also point to the possibility of more complex associations. Caregivers of young children have been found to value support from teachers and professionals more than that from family and friends, with lower priority placed on the need for empathy, understanding, or discussion of problems (Waland et al., 1993). In contrast, Ergh et al. (2002) found that social support for caregivers of adult children was directly related to family functioning, was a strong predictor of family functioning, and significantly modified family distress. In a similar population, Kolakowsky-Hayner et al. (2001) found that while health information needs were generally met, caregivers felt that instrumental support and professional support needs were often not met. It is possible that the needs of caregivers of young children and of adults differ. An additional possibility is that although the caregivers of young children valued support from family and friends, the need of

professional assistance was often unmet in these overseas studies, and was therefore seen as an area of greater need. This second possibility may explain in part the ways in which support is valued by the New Zealand parents in this study. Professional support here is in most cases readily provided through the state funded ACC system, and therapist or psychologist support is therefore valued alongside support from the family or others in the local community.

### ***Protecting and Setting Up***

Parent's actions and interactions within the two caregiving processes were directed towards Protecting their child from physical and emotional dangers and Setting Up for the child to do things with other people. Little has been written in the literature about what parents do on a day-to-day basis after a child sustains a traumatic brain injury, and this study provides some initial insights.

The use of protective caregiving actions have been found in two other qualitative studies of children with traumatic brain injury (Carson, 1993; McClusky, 2000). However these studies involved adult children, and the caregiving actions were focussed largely on protection from physical harm. Protecting actions have also been noted in other populations of cognitively disabled children (Cappelli, McGrath, MacDonald, Katsanis, & Lascelles, 1989; Holmbeck et al., 2002; Mayes, Handford, Kowalski, & Schaefer, 1988), and parental overprotection has been linked with childhood depression and behaviour difficulties (Burbach, Kashani, & Rosenberg, 1989; McFarlane, 1987). This is in contrast to the parents in the present New Zealand study, where Protecting was a strategy that brought about positive outcomes.

The concept of protecting children is described in some detail by Carson in her (1993) grounded theory study of caregiving for adult children with traumatic brain injury. As with the parents in the present study, families in Carson's study remained physically close to their child, setting up the environment safely, grading the level of assistance given, and watching out for threats to the child's wellbeing. Carson does not describe the use of routines as a protecting action, but notes the presence of the child's schedule, which also directed the way parents used their time. Additionally, Carson noted that the level of vigilance parents used decreased over time as the adult children



regained the ability to keep themselves safe. This is in contrast to this study, which found that Protective actions did not steadily decrease, but fluctuated in response to the demands on the child and the familiarity of the environment. It is possible that some of these differences arose through Carson's involvement of adult children, who may be less open to having their daily routines structured for them and who had previously learned well established safety habits.

As found by Carson (1993), the parents in this study also graded the level of assistance given with the children's daily activities, a strategy used to Protect the children from failure and frustration. However, while Carson found that the amount of assistance given reduced over time, the parents on this study modulated the amount of assistance given in response to their child's function at a given point and external demands such as needing to be ready for an outing. If, for example, the child was tired and their ability to stay on task and manage clothing was reduced, parents tended to do the dressing for them to Protect the child from Losing It. Conversely, if the child was rested and highly motivated to go on a visit, the parents would give minimal help with tasks.

Although literature generally finds that children who have had a traumatic brain injury have reduced ability to manage daily living tasks independently (Arsanow et al., 1991; Coster et al., 1994; Donders & Ballard, 1996; Fay et al., 1994; Fletcher et al., 1990; Massagli et al., 1996; Max, Koele et al., 1998; Ponsford et al., 2001; Taylor et al., 2002; Taylor et al., 1999), studies have provided contradictory results. Coster et al. (1994) found that although children had similar ability to their peers in carrying out activities of daily living, increased levels of caregiver assistance were still required. In the present study, the parents' provision of increased levels of assistance to Protect their children against Losing It provides a possible explanation for this anomaly.

Recently, clinicians have presented models of rehabilitation practice that suggest practical, community-based interventions to assist this population. Themes emerging from this study parallel several of the principles inherent to one of these models (Ylvisaker & Feeney, 1998a). In this study, within the scope of Protecting their children, parents established Safe Routines. These involved set ways and times for doing things that supported success in the

child's occupations, and that minimised the possibility of further accidents and emotional outbursts. Repetition of these routines with their parents created a safe framework for children, with habits forming and guiding their behaviour to support growing independence. Ylvisaker and Feeney (1998a) acknowledge the negative impact of traumatic brain injury on people's ability to use thought and learning, leading to impulse-guided behaviour. Their rehabilitation approach provides a comprehensive theoretical rationale for the use of positive daily routines as a foundation for successful participation in valued occupations. With the support of people who are present in the person's everyday life, skills can be successfully practised and internalised in the form of scripts that direct behaviour and prevent failure.

The routines applied by parents in this study share many of the features of the routines proposed by Ylvisaker and Feeney (1998a). Learning through trial and error and with the support of therapists and psychologists, families were assisting their children to know what to do next, developing familiar ingrained patterns of behaviour that were apparent during observations and explained in interviews. Pam described to me the way she was using routines to teach her daughter to recognise her own signs of fatigue and take appropriate action. In this way, she hoped Bailey would begin to develop independent ability to manage herself safely, and to deal with her own issues.

As time goes on, hopefully she will understand when she's fatigued and say "it's time that I had some time out now" and be able to recognise those times, because we're pinpointing them all the time for her, and maybe one day it will click with her that "this is what I feel like, so mum used to say this is the time I have to have down time so I recognise that for myself". So hopefully if she does that, then she is not going to get into a situation where she gets incredibly impulsive, get violent and gets into trouble...[Pam, I2]

The other actions used by parents in this study were those of Setting Up for their child to share in occupation with others in the family and in the wider community. Setting Up describes a broad array of strategies used by parents to foster their child's success when participating with others. Strategies were individualised, depending on the needs of the child and resources, and ranged from training specific skills in the child such as learning how to stay on task for longer or learning how to swim, through to obtaining special equipment such

as special bike pedals or a special place for their child to rest at school. Strategies also included bringing other people up to speed with what the child needed help with, or carrying over their safe routines into the new setting.

Willer and Corrigan (1994) developed the Whatever It Takes model for the community re-integration of people with traumatic brain injury. In line with what the parents in this study were trying to do for their children, the model argues for a focus on enabling people to participate successfully in the community. Intervention incorporates working with and adapting features in the environment, support networks, and activities, as opposed to the more medically based focus of “treating” the individual (p. 647). Whatever It Takes refers to finding practical solutions to day-to-day problems experienced by people with traumatic brain injury. The parents in this study were doing exactly that, as illustrated by Donna when she described what she set up for her son to join a class performance at the school assembly.

There’s going to be on a Friday their school assembly and they want the kids to get up and sing... the kids in two days would learn a song. Simon, we’d have to come home for two weeks and practise and practise and practise. He knew a song from playcentre, so he went to school and he taught the class to sing it. So at their assembly they’re singing the song Simon knows...we’re going to all that week have to just keep everything nice and quiet and stay home... so that he’ll be able to last the whole assembly without walking out. [Donna, I2]

### ***Getting Through and Occupation With Others***

We are informed by studies that after a traumatic brain injury, children initially experience a return of skills (Barry et al., 1996; Dumas & Carey, 2002; Dumas et al., 2002; Ewing-Cobbs, Fletcher et al., 1998; Jaffe et al., 1992; Jaffe et al., 1993; Ponsford et al., 2001), with relatively greater physical progress than improvements in cognitive function (Dumas & Carey, 2002; Wilkening, 1997). Contrary to earlier opinion, delays in development are now thought to take place following the injury, with gaps occurring between children and their peers which widen over time (V. Anderson et al., 2000; Chapman & McKinnon, 2000; Lowenthal, 1998; Verger et al., 2000; Ylvisaker, 1998a). The children on this study had all experienced their injury two or more years previously, and in contrast to this literature, families were still Seeing Progress,

with more focus on their children's improvements than their delays. However this acknowledgement of Progress was less apparent for parents who were finding it more difficult to Protect their child. Parents used practical knowledge to make points of comparison for the child, and noticed the differences in skills between this child and siblings or other children they knew. Nonetheless, for those parents who saw themselves as Getting Through, there was pride and confidence in their children's physical and learning achievements, which overshadowed any gaps they were aware of.

Families in this study tended to express improvement as a sense of Getting Through, or as ongoing, moving along a pathway. This is in contrast to recent 4-year longitudinal study which established the persistent presence of sequelae such as difficulties with learning, communication and daily living skills, finding little recovery of function beyond the first year (Taylor et al., 2002). It is possible that the children involved in the overseas study by Taylor and his colleagues were receiving less rehabilitation support than their counterparts in this New Zealand study, a factor that Taylor and his associates did not control for. Additionally, the present New Zealand study was small in scope, with interviews only months apart. Parents may not yet have gained appreciation of the long-term picture for their children.

Getting Through embodied both the parents' perception of their ability to handle their role and their awareness and confidence in new skills emerging in their child. This interlinking of the child's progress with the parent's ability to cope with caregiving demands lends support to studies that have identified links between family function and progress in children after a traumatic brain injury (Anderson et al., 2001; Taylor et al., 1999; Taylor et al., 2001; Yeates et al., 2001; Yeates et al., 1997). Taylor and his colleagues (2001) carried out the first study that aimed to establish the directionality of those links, gaining tentative support for reciprocal influences between child behaviour and family outcomes. Increased levels of parent distress at 6 months predicted increases in child behaviour problems at 12 months, and likewise, child behaviour problems at 6 months predicted increased levels of parent distress at 12 months. In this same way, the parents on this New Zealand study perceived Progress in their children alongside their increasing ability to Protect their children as a consequence of the Holding Things Together Process. When parents felt they

weren't adequately able to Protect their children, the consequence of the process was that children at the same time were perceived as not doing as well, with increased instances of Losing It or physical difficulties.

The consequence of the Joining My Child With Others process was about the child participating in Occupation With Other people. Participation ranged from building a toy with a sibling, through to spending mornings at school, going shopping with a parent, or joining a sports practice. As a result of effective Setting Up for their child to do this, parents perceived their child as Fitting In with other people. This study found that the degree of Fitting In varied, changing in response to things such as the child's level of fatigue, the activities that were happening, or the level of understanding by other people involved. Parents' ongoing involvement in this process was necessary, monitoring the situation and Setting Up again when problems arose or changes took place.

These findings are in line with current literature, which holds that the integration of a person with traumatic brain injury back into successful community living presents many challenges (Dell Orto & Power, 2000; Gronwall et al., 1990; Willer & Corrigan, 1994). For children particularly, integration is not a discrete event with a clear start and finish. Integration for children must take into account the changing nature of their environments as they move from pre-school through to school and adolescents. Along with ongoing physical development, children's perceptions of themselves and their relationships are also undergoing developmental changes. Added to this is the risk of increasing differences between the abilities of the child and those of their peers (Clark, 1997; Cronin, 2001; Sherwin & O'Shanick, 1998). Studies have found that the difficulties faced by such children when endeavouring to participate in the community are considerable, and are also of concern to parents (Backhouse & Rodger, 1999; Emanuelson et al., 1998; Parkin, Maas, & Rodger, 1996), concurring with the concerns of the parents in this study.

### ***Two Caregiving Processes***

This study provides us with some initial understandings of the occupations involved in caregiving for a child with traumatic brain injury. While some of these understandings support the findings of quantitative

literature in the field, some new insights were also revealed, and the study is unique in that the two caregiving processes that were identified were focussed on the parents' perspectives of their occupations. Two published studies have also used a grounded theory methodology to investigate parents providing care for children with a disability, and although the aims of these studies were not specifically focused on caregiving occupations, some similarities with this study are present (Carson, 1993; Piggot et al., 2002).

Carson (1993) explored the social and psychological processes experienced by parents living with adult head-injured offspring. While broader in focus than the present study, and following a progression over time, two of the phases identified by Carson's study lend some support to the results of this New Zealand study. The initial phase of Centering On is a time Carson identified when the parent's attention is very focused on the head-injured child. This time involves a busy schedule of activities such as carrying out the child's daily living tasks, obtaining services, structuring the environment to ensure the child's safety, and monitoring to protect against relapse or further injury. This phase corresponds with Holding Things Together in the way that caregivers were working closely with the child, and in the focus on safety and protection. However, Carson's study does not identify the distress and fear that parents in this present study faced which drove their actions. Additionally the parents in this study felt they had no choice but to adjust to the dramatic changes in their child, while during Centering On, parents maintained a focus on searching for the pre-injury child as they adjusted to the changes. This difference may be explained by Carson's involvement of adult children, who would have already developed distinct personalities and behaviours over their adult life which remained more evident to the parents.

The second phase identified by Carson (1993) has some similarities with the Joining My Child With Others caregiving process identified by this study. Fostering Independence is a time identified by Carson when parents are beginning to adjust to the possibility of permanent changes. Parents are working towards their children resuming responsibility for their daily living activities, strictly limiting the amount of assistance they provide and also encouraging the children to participate more in social activities outside the home. In Joining My Child With Others, parents were also directing energy

towards participation. However for this study there was an ongoing focus on Setting It Up and, in contrast to the withdrawal of support discussed by Carson, Protective actions were not discontinued. Again, the differences may be explained by the involvement of adult children, for whom there are higher societal expectations for independence.

Phases of adjustment were also identified by Piggot et al. in their New Zealand study of parents' participation in home therapy programmes for children with cerebral palsy (2002). In line with the New Zealand parents who participated in this study, Piggot et al. found that the parents felt strongly driven to meet the challenges involved in caring for their children, and two distinct processes emerged. The first process identified by Piggot et al. is called Coming to Grips, and is a time of adjustment when parents are adjusting to their child's diagnosis, and are feeling unready to cope with meeting their child's demanding and complex needs in the face of inadequate support. Families in Piggot et al.'s study and also in this study were initially in a state of shock at what had happened. For both groups of parents, this was a time of learning: for the parents in Piggot et al.'s study, it was learning of the diagnosis, while for the parents of the children with traumatic brain injury, there was learning about the dangers now facing their child. Although the parents in Piggot et al.'s study then went on to a period of intense grief, both groups acted to contain things. Piggot et al. describe these actions as survival strategies, and in line with this study, these are seen as a way of keeping things together. As a result of the actions of the parents, both studies found that the parents noticed improvement in their children and there was a shift in parents' perceptions of their ability to cope.

It is at this point that the studies diverge more in their findings. Parents in Piggot et al.'s study (2002) experienced this improvement and change in their coping as a time of breakthrough, enabling them to move on to a second phase where they were highly motivated to maximise the children's potential and become involved in the therapy programmes. Actions were directed towards learning, scheduling, and mastering the skills they needed to handle their child and facilitate his or her future development. Contrasting with these findings by Piggot et al., the two caregiving processes identified in this study were often occurring simultaneously, with Joining My Child With Others

focussed on the need to integrate the child with other people in the family and wider community. Apart from the differences in the onset of disability, the children in the study by Piggot et al. were all pre-schoolers and had significant mobility difficulties, while the children in this study were all but one attending school and had relatively good physical function. Along with the different focus of Piggot et al.'s study on adjustment and participation in therapy, it is possible that differences in the participants' ages and physical presentations accounted in some part for these variations in findings.

### ***The Notion of Structuring***

Structuring is a notion that occurs frequently in the traumatic brain injury literature, although there has been little focus on defining it or explaining the actions that are involved. The term is variously used in texts to describe the organisation of time (Conoley & Sheridan, 1996), a strict sequence of activities (Ylvisaker, Szekeres, & Feeney, 1998), or the set-up of the physical environment to support a child (Carson, 1993). D'Amato and Rothlisberg (1996) use the word structure broadly to describe the individual plan which is set up to meet the child's educational needs, linking the word with stability in the way things are done, clear understandings of what is expected, and a consistent routine. Structure in this way is seen as providing a safety net that supports the student while they focus on learning. Other authors have used the word to refer to the way ideas are organised in the mind, or knowledge structures (Ylvisaker & Feeney, 1998a). Building from this theme is the concept of providing support in the way of coaching, maps, plans, and routines to compensate for impaired executive function, language, memory, and organisational skills ( Ylvisaker, Szekeres, & Feeney, 1998; Ylvisaker, Szekeres, & Haabauer-Krupa, 1998).

This study has explored the concept of Structuring in greater depth and in terms of its meaning to parents. It contributes further understandings of the inherent processes involved, and acknowledges the value of Structuring for parents after a child's traumatic brain injury. Structuring was a term that was used by parents in this study that described what they were doing on a day-to-day basis, possibly reflecting the influence of clinicians, but also the parents feelings about their own and their children's needs. The word has been adopted



to explain the overarching theme of this research, encompassing the caregiving actions and interactions that were involved for parents. Taken in this broad interpretation, Structuring incorporates many of the notions that are already in the literature, and involves deliberate arrangements made by the parents for time, physical space, and ways of doing things to protect the child and to provide a foundation for ongoing development and achievement in the world.

### ***The Occupations of Caregiving***

Human occupation is about action or doing, and theories of occupation acknowledge the dynamic nature of occupation, which can bring about change and which responds to change (Kielhofner, 2002; Wilcock, 1999). This study aimed to find out what family caregivers of children with traumatic brain injury were doing on a day-to-day basis. In carrying out the study, it was necessary to consider the interrelationship between the occupations of both the parents and the children. The findings of the study provide us with some initial understandings about the occupations of caregivers for this population. They also lend support to some aspects of the Model of Human Occupation offered by Kielhofner (2002), and provide an example of the way these aspects are involved caregiving occupations.

The study has found that the occupations of the caregivers were dynamic, comprising two interrelated and ongoing processes, which were driven by the changes that took place in the child and by the children's needs. Following the accident, parents found their pre-existing parenting occupations were no longer effective, and that different actions were required. The immediate and wider social environments impacted on the parents' ability to deal with the changes and carry out caregiving occupations effectively. Parents described and were observed to engage in a wide variety of caregiving actions, and analysis found that these actions fell into categories of Protecting and Setting Up for their children. Actions involved both direct contacts with the child and also indirect action such as doing things with the objects in the physical environment or working with other people to inform them of the child's needs. As a result of their actions, changes took place in the parents' perceptions of the way they were managing the caregiving role, and in their perceptions of progress in the children. Parents increased their knowledge as a

result of their caregiving, and were able to use that knowledge to support further caregiving actions. Caregiving occupations did not cease when parents perceived these changes, but continued to be necessary to meet their children's changing needs in a changing environment.

Kielhofner's model (2002) addresses the motivational factors involved in occupation, posing people's innate human need to act along with personal causation or awareness of one's capabilities and effectiveness, one's values, and interests. The parents in this study expressed a feeling of being driven to act, that they had no choice but to get on with doing the job of looking after their changed children. Although the parents initially expressed a sense of no longer knowing how to do their job, and of their actions no longer being effective, this was the point where Close Support from their environment assisted them to begin caregiving, triggering learning and an emerging sense of capability. With ongoing action came further learning, and parents increasingly perceived themselves as becoming more capable.

Another important aspect of Kielhofner's model (2002) is that of habituation, which acknowledges the way repeated patterns of behaviour guide performance of occupations. The use of habitual patterns of behaviour featured strongly in parents' Protecting actions with their children. Parents established and used Safe Routines to provide set ways and times of doing things with the children to prevent them becoming tired or having further injuries, and to help guide the children's own independent actions. These routines were also carried over to support the children's performance when they began doing things with other people in the community.

This study found that many of the parents' occupations involved acting on the environment, both physical and social, in order to create change. This was particularly apparent when parents were Joining their Child With Others. Kielhofner (2002) sees the environment as providing opportunities for occupation, resources that motivate and facilitate, and also at times as limiting occupation. However he does not widely discuss people's need to act on their environment or the outcomes of such action. The parents on this study evaluated the environment in terms of the risks it presented to the children and its ability to support the child's occupations. Many of their caregiving actions were not directly with the child, but supported the child indirectly through the

environment. They arranged furniture and living spaces differently to protect the child, and spent time in meetings where they worked to ensure other people had adequate knowledge of how to support their child. They adapted the child's clothing and obtained aids to support the child to swim or ride a bike. They put up fences to prevent the child running off, and organised neighbours' children to assist in getting their child to school. The word Structuring has been used in this study as it incorporates these indirect actions which brought about the child's safety and success, building future security for them.

### ***Strengths and Limitations of this Study***

Although the strengths of the study design have been described in depth in Chapter Three of this thesis, they are briefly revisited here alongside other strengths and limitations that became apparent during the research process. As in Chapter Three, Maxwell's (2002) notions of different levels of validity are used as a basis from which to outline and consider the strengths and limitations of the study. Definitions of Maxwell's levels of validity have been provided in Chapter Three, and are not reiterated here.

The use of both interviews and observations as data collection methods and checking of transcriptions proved valuable in assisting "Descriptive Validity" (Maxwell, 2002, p. 45). Inconsistencies were noted and amended as a result of these activities. When participants were provided with copies of their transcriptions none reported inaccuracies.

Prior identification of the researcher's understandings during a taped interview and the utilisation of a reflective journal were particularly beneficial in alerting the researcher to beliefs and biases which might have affected the "Interpretive Validity" of the findings (Maxwell, 2002, p. 48). As the study progressed, times when these beliefs may have been impacting on interpretation of data were also recognised during supervision sessions, and interpretations were re-considered.

The parent participants in the study had all been caregiving for their children for several years, and their own learning and rich experience formed an important contribution to the researcher's valid interpretation of the data. "Interpretive Validity" was also assisted by the presence of the children during

interviews and observations. Although this created interruptions on occasions, their interactions facilitated first-hand understanding of the issues the parents were describing. Data coding drew frequently on the use of the participants' own names for concepts, or "in vivo" codes (Strauss & Corbin, 1998), and this feature further helped the researcher to ensure that interpretations were grounded in the data. When these codes were later checked with participants, they expressed their clear recognition of the understandings that were incorporated.

Positive feedback from clinicians at a seminar presentation and feedback from participants when the theory was checked with them provided strong support for the "Theoretical Validity" of the study (Maxwell, 2002, p. 52). Additionally, the legitimacy of the theory is corroborated by its fit with existing literature as described in the previous sections of this chapter.

At this level of validity, some weaknesses in the study became apparent due to the study design and also due to the time constraints of completing a masters level thesis. The study relied on gathering information from each participant at two interviews and two periods of observation. While the observations proved to be very valuable in gaining insights into the interactions between the parents and their children in the home environment, the limits of only two one-hour interviews combined with the researcher's lack of interview experience placed some restrictions on the density of data gathered. Although the limited number of interviews reduced demands on participants, the option of further interviews to explore emerging categories in greater depth would have contributed greater depth of understanding of the categories.

Also at this level, further theoretical sampling could have provided a more robust understanding of changes in the caregiving across time. Only a small number of families were involved and the study relied on information about families' feelings around the accident event some time after the event. Additionally, the interviews and observations were carried out over only one year, and these factors placed limits on the theory's ability to explain changes that might be taking place over time. Saturation was reached for the categories that are described in this study, and the data was able to explain variation between families. However theoretical sampling around categories such as Black Days, where families were actively experiencing that stage or sampling

for people who had been caregiving for children who had greater demands placed on them in terms of Needing To Be Part of Things may have increased the depth of understanding of the processes that might be involved in these areas.

The theory that emerged from the study, particularly the process of Joining My Child With Others, has a number of similarities with existing theory around occupation and rehabilitation practices. Although these similarities could be seen in the light of a strength of the theory, insofar as it is supported by existing knowledge, and although data analysis processes and categories were checked by supervisors, it is possible too that the categories reflect to some extent the researcher's own understandings. A further consideration is that the participants may have been those caregivers who were particularly motivated in their role, and who were therefore more influenced by their contact with clinicians than other families who were not part of the study. Not all areas in New Zealand have the availability of therapy supports that are present in Auckland, and this limits confidence in the theory at the next level.

At the level of "generalizability" proposed by Maxwell (2002, p.54), the explanatory power of the theory that emerged is limited specifically to the population involved in the study. By chance, the study included participants from several different cultural backgrounds, both mothers and fathers, and male and female child participants, which lends some confidence to the theory's ability to predict what will take place in the caregiving processes for these all these groups. Unfortunately, all the caregivers were parents, with no other family caregivers (e.g. aunts, grandparents) returning consent forms. Although the study aimed to find out about family caregiving, generalisation to the wider family involved in caregiving remains to be explored.

The "generalizability" of the study is also limited to the level of disability involved for the children. The child participants were all independently mobile, and were able to communicate and carry out basic living skills with only moderate needs for assistance. The literature review revealed that parent distress and family burden are associated with greater deficits in children (Taylor et al., 2002). It must be acknowledged that for this study, a bigger sample involving a wider range of disability may have revealed greater variations in the dimensions of the categories.

Maxwell stresses the benefits of considering the “generalizability” of the theory to different time frames and environments (2002, p. 54). While data was gathered relating to both school and home and the wider community, the narrow range of ages of the children reduces the information available about caregiving across different time frames such as when the children enter intermediate, high school, or school leaving age. As stated earlier, the theory may have limited application outside the Auckland area where therapy may be less accessible.

Support for the validity of the study at this level has however been provided through its tentative application in the clinical setting. The theory that emerged from the study has shown some practical use with different clients in the areas of clinical reasoning and goal setting. Additionally, the theory has shown some benefits by contributing to the foundations of a framework to assist parents in learning the caregiving skills they need as they transition home with their children from an inpatient rehabilitation setting.

Although Maxwell acknowledges the issue of “Evaluative Validity”, he does not consider it as a central question for qualitative studies (2002, p. 57). Notwithstanding this, in line with my understandings as an occupational therapist, this chapter has reviewed the fit of the theory with the perspectives of the Model of Human Occupation (Kielhofner, 2002). The theory that emerged from the study is congruent with these perspectives. While this congruence could be interpreted as a strength of the study, it must also be acknowledged that these similarities could indicate the influence of the researcher’s own beliefs.

While considering the presence of both strengths and limitations, this study contributes to an understanding of the processes that are involved in family caregiving for a child with traumatic brain injury. These processes hold implications for families, professional supports, and policy makers.

### ***Implications of this Study***

#### ***Implications for Families and Professional Supports***

Arguably the most important issue to arise from this study is the understanding of parents’ initial bewilderment about caregiving after a child’s

traumatic brain injury, which is followed by actions that form part of two caregiving processes. Parents describe feeling overwhelmed and unsure about what to do. Previous actions are no longer effective in the face of the changes in their child, and it takes time and experience for parents to learn how to put Structures in place to Hold Things Together and Join Their Child With Others. A parents' perception of their child's progress and their own ability to manage the caregiving occupations rests on the effectiveness of their actions, drawing attention to the central role caregiving plays for both families and children.

Literature cited in Chapter Two of this study also shows that outcomes for parents and children are mediated by family function, involving parent's actions and interactions (Anderson et al., 2001; Rivara et al., 1996; Taylor et al., 1995). There are important implications that arise from these understandings for families and clinicians as they assist children with traumatic brain injury over the transition from inpatient settings to the community. This study suggests a need for collaboration between families and rehabilitation professionals in developing sound caregiving practices that are in line with the two processes and which meet the needs of the individual family and child. The model of the caregiving processes of Holding Things Together and Joining My Child With Others provides some initial foundations for a framework around which training for such practices might be based. Also towards this end, the study contributes information about the actions parents find useful in Protecting their child and Setting Up for the child to be with others. Further information is contributed about the types of knowledge and support that are needed for these actions to take place.

The two caregiving processes were seen to be interdependent and often simultaneous, although caregiving efforts shifted in focus between processes at different times. Clinicians might usefully consider which process parents need most support with at a given point in time. Parents who were Holding Things Together established safe routines, gained knowledge, and facilitated progress in their child. The routines, knowledge, and progress from this process were used to assist Joining the Child With Others. Most parents began early attempts at Joining their Child With Others in response to the child's needs and other demands, albeit with limited degrees of success early after the accident. However an early overemphasis on Joining My Child With Others without the

strength from the Holding Things Together part of the structure often contributed to collapse of the process, and parents were left with a perception of Black Days and a child who still Needed to be Part of Things. This understanding suggests that an initial focus of training for families should be with Holding Things Together, and that parents' early efforts at Joining My Child With Others may need additional support in terms of weighing up the options, predicting risks, and setting the event up.

In terms of educating families about traumatic brain injury, much of their learning seemed to take place on the job, with initial difficulty taking in information. Families may benefit from clinician support to participate in observational and trial and error learning. Initial priorities might be about the practical aspects of caregiving that protect the child from physical and emotional danger, as these are the issues that initially concern families the most, and that are then used in Joining the Child With Others. This would include realistic appraisal of and awareness of the risks presented by physical difficulties, fatigue, frustration, overload, or running off. Clinicians and families should work together in learning to read a child's signs, and understanding threats that might be present in the environment.

In light of the frequency of repeat head trauma that appeared to be present for the children in this study, the importance of facilitating their physical safety cannot be overestimated by parents and clinicians, particularly in the early stages after a head injury. Reductions in physical skills and fatigue contributed to increased risks of trips and falls in the children. Although the literature emphasises the relatively rapid recovery of physical skills in children (Dumas & Carey, 2002; Wilkening, 1997), even the mild physical difficulties seen in the children involved in this study would appear to warrant careful monitoring and intervention where appropriate.

The support of others was a factor that had the ability to either assist or hinder the caregiving processes. When families were Holding Things Together, Close Support was particularly important. When families are focusing on this process, the involvement of a small number of familiar clinicians who are readily available, who understand what the family is going through and who understand the child's needs will support the families more than a large number of different professionals. For families who do not have the availability of



Close Support, Holding Things Together will be more difficult. Clinicians and case managers may need to consider this aspect for families who are at risk in this way, and understand that for these families, Close consistent Support from a professional will be even more important. The type of support needed when families were Joining Their Child With Others shifted in emphasis, and at this time, those most closely involved needed to understand the child's difficulties and areas of strength, and also how to best help them to participate. Therapy support at times of transition to new educational settings might assist parents to ensure that those who are involved are provided with essential information about the child, and understand the parents' concerns.

The study also has important implications for paid attendant carers. Although many of the children appear to have little if any physical disability, there are a number of dangers involved for them, both physical and emotional. Families will be reassured by attendant carers who are open to learning about these dangers, and who are responsive to a child's individual signs. It is important for the parents' peace of mind and for the child's safety and progress that carers follow through with the Safe Routines that have been established. They need to understand the child's daily routines, the way that particular activities are carried out, how much assistance to give, and the ways to respond if a child Loses It. In this way, paid attendant carers can effectively assist parents to Hold Things Together.

### ***Implications for Policy***

The Accident Compensation Corporation is proactive in its provision of services after a child sustains a traumatic brain injury, and it supports parents in caregiving. However this study has shed some new light on the processes that are involved, and raises some questions regarding the focus of services.

A feature of the study that stood out was parents' concern with Protecting their children. This appeared to arise in response to the emotional impact of the accident event on parents, and also as a realistic response in light of the risks presented by childrens' behaviours, and the reality of further injuries. ACC policy currently provides psychological services for the person with the injury (Accident Compensation Corporation, 2003a). Unfortunately these services are not available for immediate relatives who may be

traumatised by what has happened to their child, and many of whom are simultaneously endeavouring to manage caregiving activities. Acknowledgement of this trauma, and the provision of a limited number of sessions in the early stages after the accident may greatly assist parents such as those involved in this study both in their adjustment, and in their ability to Hold Things Together for their child.

Accident Compensation policy also provides attendant care support where there is an identified need to keep a person safe due to behavioural or physical dysfunction resulting from the accident. In the case of Protecting a child from further injuries, equipment (e.g. a helmet) or housing modifications (e.g. a safety gate at stairs) may additionally be provided where the need is resulting from the accident, and where the requirements are above and beyond those required by a typical child (Accident Compensation Corporation, 2002, 2003a, 2003e). In practice, it can be difficult to clearly identify areas that are the responsibility of ACC and areas that should remain the responsibility of the parents. Obviously certain items such as a car-seat for a pre-schooler are up to the parents to provide. However, for the older child, other items such as a fire-guard or a locking gate onto the road are open to debate, and their relative cost-effectiveness must currently be weighed up by assessors and case managers against the option of providing attendant care to prevent further accidents. In light of parents' particular concerns for their children's safety, this area of legislation may benefit from clarification of different parties' responsibilities and provision of specific examples.

A second feature that emerged from the study was the role played by others' understanding. Disability in these children did not involve obvious physical limitations, but overt changes in their behaviour. When people who had contact with the child understood what the issues were, it was much easier for parents to Join their Child in With Others, such as going out to do the grocery shopping, or attending a sports practice. On the other hand, when people did not understand, with instances of passing comments about the child's behaviour or bumping into the child when they got in the way, parents felt judged and limited in their ability to involve their children in the wider community.

These difficulties highlight an important role for increasing public awareness of brain injury and its consequences. ACC currently has a responsibility and focus on preventive education, and advertising tends to focus on death and physical disability arising from dangerous practices such as speeding or falls. While the behaviours shown by these children are less dramatic than a person with an obvious physical disability, in many ways the behaviours had a far greater impact on the children's ability to spend time with other people. This issue is backed by other studies, which show that social isolation is a common outcome of brain injury (Burleigh, Farber, & Gillard, 1998; Emanuelson, Von Wendt, Beckung, & Hagberg, 1998; Fletcher et al., 1990; Jaffe et al., 1993; Polinko et al., 1985; Sherwin & O' Shanick, 2000; Warzac et al., 1995). While increasing public awareness of this side of brain injury could be seen as part of ACC's role, and thus indirectly supporting children and their caregivers for a successful and productive future, other voluntary agencies such as the Brain Injury Association may also be able to play a part.

The assessment of attendant care needs is another area that was highlighted by this study where a shift in focus may enable better support for parents. The current emphasis of attendant care assessment is breaking down the number of hours required to assist a person to achieve routine daily living activities such as bathing, dressing, communicating, and keeping safe (Accident Compensation Corporation, 2002, 2003e). The breakdown is supported by the use of a 24-hour diary, which lists the types and amounts of assistance provided for particular tasks across a typical day and a night. While the diary is an important tool in identifying immediately observable actions that may be needed to assist a child, it cannot capture the varying or qualitative aspects of care that parents are managing on and off throughout the week, such as noting and responding to signs of fatigue, joining a child in a play activity to increase their concentration, setting things up for a child's visit to a friend, or meeting a number of times with a teacher to enskill them in the child's routine. Currently, such aspects of care rely on the judgement of individual assessors for their identification, and their value may or may not be acknowledged. Development of assessment protocols and a framework that acknowledges these fluctuating and qualitative aspects of care required for children may

prove more relevant for parents, increase consumer satisfaction, and may benefit the children.

### ***Implications for Further Research***

This study has contributed an initial understanding and model of the processes involved in caregiving for a child who has had a traumatic brain injury. The model is however limited in its scope, in terms of the number, age and presentation of the child participants and in terms of the amount of time since the injury. The study did not involve any adolescents who had had a traumatic brain injury. The child participants in the study were all independently mobile, were able to communicate their needs independently, and were not reliant on technology for feeding or breathing. While families in the study referred back to the time immediately after the accident, they were not directly experiencing it, and only one child participant had sustained the accident more than 3 years previously. Further research in this field involving older children or children with more significant disabilities may well paint a different picture of parents' concerns when caregiving, as may the involvement of families shortly after the accident or families for whom a number of years have passed.

The concept of Structuring is one that is mentioned in both past and in more recent literature, although there has been little focus on defining it and examining its application in rehabilitation. This study has identified the importance of Structuring for these New Zealand families in the caregiving role, and the model has shown some tentative uses in the clinical setting. Given the limited scope of this initial project, future research into the use of Structuring by parents, educators, and clinicians may build further on this concept, and extend its use as a model for assisting parents and others in managing the caregiving role.

### ***Summary***

This study has sought to answer the question “what is involved in the day-to-day occupations for caregiving for a child who has had a traumatic brain injury?” It has generated answers that are founded on the understandings of New Zealand parents who have been faced with the need to set about

caregiving following the distress of a child's injury. Parents' occupations form part of two interactive and interdependent caregiving processes, Holding Things Together, and Joining My Child With Others. Fundamental to the two processes is parents' active involvement in Structuring For Security for their child. The study highlights the importance of caregiving occupations for both parents and children, and informs us about the ways parents might best be supported through their day-to-day actions and interactions to help bring about positive outcomes.

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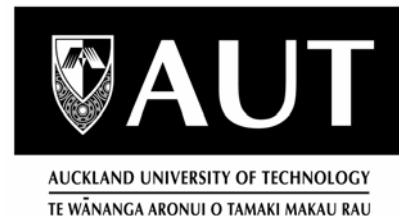
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## Appendices

### *Appendix A*



#### *Participant Information Sheet*

#### **Caregiving for the Child with Traumatic Brain Injury**

##### **About the study**

You are invited to take part in the above study.

My name is Margaret Jones, and I am an occupational therapist working at the Wilson Centre in Takapuna with children who have had brain injuries. I am undertaking this study as a part of the Masters of Health Science Programme at AUT. I expect to complete the study in June 2003.

The aim of the study is to find out about what is involved for parents and family caregivers on a day to day basis when they are caring for children with traumatic brain injury.

I plan to spend time with English speaking parents or family caregivers of children with traumatic brain injury aged 3-17 years who are living in the Auckland area. Your therapist has identified you and your child as meeting these criteria.

It is possible that not all parents/family caregivers who give consent to be part of the study will be selected to participate in interviews and observations. If this occurs, you will be advised by the researcher and thanked for your time.

##### **What will be involved for you?**

If you agree to participate, first you will be asked to fill in a short information sheet about your child and the family.

There will be a 1-2 hour interview with you to talk about what you have to do when you are looking after your child. A second interview and/or phone call may be needed to clarify some things. The interviews will be at your home, at

AUT, or at the Wilson Centre- whichever you prefer. The interviews will be audio-taped, and later typed out.

I would also like to spend 1-3 hours with you and your child on 1-2 occasions at home to see what sort of things you need to do and what is happening. I will take notes, which will also be typed out.

The total time involved for you will be 2-10 hours.

**What will happen to the information?**

You will be offered a copy of my notes and the typing. If there is information you want to change or which you want deleted, I will do this.

A report will be written for the examiners at AUT. You will be offered a copy of the report, and an opportunity to discuss the results with me. I will also present the results of the study at a meeting, and you will be invited to attend this. Copies of the report will be provided to ACC, the Brain Injury Association of New Zealand, the Wilson Home Trust, and interested journals.

**Benefits, Risks, and Safety**

You may not gain any direct benefit from taking part in this study. However the study will give you an opportunity to have your thoughts and concerns heard. The study may help therapists, agency caregivers, and funding bodies to identify the most appropriate supports for children and families, based on information directly from families.

The interviews and observations will be at times that are convenient for you. If you choose to have the interviews away from home, you will be provided with travel vouchers. Any other reasonable expenses will also be reimbursed. Child-care will be offered for the times of the interviews.

It is possible that discussing your caregiving role or having an additional person observing you and your child may be stressful for you. You may wish to have a support person with you.

You do not have to answer all the questions and you may stop the interview or observations at any time. Your participation will be stopped should it be felt that it is not in the best interests of yourself or your child to continue. If support were needed for any issues, you may wish to see your doctor. If longer term difficulties resulting from the accident became apparent, you would be referred back to your ACC Case Manager if you wished.

**Compensation**

In the unlikely event of a physical injury to yourself or your child as a result of your participation, you will be covered by the accident compensation legislation with its limitations. If you have any questions about ACC please feel free to ask the researcher for more information before you agree to take part in the study.

**Confidentiality**

No material which could identify you, your child, or your family will be used in any reports which may arise from this project.

The information will be seen by the supervisor, and may also be seen by a typist. It will be kept locked away. It will be destroyed after 10 years by deleting tapes and computer discs and shredding documents.

**What to do now?**

Your participation is entirely voluntary (your choice). You do not have to take part in this study, and if you choose not to take part you and your child will receive the usual care. If you do agree to take part, you are free to withdraw from the study at any time, without having to give a reason, and this will in no way affect the future care of yourself and/or your child.

If you agree to take part, complete the enclosed consent form and caregiver details sheet, and return them in the stamped addressed envelope.

**More Information**

More information about the study can be obtained from the researcher, Margaret Jones (Tel. 09 489 9134 ext 5881), or the primary supervisor, Clare Hocking (09 917 9999 ext 7120). If you have any queries or concerns about your rights as a participant in this study you may wish to contact the Health Advocates Trust, Northland to Franklin (Tel. 0800 55 050).

**Statement of Approval**

This statement has received ethical approval from the Auckland Ethics Committee.

**Thankyou for taking the time to read this sheet. Please feel free to contact the researcher if you have any questions about the study. You are free to take as long as 12 weeks to decide whether or not to participate.**

*Appendix B**Consent Form: Parents/Family Caregivers/Children*

Title of Project:       **Caregiving for the Child with Traumatic Brain Injury**

Project Supervisor:   **Clare Hocking**

Researcher:           **Margaret Jones**

I have read and understood the information sheet dated 07/02/02 for volunteers taking part in the study, designed to find out about what is involved in looking after a child with traumatic brain injury.

I have had the opportunity to ask questions about this study. I am satisfied with the answers I have been given.

I have had time to consider whether to take part.

I understand that the interviews will be audio-taped and transcribed, and that notes will be made during the observation periods which will also be transcribed.

I understand that taking part in this study is voluntary (my choice), and that I may withdraw myself, or any information I have provided, from the study at any time. I understand that this will in no way affect the continuing health care/rehabilitation of either myself or my

child. If I withdraw, I understand that all relevant tapes and transcripts or parts thereof will be destroyed.

I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.

I understand the compensation provisions for this study.

I know whom to contact if I have any concerns or questions about the study.

I wish to receive a copy of the results YES/NO

I wish to have the results discussed with me individually YES/NO

I wish to review my transcripts YES/NO

I (full name) ..... hereby consent to take part in this study.

Participant signature/Proxy ..... Date.....

Name of witness .....

Signature of witness ..... Date.....

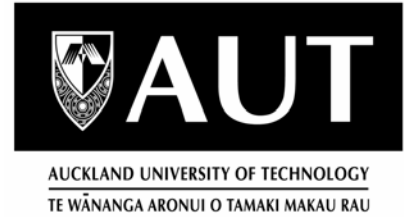
Project explained by .....Project Role.....

Signature ..... Date.....

Project Supervisor Contact Details: Clare Hocking, Principal Lecturer, School of Occupational Therapy. Tel. 09 917 9999, ext 7120

Researcher Contact Details: Margaret Jones, Occupational Therapist, Regional Rehabilitation Service, Wilson Centre. Tel. 489 9134, ext 5881.

This study has received ethical approval from the Auckland Ethics Committee.



***Consent Form (Child)***

Dear .....

I am a therapist, and I would like to learn more about what it is like at home after children have had a brain injury, and how their families look after them.

I would like to talk with your family about these things, and to visit you at your home.

Is it alright with you for me to visit?

If it is alright for me to visit, can you tell your Mum or Dad or family, or write your name here.

Thank you,

Margaret Jones.

Child Participant/Proxy signature .....

Name of witness .....

Signature of witness .....

Date .....

## *Appendix C*

### *Caregiver Details Sheet*

#### **Caregiving for the Child with Traumatic Brain Injury**

If you agree to take part, please could you complete this form, and return it in the envelope provided. The information will be used to help organize interviews and observations, and to find out about things that may be important when someone is caregiving for a child with a traumatic brain injury.

Date questionnaire completed	Main caregiver(s) name(s)  ..... .....
	Name of Child with Traumatic Brain Injury  ..... .....

Address	Phone Numbers: Home, Work, Mobile

Child's age	Child's sex	Date of Injury

How many other children live at home and how old are they?	Number	Ages
How many other adults live at home?	Number	

--	--

<p>What life roles do you have (eg. Home-maker, paid worker, student, parent, volunteer)</p>
--

<p>What therapies and/or other assistance does your child receive? (eg. physiotherapy, occupational therapy, speech language therapy, psychologist)</p>
---

<p>What other people help you? (eg. friend, family, neighbour, doctor)</p>	
<p>If you have an ACC funded caregiver, how many Hours/week do they help?</p>	

<p>What main effects does the brain injury have on your child's ability to function?</p>
--



How many hours per week is your child attending school/preschool?	
When did your child return to school/pre-school?	

What is the best time for me to talk with you?			
Day of week:		Time:	
Whereabouts would you prefer the interview to be? (Please tick)	Home	AUT	Wilson Centre
Do you require child-care during the interview? (Please tick)	Yes	No	

What would be the best times for me to visit you and your child at home?
Day of week: Time:

Any other comments?
---------------------

If you have any questions, please call me on 489 9134, ext 5881.  
Thankyou for completing this questionnaire.

Margaret Jones (Occupational Therapist, Researcher)

## *Appendix D*

### *Semi-Structured Interview Schedule*

#### **Caregiving for the Child with Traumatic Brain Injury**

##### **Warm up**

Introduce the interview by saying what its' purpose is, and reminding the participant that they can stop the interview at any time or delete any information they are at all uncomfortable.

Say/ask something about how today is for you.

##### **Schedule of Questions**

If you were to make a list of the sorts of things that you do in your day with your child, what would you put on that list?

Tell me about different things you might do on other days?

How is it if things don't go to plan?

What is important about doing these things (prompt)?

What is the one most important thing that you do for your child?

How do you choose what sorts of things you do in your day?

Tell me what it's like caring for your child.

What sorts of things are hardest? Can you tell me about that?

What do you do to make things easier? How helpful is this?

Looking back, are there things that other people have done that you have found useful?

Somebody who was looking after a child with a brain injury once said “it makes you appreciate every little thing, every day”. What do you think about this statement?

What do you notice about the way your/the child responds to things you do?

In an ideal world, what things would you have wanted done to help make life easier for you and your child.

Some families of children with disabilities say that they re-organize their space and things around the home. Is there a difference at home since your child had the brain injury?

What is the family doing differently these days?

How are the others involved in looking after .....? What is it like for the others?

Is there anything else you would like to say?

### **Sample Prompts**

Can you say more about that? Why was that? How was that for you? What does that mean to you? What do you do then? What tends to happen then? What was it that led to doing it that way? Earlier on you talked about -. Can you tell me more about that?

### **Close**

Close by asking the person to say something about how the interview has been for them, and thanking them for their help.

## *Appendix E*

### *Follow-up Interview Guide: Participant 2: 20/02/03*

What is important about going to places with U?

What sort of places do you go to with U now?

Has this changed over time?

You talked about the class adjusting to things for U- what does “adjusting” involve?

I notice that you spend a lot of time “doing things” with U- e.g.) playing, eating.

How is this important to you?

You also talked a lot about the special things that U uses (e.g. noodles, calculator, computer, pedals on a bike). What is important about these things... Overall?

How do they help?

Tell me some more about U “resting”. How does he rest?

What happens if he is too tired?

What happens if he doesn’t rest?

How is it for you when he rests?

What happens if you try and make him do something he doesn’t want (e.g. wearing tight clothes)?

What is it about U’s room that works?

What makes him go there?

Tell me some more about what happens when U packs a sad.

Has this changed over time?

What sort of things has U learned to do better on his own in the last 6 months (e.g. controlling temper)?

Why are these things important in the big picture?

Can you tell me more about having people around who've "been through everything" with you? What does this mean?

Has U had further injuries? How does this worry you?

Tell me about the sort of things you keep him safe from.

When is it hardest? How do you keep him safe?

You talked about things you notice with U, (e.g. his eye, his foot, his shakes), why is it important to know these things?

How do you think U has changed to how he was before the accident?

Do you wonder how he might have been doing if he didn't have the accident?

Are you able to talk to me about how you feel around U's accident?

What sorts of words describe your feelings about what happened?

When is it important to be right there beside him?

You talked about getting set up (P.15) for U. What is setting up? What are you aiming for?

What is the paperwork for? What is important about getting it done compared to other stuff? (p27).

Can you tell me about how some of U's behaviours are difficult?

What does he do that is hard to manage?

Where do you see you are aiming at for U? What is important in the long term?

A lot of the things caregivers describe initially seem to be around controlling or containing things such as safety routines, fatigue, behaviour. How do those words fit with how you have done things with U?

How would you describe these activities?

What is it like working like this?

What happens if you don't?

What happens if you do this well?

Can you tell me about more about the times when you felt frightened.

What words would you use to describe how it is letting U go e.g. off to school?

Why does this happen- why do you need to do this?

What happens when for him when he goes somewhere and you've got it right?

How is this for you?

What do you do if it doesn't work out / you get it wrong?

How has the structuring changed since he began joining in more?

How do structuring and letting go the reins relate to each other?

What does he enjoy going when he goes somewhere?

What is important about talking with U about how he feels?

What sort of things does he tell you?

Can you tell me about how you felt in your black days?

A lot of families have talked about support people being understanding. Can you explain about what "Understanding" is?

How do you explain to people that don't understand

## *Appendix F*

### *Memo: 01/02/03*

I continue to wonder about my central category. Early on I thought this was about being safe. And then I felt it was about “going to”- this is a key concept in everybody’s interviews. Then I realised that it was less about “going” and more about joining in, and that there are different levels and locations of joining in. Also that children have different levels of success at it.

Last week I diagrammed and came up with other categories of Safety, Knowing, & Progress which contribute to joining in. Today I wondered again if safety is the key category- safety from unsuccessful interactions, from fatigue. But this does not include the progress category. And progress... how does it relate to joining in? Progress relates, for different families, to healing, to joining in, to developmental progress, to family progress.

### *Memo: 06/02/03*

I am still unsure about my main categories, and have been thinking about this on and off for several days.

Containing the risks- I am sure this is one quite central category. It includes subcategories of safety, structuring routines, and noticing/responding (reading the signs) and managing the environment (perhaps = safety). Another central category is Joining In. This category has a lot of overlap with containing- Families try to contain in order to begin successful joining in. Is this Letting Go?

There is another category- this is the one I am unsure how to capture/represent. Letting Go? Getting There? My Changed Child?/Family? My Changing Child? Perhaps this is a subcategory/a context? I think it involves the monitoring, comparing, judging skills; is this a letting go category, a progress category? Yet the progress seems to be about Joining In. Is the dealing with problems part of the progress? Is this the central category?

Where does the support/envt fit? Perhaps this is a context for both categories, or for all categories. I feel as though I need to know about this before I do my next interviews. Or perhaps the interviews will help.